Design of Therapeutic Education Workshops for Home Heamodialysis in a Patient-Centered CKD Research: A Qualitative Study

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Research Article

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Abstract

Rationale & Objective: A quarter of the patients did not receive any information on any modality before the start of Renal Replacement Therapy (RRT). We have therapeutic education workshops for all RRT except for home haemodialysis (HHD). We aimed to identify and describe the needs of patients and caregivers for RRT with HHD. Lastly, to conceive and carry out a Therapeutic Education Workshop.

Setting & Participants: Two sequential methods of qualitative data collection were undertaken: (1) interviews with a patient who had been on HHD and a doctor specialized in HHD (2) semi-structured interviews with HHD patients in our center.

Analytic Approach: Thematic analysis.

Results: We identified six themes related to the barriers, facilitators, and potential solutions to home dialysis therapy: (1) HHD allows autonomy and freedom with constraints, (2) safety of the care environment, (3) the caregiver and family environment, (4) patient's experience and experiential knowledge, (5) self-treatment experience - Impact on life, and (6) factors that impact the choice of treatment with HHD.

We designed a model for a therapeutic education workshop in a group of patients and caregivers.

Conclusions: Our study confirmed previous results obtained about the major barriers, facilitators, and potential solutions to HHD. There are three important points regarding HHD: (1) the impact of the HHD on the caregiver, (2) the experience of patients already treated with HHD, and (3) the role of nurses and nephrologists in informing and educating. A program to develop patient-to-patient peer mentorship, allowing patients to discuss their dialysis experience, would be invaluable.

Background

It is well recognized that early kidney transplantation is the best RRT option for many patients with end-stage renal disease (ESRD). However, most patients will need to spend some time on dialysis prior to transplantation or when a transplant fails [1-2-3-4-5]. The duration of the transplant waiting list can be variable, depending on the circumstances of each country. This implies that transition between dialysis modalities will be a reality for the majority of patients, especially those who face a long wait for transplantation or those for whom a kidney transplant is not possible.

Transition of care

A single treatment option may not be adequate throughout a patient's life and many patients will need to change treatment modalities to adapt the treatment to their needs. Changing the dialysis modality is not only about technical optimisation or improving patient survival, but also about the patient's experience of the transition. The reasons for changing a patient's treatment modality should be assessed, taking into account both short and long term benefits and risks.
When shifting to HHD, it is of utmost importance to raise patients’ awareness of their condition through appropriate education. This would also increase their acceptance of the need for RTT throughout their life, while encouraging self care at the same time [1-6-7].

**The benefit of HDD**

HHD has many advantages:

- Autonomy at home,
- Patients control the flexibility of their dialysis schedule,
- Decreases the mortality and morbidity rates,
- Eliminates transportation to dialysis centers, Reduces travel time/cost,
- Improves the patient’s quality of life, mood, sleep, depression,
- More independence, personal freedom, time for family and community engagement,
- Enhances ability to work,
- Reduces fatigue,
- The patients who benefit from this system feel much less tired.

There is considerable evidence of the benefits of assisted self-care in long-term conditions [8-9]. Lack of health literacy in dialysis patients is associated with poor survival [10]. While self-motivation and patient education can improve care [11-12]. To ensure quality of care is to engage patients as true partners in their own care; self-management is an ambition in "Kidney Health: Delivering Excellence" [13].

However, a quarter of the patients did not receive any information on any modality before the start of RRT. 44% received no information on home haemodialysis (HHD), 24% received no information on peritoneal dialysis (PD). The majority of those who received information were very satisfied with the information (range from 57% for HHD to 86% for deceased kidney donor transplantation (Tx) [14]. Two-thirds of the patients felt that the decision was shared with the medical team.

When a pre-dialysis information program is developed with patients, 40% of them choose a home dialysis modality [15]. For patients who are already treated with hemodialysis, some learned societies estimate that, 10 to 15% of hemodialysis patients could opt for home care [16].

Knowing the reasons for having a particular form of RRT will provide a better understanding of the treatment choices made by patients. In the EDITH study, the most important factors influencing modality choice were quality of life, survival and safety (resp. 97.3%, 96.6% and. 92.2% rated as very important). Results were similar by age group, sex, educational level and start of RRT time period [14-17].
An important mechanism to ensure that quality of care is maintained is to engage service users as true partners in their own care; self management is an ambition in “Kidney Health: Delivering Excellence” [13].

In this sense, we decide to include patients in this research work, in a person-centred reaearch model (PCR) [18-19-20].

**Person-centered care (PCC) - Patient-centered outcomes research (PCOR)** [19].

The person-centered are: care is (a) delivered with dignity, compassion, and respect; (b) well coordinated; (c) personalized by taking into account clinical, social, emotional, and practical needs; and (d) care enables people to take an active role in their own care [20-21]. It’s centred on the individual, and his or her family, rather than on the disease.

Person-centred care requires a partnership between patients and health professionals. The patient-centred approach has been extended to research, with patients and care partners joining with researchers to conduct patient-centred outcomes research (PCOR). PCOR helps people and their caregivers communicate and make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options. It’s inclusive of an individual’s preferences, autonomy, and needs, focusing on outcomes that people notice and care about such as survival, function, symptoms, and health-related quality of life. PCOR requires the integration of input from patients, caregivers, and researchers to ensure that each project is tailored to the needs of patients and that the results are widely disseminated and useable in health care setting [19].

We aimed to identify and describe the needs of patients with ESRD and caregivers for RRT with HHD. In addition, we also aimed to conceive and carry out a Therapeutic Education Workshop to help patients to choose renal home hemodialysis.

This project is carried out according to the Training Engineering technique in 4 steps: Analyze, Design, Realize, and Evaluate [22].

**Methods**

**Conception interview guide by two investigators (A.G, and V.B):**

The first two interviews were realized with a transplanted patient who had been on HHD treatment and a doctor specialized in HHD treatment.

These interviews enabled us to develop an interview guide. The objectives of the interview guide are to understand the choice of HHD patients, the factors that influence their choices, their experiences as well as the obstacles for HHD, (Appendix 1 interview guide)

**Semi-structured interviews by two investigators (F.B, and O.D).**
Then we conducted semi-structured interviews with HHD patients in our center. Interviews were conducted between February and October 2019 and were analyzed using thematic analysis. All participants provided written informed consent.

Lastly, the results allowed us to design the pedagogical objectives for the Therapeutic Education Workshop.

**Participant selection**

Individuals receiving maintenance hemodialysis were eligible to participate if they were at least 18 years old, had been receiving HHD for 3 months and were French speaking. Hospitalized patients or those who were medically unstable according to their treating nephrologists were excluded. Study staff screened interested individuals for eligibility and obtained informed consent.

**Data Collection**

Interviews with doctor and transplanted patient were conducted by two experienced interviewers (A.G, and V.B). These two interviews allowed us to design the semi-structured interview guide.

We used this semi-structured interview guide (Appendix 1 interview guide) and invited participants to respond to questions about: (1) the factors which triggered their decision to dialyze at home, (2) the obstacles and the difficulties that they thought at that time would hinder the HHD, (3) what are the elements that made them favor being on home dialysis rather than in the dialysis center, (4) do they feel any kind of discomfort or negative reluctances about their current experience, (5) if they had to talk about HHD to another patient, what would they say to them.

The interview questions were open and participants were encouraged to provide examples and expand on their responses [23-24-25-26-27]. Interviews were conducted from February to October 2019 by two experienced interviewers (F.B, and O.D). In-person interviews occurred in dialysis clinic conference rooms. Interviews were digitally recorded and professionally transcribed verbatim. Field notes were taken by the interviewers. Participant characteristics were self-reported. We conducted semi-structured interviews until we reached data saturation (ie, the point at which little or no new information emerged).

**Data Analysis**

Semi-structured interviews were transcribed verbatim and verified. Transcripts were entered into RQDA 3.6.1 (2019-07-05) software for data organization and coding purposes (Version 3.6.1) to facilitate data management and analysis (eg, store, review, code, and search data). We used thematic analysis and systematically coded and identified themes inductively from data [23-24-25]. To ensure that the range and depth of data were reflected in the analysis, transcripts were independently analyzed by 2 research team members experienced in qualitative research (A.G, and P.S.) [26-27].
The team identified conceptual patterns among the themes and developed a thematic schema. Concepts were repeatedly discussed by the research team at regular meetings to ensure that the theme reflected the interview data depth. During these discussions, the team returned to the source data (transcripts) to verify findings and ensure that the theme accurately reflected data. Finally, the research team members along with patient partners (C.S, F.R, and J-C.Z), collaboratively revised the themes until agreement [26-27].

Patient interviews were ceased when no new codes were identified (data saturation) after five consecutive interviews.

We reported our study according to the Consolidated Criteria for Reporting Qualitative studies (COREQ) checklist [28].

**Results**

**Participant characteristics**

10 HDD patients were selected to participate in this study. After five interviews, a thematic saturation was achieved, meaning that no new themes emerged from the data. Patient interviews were ceased [23-25].

Among patients, the mean age was 55, 2 years (+/- 14.4), mean HHD vintage was 25 months, 4 (80%) were male and 4 (80%) were married. (Table 1 displays participant characteristics).

**Patient interview themes and subthemes**

We identified 15 subthemes that we could group into six major themes. Table 2 displays illustrative quotations for the identified themes and subthemes.

The major themes were:

1. HHD allows autonomy and freedom with constraints
2. Safety of the care environment
3. The caregiver and family environment
4. Patient's experience and experiential knowledge
5. Self-treatment experience - Impact on life
6. Factors that impact the choice of treatment with HHD

The figure 1 presents a diagram of the conceptual links among themes and illustrates how themes may relate to subthemes. The 3 main themes are: 01; 04; 05. They include 9 (60%) sub-themes.

71% of the subthemes, which the patients interviewed considered as beneficial and that improve the quality of life, include freedom, life and work projects, less hospital visits and saving time, organisation, space and care management, safety, as well as the patient's experience of care (11%). (resp. 17%, 15%, 15%, 12% and 11% of quotes). Fig 2
83% of the subthemes considered by the patients interviewed and which had an impact on life and a decrease in the quality of life, included stressed, worried and exhausted caregivers, constraints and learning difficulties. (resp. 33%, 25% and 25% of quotes). Fig 3

**Analyses and model:**

The patients interviewed describe HHD as a technique that increases autonomy and freedom. This allows them to be actors in their own care, and to reduce trips to the hospital (saving time). De facto, having flexibility on dialysis schedules.

Testimonials, the experience of other HHD dialysis patients and home visits by HHD patients had a major impact in their decision to choose HHD. Indeed, the lived experience, the experience of other patients, is perceived by the patients as the major trigger for their decision. In fact, the interviewees made a clear distinction between the expertise of the medical-nurse staff (expert in HDD) and the expertise of patients who have been treated with HDD (expert in living with HHD).

- Patients reported that the medical staff plays an important role in improving the theoretical knowledge of HDD treatment. The nursing staff is described as having a leading role in raising awareness and providing support in the choice of HHD technique. Feedback and visiting other HHD patients at home make them more aware of "living with HDD treatment".

HHD requires an apprenticeship for the technique, the dialysis machine as well as the self-puncture of the arteriovenous fistula. Learning to self-puncture fistula is described by all patients interviewed as the most difficult step in the learning process.

- HHD requires a new organisation of life at home. This may impact family life, mainly the caregiver. Involvement of the caregiver from the very beginning of the process seems indispensable for the smooth running of the process.

**Model of therapeutic education workshops:**

- We designed a model for a therapeutic education workshop in a group of 4 patients and 4 caregivers. An educational assessment of the patient and his caregiver was carried out by a nurse trained in therapeutic education before and after the workshop. The workshop is composed of 4 educational sequences. Table 3 shows the course of the therapeutic education workshop. The patient's experience is collected in the form of a video testimony. We applied a pedagogical method (constructivist pedagogy) and pedagogical tools facilitating the expression of the group.

The patient experience movie is available on our youtube channel.

Table 3 regroups the title and the pedagogical objective of each pedagogical sequence.

**Discussion**
We identified six themes related to the barriers, facilitators, and potential solutions to home dialysis therapy: (1) HHD allows autonomy and freedom with constraints, (2) safety of the care environment, (3) the impact of the caregiver and family environment, (4) the patient's experience and experiential knowledge, (5) self-treatment experience, impact on life, and (6) factors that impact the choice of treatment with HHD. These themes can be a positive or a negative outlook about performing HHD. These findings are consistent with the previous assessment. Seshasai RK [29] identified in a qualitative study, five themes related to continuation or discontinuation of HHD emerged: (a) degree of independence (increased flexibility, burden of therapy), (b) availability of support (emotional and physical support and caregiver burden), (c) technical aspects (familiarity with machine), (d) home environment (ability to organize supplies, space at home), and (e) attitude and expectations (positive or negative outlook about performing HHD) [29].

In 2017 National Kidney Foundation-Kidney Disease Outcomes Quality Initiative sponsored a home dialysis conference designed to identify barriers to starting and maintaining patients on home dialysis [30]. They identified a barriers to the implementation of HHD include patient and caregiver factors: (a) lack of adequate education on home dialysis modalities (may not be provided at all to caregivers or patients...), (b) psychological, including lack of confidence, fear of self-cannulation, fear of catastrophic events and (c) exhaustion of caregivers [30].

We also identified the subthemes that can promote the choice of the HHD (freedom, life and work project, less hospital visits and saving time, organisation of space and care management and security, and patient’s care experience). We have also identified difficulties encountered with this treatment among the patients treated with HHD: stressed, worried and exhausted caregiver, constraints and learning difficulties.

**In summary**, our study confirmed previous results obtained about the major barriers, facilitators, and potential solutions to home dialysis therapy initiation.

Based on the results of our research, we believe that all patients should have information and assistance in choosing replacement therapy, including HD, PD, TX and HHD. There are three important points regarding HHD: (a) the role of the caregiver, (b) the experience of patients already treated with HHD, and (c) the role of nurses and nephrologists in informing and educating.

We have designed a therapeutic education program that includes four educational sequences that take into account the results of our research. A program to develop patient-to-patient peer coaching that would allow patients to discuss their dialysis experience would be priceless. Regarding the patient’s experience, we filmed a patient who is a partner in this research and who is dialysing at home.

Our approach is the person-centered model of care, which allows individualized information. That's why our pedagogical sequence is preceded by an educational assessment. This assessment enables us to identify the patient's needs, preferences, therapeutic and life projects.
Although most nephrologists believe that HHD is too complicated and burdensome for the majority of patients with kidney failure [31-32], this therapeutic education program is now delivered to all patients in our center, as well as other replacement therapies (Tx, HD, PD).

**Abbreviations**

RRT : Renal Remplacement Therapy

HHD: Home Heamodialysis

ESRD: End-Stage renal Disease

Tx; Transplantation

PCC : Person-Centered Care

PCOR : Patient-Centered Outcomes Research

**Declarations**

**Conflict of interest statement**

The results presented in this article have not been published previously in whole or part.

All of authors have nothing to declare.

**Ethics declaration and consent to participate**

Research ethics approval has been obtained through the CNIL (Commission nationale de l'informatique et des libertés) in France. (Ref: 2219281). MR-4 Non-personal research, studies and evaluations in the health field

All methods were carried out in accordance with the relevant guidelines and regulations.

Informed consent was obtained from all subjects, no subjects were under 18 years of age

**Consent for publication: not applicable.**

**Availability of data and materials.** The data analysed during this study are included in this published article [Table 1-2-3 and Additional File 1].

**Competing interests:** The authors declare they have no competing interests.

**Funding:** The study did nont receive funding .

**Author’s contributions**
Each author should have participated sufficiently in the work to take public responsibility for the content. This participation must include:

1. AG. Designed the study, conceived the guide *interviews*, analyzed, interpreted qualitative data, and conceived a therapeutic education workshop. Drafted the article. Provided intellectual content of critical importance to the work described,
2. FBD, OD. semi-structured interviews, transcribed verbatim, conceived a therapeutic education workshop, reviewed the article,
3. RG. Designed the study, drafted the article,
4. ACB. Provided intellectual content of critical importance to the work described, reviewed the article,
5. PS. Analyzed and interpreted qualitative data, reviewed the article,
6. VB. Conceived a therapeutic education workshop,
7. JCZ, CS, FR. Provided experience of living with HHD, patient feedback and final approval of pedagogical sequence and validation of education workshops.

**Acknowledgements** We would like to thank Emeline MODERNI (RESCUe RESUVal Network) for her professional writing assistance in the development of the manuscript.

**References**

over 1 week versus 5-day DAFNE training delivered over 5 weeks: the DAFNE 5 x 1-day trial. Diabet Med. 2015;32(3):391-8.


Tables

Table 1. Patient characteristics
<table>
<thead>
<tr>
<th>Patient participants</th>
<th>n (%) or mean +/- SD;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient participants</td>
<td>n : 5</td>
</tr>
<tr>
<td>Age (years)</td>
<td>55.2 (+/- 14.4)</td>
</tr>
<tr>
<td>Male</td>
<td>4 (80%)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>4 (80%)</td>
</tr>
<tr>
<td>Not married</td>
<td>1 (20%)</td>
</tr>
<tr>
<td>HHD treatment history (month)</td>
<td>28 month (4-68)</td>
</tr>
<tr>
<td>Number of HHD session per week</td>
<td></td>
</tr>
<tr>
<td>- 5/week</td>
<td>3 (60%)</td>
</tr>
<tr>
<td>- 3/week</td>
<td>2 (40%)</td>
</tr>
<tr>
<td>Interview length (min)</td>
<td>54 min +/- 12 min</td>
</tr>
</tbody>
</table>

Table 2: Themes, Subthemes and illustrative quotes
<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Quotes</th>
</tr>
</thead>
</table>
| 01. HHD allows autonomy and freedom with constraints | Actor of my care                 | interview 1 Mrs. M [817:865]  
I no longer wanted to dialyze at the center  
interview 2 Mr. B [2225:2337]  
I am in charge of my own care. I drive myself to come for dialysis. |
|                                            | Autonomy                         | interview 1 Mrs. M [3200:3426]  
When I am on vacation, I adapt my sessions according to my schedule, I dialyse early in the morning. Otherwise when I work, I dialyze at night. It also depends on my spare time activities: hiking, biking.......... |
|                                            | Dialyzing whenever I want        | interview 4 Mr. S [1510:1601]  
I can change my dialysis time table according to my own schedule, and even my sessions.  
interview 5 Mr. Z [3562:3668]  
I can connect any time I want by continuing to do dialysis 3 times a week for 4 hours each. |
|                                            | Less hospital visits and Saving time | interview 3 Mr. F [601:801]  
You don't think much of the time you waste because of the center schedule, waiting for taxis and traffic congestions. You don't feel all this right away, but it is very important after all!  
interview 5 Mr. Z [3197:3325]  
Staying at home saves me the 70 km round trip between my workplace, the dialysis center and my home.  
interview 5 Mr. Z [4176:4335]  
The good thing about home dialysis is that I don't need to wait for taxis nor any help to dialyze. Thus, we can choose the dialysis time. A little freedom for me! |
|                                            | Freedom                          | interview 4 Mr. S [1601:1614]  
I am free to dialyze whenever I want.  
interview 1 Mrs. M [939:1304]  
I went on vacation for 2 weeks with my husband and my daughter. I was able to dialyze early in the morning and then I had the whole day for us. If I had dialyzed in the center it would have been mandatory in terms of dialysis duration as well as the trip to the center. The nearest dialysis center was located 30 minutes away from the vacation residence. |
<p>|                                            | Life and work project            | interview 1 Mrs M [2048:2379] |</p>
<table>
<thead>
<tr>
<th>02. Safety of the care environment</th>
<th>Organization, space and care management</th>
<th>interview 5 Mr. Z [3740:3846]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Space is needed for the reverse osmosis, the hemodialysis machine as well as the stocked material. We need a whole room dedicated to this.</td>
<td></td>
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<tr>
<td></td>
<td>interview 1 Mrs. M [4756:5515]</td>
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<td></td>
<td>You also need to be well organized regarding the storage. In my dialysis room I have a closet reserved for my dialysis equipment. I always have some compresses at hand, in case of bleeding. I can ask my husband or my daughter, but I prefer to be organized.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>interview 4 Mr. S [2505:2864]</td>
<td></td>
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<tr>
<td></td>
<td>When I get up, I get the hemodialysis machine ready, then I take my breakfast and connect myself. After disconnection, I can eat with my daughter and my wife, no need to wait.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>03. The caregiver and family environment</th>
<th>Stressed, worried and exhausted caregiver</th>
<th>interview 2 Mr. B [1797:1899]</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dialyzing at home weighs on my wife, who is exhausted and stressed. She is also very much worried if my blood pressure is too low.</td>
<td></td>
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<tr>
<td></td>
<td>interview 2 Mr. B [3607:3787]</td>
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<td></td>
<td>I impose the dialysis on my partner. Dialyzing at the center has much less impact on her. She is the one who puts up with the illness. Home dialyzing means bringing the illness at home.</td>
<td></td>
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<tr>
<th>04. Patient's Actor of my care</th>
<th>interview 1 Mrs. M [1827:2000]</th>
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<tbody>
<tr>
<td></td>
<td>My husband agreed to the home dialysis, he is a great helper, including with the cycler (disconnects, cleans the cycler, puts the material away and deals with the stock).</td>
</tr>
<tr>
<td></td>
<td>interview 5 Mr. Z [3345:3559]</td>
</tr>
<tr>
<td></td>
<td>My partner helps me by setting up my hemodialysis machine, when I compress the needle site; she disassembles the hemodialysis machine and cleans it. My partner helps me a lot with my dialysis, a real assistance. She discontinues dialysis for me from time to time.</td>
</tr>
</tbody>
</table>

The HDD adapts to my lifestyle and not the other way around.
<table>
<thead>
<tr>
<th>experience and experiential knowledge</th>
<th>Dialyzing during my vacations had no impact or constraint on my family or my activities. This weekend, my husband and I are going to go on a camping car trip to my daughter's summer camp in the mountain. We put all the material in a closet in our camping car.</th>
</tr>
</thead>
</table>
| Know my own body | interview 3 Mr. F [1196:1449]  
The fistula cannulation feels different with the nurse even if she is well trained and is more used to it. I can feel the needle from inside. Even if I miss the cannulation, I feel I am not in, I feel both sides. |
| Dialyzing whenever I want | interview 5 Mr. Z [2886:3029]  
I think it is very important to have a good knowledge of one's anatomy and arteriovenous fistula. You feel immediately if you are inside the arteriovenous fistula or beside. |
| Learning difficulties | interview 5 Mr. Z [3562:3668]  
I can connect any time I want by continuing to dialysis 3 times a week for 4 hours each. |
| Autonomy | interview 2 Mr. B [513:583]  
it was hard for me to cannulate by myself. |
| Constraints | interview 1 Mrs. M [867:938]  
With the cycler I can move, I am not bothered any longer by the lines. |
| Learning difficulties | interview 2 Mr. B [4340:4431]  
Knowing that the accompanying person will be involved in the management. Sometimes it can be oppressive. |
| Freedom | interview 3 Mr. F [1111:1160]  
I didn't want to bring the hospital at home. |
| 05. Self-treatment experience - Impact on life | interview 1 Mrs. M [2510:2637]  
I had difficulties during the first self-cannulation, but I knew it was mandatory for home dialysis. |
| Constraints | interview 5 Mr. Z [2611:2885]  
The first cannulation was painful for me. The nurse was telling me to push on the needle but as I have very dry skin, it was hard. I was a little apprehensive about my first cannulation but it was necessary to start it. It was painful and up to now it still hurts at the fistulae. |
| Freedom | interview 2 Mr. B [947:1118]  
More freedom, more flexibility. I can adapt my schedule and even my sessions according to my own schedule/time table. When I dialyze in Vienne, I have time constraints. |
You have to think about your lifestyle before dialysis, if you like to be autonomous, you have to go ahead and be motivated to do HHD.

Home dialyzing is challenging for me. I get up at 5am every day to run my business, and I dialyze around 8.30 pm, when my wife gets back from work. She works in Lyon and it takes her an hour to arrive (Pelussin Lyon). I go to bed at midnight or 1am as I am exhausted as much as my wife is.

My wife used to tell me that I was crazy to dialyze at home, and that it's too difficult.

I dialyze daily, 6 times a week: 3 times for 3 hours and 3 other times for 2 or 2 hours and a half. I feel much less tired when I dialyze 3 times a week for 4 hours. I recover faster and I can eat better. I can also allow myself an aperitif that I usually wouldn't take.

One day, I went online to get information about home dialysis to better understand how it works. I talked to my doctor who seemed to agree with home dialysis. I gathered a lot of information.

Table 3: The education workshop is composed of 4 pedagogical sequences (PS)

<table>
<thead>
<tr>
<th>Title of PS</th>
<th>Pedagogical objective</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PS: 1</strong> HHD representations</td>
<td>At the end of the sequence, the patient and his/her companion will be able to express themselves on their representations/feelings about HDD.</td>
</tr>
<tr>
<td><strong>PS: 2</strong> Benefits and constraints of HHD</td>
<td>At the end of the sequence, the patient and his caregiver will be able to identify the benefits and constraints of HDD.</td>
</tr>
<tr>
<td><strong>PS: 3</strong> Recognize the different types of machines for HDD (conventional, daily generator and cyclers)</td>
<td>At the end of the sequence, the patient and his caregiver will be able to recognize the different types of HDD machines (conventional and cyclers) as well as the one that would be the most adapted to the patient's needs and expectations.</td>
</tr>
<tr>
<td><strong>PS: 4</strong> Benefits (for me) of the HHD</td>
<td>At the end of the sequence, each participant will be able to recognize the advantages of home hemodialysis to him/her.</td>
</tr>
</tbody>
</table>

Figures
Figure 1

Connection between themes and sub-themes (The themes are in blue, the subthemes positive aspects of HHD are in green and the subthemes negative aspects of HHD are in red).

<table>
<thead>
<tr>
<th>Theme</th>
<th>Bar Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freedom</td>
<td>15%</td>
</tr>
<tr>
<td>life and work project</td>
<td>15%</td>
</tr>
<tr>
<td>Less hospital visit and Saving time</td>
<td>15%</td>
</tr>
<tr>
<td>Organisation and space and care...</td>
<td>10%</td>
</tr>
<tr>
<td>Security, Patient’s care experience</td>
<td>10%</td>
</tr>
<tr>
<td>Caring, reassuring caregiver</td>
<td>5%</td>
</tr>
<tr>
<td>Actor of my care</td>
<td>5%</td>
</tr>
<tr>
<td>Know my own body</td>
<td>2%</td>
</tr>
<tr>
<td>Dialyzing whenever I want</td>
<td>2%</td>
</tr>
<tr>
<td>Autonomy</td>
<td>2%</td>
</tr>
<tr>
<td>Infuent factors more choice with HHD</td>
<td>1%</td>
</tr>
</tbody>
</table>
Figure 2

The HHD benefits experienced by the patients interviewed (Quotes: N = 65)

- Stressed, worried and exhausted caregiver
- Constraints
- Learning difficulties
- Influential factors less choice with HHD

Figure 3

The impact of HHD felt by the patients interviewed (Quotes: N = 24)

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- Appendix1.docx