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Bulletin de la Dialyse à Domicile

Narrative interviews to assess quality of life in Peritoneal Dialysis

(Evaluation de la qualité de vie en Dialyse Péritonéale par les entretiens narratifs)

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Résumé

L'objectif de la dialyse est non seulement d'améliorer la survie des patients, mais également leur bien-être.

Nous nous sommes intéressés à la perception de la qualité de vie des patients en Dialyse Péritonéale, sans comparaison avec les autres techniques de dialyse, par une méthode d'évaluation moins classique que PROMIS-29, KDQOL-36 : l'entretien narratif, basé sur le recueil du ressenti, du vécu au quotidien et des impressions concernant la prise en charge.
Nous avons mené quatre entretiens approfondis, en suivant le principe de la saturation théorique des données, auprès de quatre patients adultes pris en charge à Nice.
Ces entretiens ont montré que la Dialyse Péritonéale a apporté une amélioration rapide de leur état de santé, tant sur le plan physique qu'émotionnel.
Les patients regrettaient cependant le maintien de restrictions alimentaires, notamment en apport sodé. Ils appréciaient un accompagnement temporaire par un infirmier libéral, proposé systématiquement par notre centre en début de traitement.
L'implication, en amont de la dialyse, de patients en Dialyse Péritonéale a été suggérée tant pour leur témoignage que pour l'apport d'explications et de démonstrations pratiques.
La qualité de vie est importante à évaluer lors du choix de technique de suppléance ou en début de traitement. La méthode de l'entretien narratif est un outil d'évaluation qui peut aider les soignants à mieux comprendre les attentes et souhaits des patients afin de les orienter vers la technique la plus adaptée à leur mode de vie et préférences. Les résultats cliniques en seront améliorés.

Mots clés : entretien narratif - qualité de vie – dialyse à domicile – dialyse péritonéale

Summary

It has been found that people undergoing dialysis have a lower quality of life than the rest of the population. The aim of dialysis is to improve physical health, but also well-being.
We were interested in the perception of the quality of life of patients undergoing Peritoneal Dialysis. We used the narrative interview method to collect their feelings, their daily experience, and their impressions about their care. We conducted four in-depth interviews, following the principle of theoretical data saturation, with adults treated at the Hospital of Nice.
These interviews indicated that Peritoneal Dialysis rapidly improves physical and emotional health. Patients are satisfied with the technique, which allows them to return to a social, familial, and professional life.
However, they regret that it does not relieve them of dietary restrictions, especially on salt. Patients appreciate the temporary support of a private nurse, which is systematically offered by our center at the beginning of treatment. They wish the involvement of peers to benefit from their experience, explanations and practical demonstrations.
Quality of life is important to assess when choosing a renal replacement technique. Caregivers have to understand patients' expectations and wishes in order to guide them towards the dialysis modality that suits their lifestyle and preferences best. This will improve treatment outcomes.

Key words : narrative interview - quality of life – home dialysis – peritoneal dialysis

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INTRODUCTION

The course of chronic kidney disease can lead to End-stage Chronic Renal Desease, at which stage it is necessary to consider a replacement technique: dialysis or transplantation [1]. While kidney transplantation presents the best therapeutic option in terms of quality of life for people with Chronic Renal Failure (CRF) [2], it is not always possible or immediate. A more or less long period of dialysis is then necessary.

Although dialysis is an effective renal replacement therapy, it can affect patients' social and daily activities. It has been shown that people on dialysis have a poorer quality of life than the general population [3]. The objective of renal replacement is therefore not only to improve the patient's survival, but also his well-being [4].

Assessment of quality of life is subjective and involves multidimensional measures that include physical, emotional and social function as well as treatment effectiveness [3].

Several questionnaires are available to assess the quality of life of patients such as PROMIS-29, SF-36, KDQOL ... However, in order to obtain more personal and qualitative responses, we have chosen a narrative approach. According to narrative theories [5], the purpose of the story is «to clarify the meaning of the experience of the disease by ordering the events». Narrative medicine has shown its interest in the health field [6], in nephrology [7,8] and in patients on dialysis [9].

Our idea is not to compare the quality of life of patients according to the different dialysis techniques adopted, but to offer them a time for discussion during which they can express themselves freely about their own feelings about chronic kidney disease and dialysis. We focused on patients on home dialysis and particularly on Peritoneal Dialysis (PD), followed exclusively at the Nice center, in order to organize interviews under identical conditions.

Our objective is to verify the relevance of the narrative interviews, without comparison with other methods, to assess the perception of the quality of life of PD patients. The collection of their feelings, their daily experiences, their impressions concerning their care, in relation to kidney disease and dialysis will highlight the points that we could improve in order to better respond to the needs and expectations of our patients.

METHOD

In order to assess the value of narrative interviews in the perception of the quality of life of PD patients, we tested this method on patients treated at the Nice University hospital (CHU). Narrative interviews are a variation of narrative medicine based on the story of patients, from their experience. It consists in letting the patient speak freely and listening attentively to his story, with empathy. The different themes we wanted to collect are related to the PROMIS-29 questionnaire [10] and concern: physical capacity, emotional state, ability to participate in social roles and social activities, sleep disorder , the impacts of the management of chronic kidney disease, the interference of pain and its intensity and patient satisfaction on its management.

An interview grid (Table 1) was developed upstream in order to follow the story and have a vision of the different themes of the PROMIS-29 questionnaire addressed by the patient. The following participated in the development of this grid: a representative of users of the Nice University hospital , a patient partner, PD professionals and the patient pathway team. We also gave a logbook to each patient followed in PD, in which he could mention his feelings, his needs and his expectations. He was then free to share the contents of this diary during the interview. We were interested in his quality of life during the four weeks leading up to the interview.

🡇 *Table I. an additional column is used during the interview to enter the comments corresponding to each item*

Dimensions	**Criteria**	**Sub criteria**	**Reminder questions**
Physical capacity		Move objects, furniture, vacuum, play sports	
	Significant / moderate physical effort to perform simple daily tasks	Go up / down the stairs	Are you able to perform simple daily tasks?
		Walk at least 15 minutes; walk more than 1 km / more than 100 m	
	Evolution of the patient's health during the day or the last weeks / days		Do you perceive any change in your state of health over the day or the week?
	Evolution of the patient's health between the current year and the previous year.		Do you perceive any change in your state of health between the current year and the previous year?
Emotional state	Anxiety	Fear, worry, nervousness, aggressiveness	
	Depression	Feeling of being good for nothing, helpless, sadness	how do you feel ?
	Tired	Feeling tired, feeling exhausted, being motivated to do things	
Ability to participate in social roles and social activities	Activities, leisure	Alone	Do you participate in activities? Do you exercise leisure?
		With family / friends	
	Professsional activty		
Sleep	Sleep disturbance	estful sleep, problems falling asleep, etc.	
Impacts of the managment of CKD	Limitations in everyday life	Dietary restrictions	How do you deal with the restrictions due to CRF in your daily activities?
		Trips / travel restrictions	
	Bothersome symptoms of CKD	Itching, cramping, shortness of breath, dizziness, numb hands / feet, urge to vomit, muscle aches / pain, etc.	
	Organization of home dialysis care	Suitable space in the home, presence of an "accompanying person", patient or third person available to receive the delivery, etc.	How do you manage the organization of home dialysis care?
	Compliance with treatment		
	Dependencies on doctors and nursing staff		
	Sexual life	Difficulty in having sexual pleasure, absence or insufficiency of desire.	
Pain	Impact on daily life		How does pain impact your daily life?
Satisfaction	Satisfaction with the care provided by the healthcare team, quality of the information obtained		How do you rate your care in the dialysis service?

The participants were informed of the objectives and modalities of the interview and their oral consent was obtained. These exchanges were confidential, subject to professional secrecy and digitally recorded. They took place in a quiet location conducive to confidentiality.

Interviews, lasting approximately one hour, were conducted in the presence of a caregiver (Advanced Practice Nurse in Nephrology) and a patient partner. The latter was able to welcome, support and encourage the patient to share experiences. A quality engineer was also present to take notes and then transcribe the information verbatim. A copy of this transcript was then given to participants to confirm compliance.

These interviews were conducted with adult patients treated for PD at the Nice University Hospital. The patients all chose PD after receiving complete information. The PD technique (DPCA / DPA) is left to the patient's discretion. Patients with mental and / or physical disabilities and those not fluent in French were excluded.

The interviews took place between December 2020 and February 2021 at the Nice University Hospital. Interviews were offered to all eligible patients at the center (Table II). All have agreed to participate. Recruitment was carried out chronologically, that is to say according to the dates of follow-up appointments already scheduled.

⬇ *Tableau 2. characteristics of eligible patients*

	Interviewed n=4	Not interviewed n=8
Age	23 à 72 years Average age : 42 ans	22 à 86 ans Average age : 63 ans
Sex	M : 4 F : 0	M: 6 F : 2
Time on PD	4 à 26 months Mean :11 ½ months	1 à 57 months Mean :17 ½ months
Autonomy	Autonomy (+/-Private nurse<4 months) : 4 Private nurse : 0	Autonomy (+/-I Private nurse <4 months) : 5 Private nurse : 3
Professionnal activity	Retained employment : 2 Job earch/Requalification :1 Retired: 1	Retained employment: 3 Job search/Requalification : 0 Retired : 5
PD Modalities	CAPD : 3 APD : 1 Nb PD days /week :7D/7 : 3 6JD7 : 1	CAPD : 7 APD : 1 Nb PD days /week :7D/7 : 4 6D/7 : 4
Registered / In the process of being registered on the transplant list	Yes : 4 No : 0	Yes : 6 No : 2

Number of patients excluded for mental and / or physical impairment: 3
Number of patients excluded for language problem: 2

The interviews began with a description of the announcement of the disease, which provided the basis for the patient's story and the context. The themes to be studied were systematically addressed. The information was reported directly by the patient without professional interpretation. Relaunch questions could be proposed to allow him to express himself more on a specific theme. These questions were adapted to the patient, his pace and the context.

The number of interviews was determined following the principle of theoretical data saturation, which means, the recruitment of participants ceased when no new concept emerged during the next interview.

We conducted four in-depth interviews.

RESULTS

The content analysis made it possible to respond to the following themes.

Physical capacity

The patients all reported rapid improvement in their health: *«I have recovered to 70% capacity»*, *«my body is feeling better»*. They referred to the symptoms present during pre-dialysis as *«I didn't think kidney failure was denaturing the body like that»* while mentioning that they disappeared once on dialysis. Physical and even sporting activities were resumed *«despite the heaviness of the abdomen»*.

Emotional state

Everyone speaks of emotional shock at the announcement of the disease: *«it puts you in the hole», «it changes the outlook on life because when you're young you think you're invincible»*. They evoke the difficulty of choosing replacement therapy and speak of *«fundamental decision-making at a difficult time»*. They also report a *«sudden onset of dialysis»* although they *«expected, prepared and suspected it»* (only one patient started dialysis three months after the discovery of his CKD). They mention their *«surprise»* even though they knew that *«the last step is dialysis»*. They talk about the step by step in accepting the disease and the dialysis: *«we movr forward in stages, before I was trembling with fear»*. They then describe the feeling of *«appeasement»* because the dialysis *«makes me feel good»* until it is accepted and integrated into daily life: *«I feel better in my life», «it is the disease that changes my health. life, not PD»*. Patients also mention the satisfaction of being in control of their treatment: *«I am the one doing my care»* even if *«the hardest part for me is seeing myself undergoing dialysis»*.

Ability to participate in social roles and social activities

- Relationship with family / friends

The patients benefited from the support of their family circle but sometimes experienced some difficulties within the family unit: tiredness badly experienced, handling time too long.
Children easily accept this treatment carried out by their father or grandfather, which brings back a privileged moment during the manipulations, a calm time and a care which arouses the curiosity of the children. Dialysis has little impact on friendships: my friends *«treat me as before», «nothing has changed in their eyes»*. Some patients mentioned avoidance on their part at the start of treatment to *«not to have to talk about it», «not to have to explain their illness»*.

- Activities and professional life

The social life is maintained through leisure and artistic activities. Regarding their professional activity, two patients kept their jobs even if *«it is not easy to juggle between work and dialysis»*, another takes the opportunity to make a professional retraining. One of them specifies that professional difficulties arise from the CRF stage which can lead to incapacity for work. Then there was the problem of loss of income and the difficulty of obtaining bank loans.

Impacts of chronic kidney disease management

- Food

Food restriction is consistently described as *«the most difficult to bear»*. The patients evoke the loss of the pleasure *«of the table»* and of the social life related to the meals. You have to *«think about it all the time»* and *«it sidelines»*. They all report the immediate repercussions of a diet that is too salty, experienced as *«a call to order»: «I pay it immediately», «it's dangerous for me»* and *«I learned from my body»*.

- Body image

Patients speak of the difficulty in accepting the presence of the catheter: *«I avoid getting topless even in private», «I go to the beach but with a T-shirt»*.

- Home organization

After a period of adaptation, an automatism sets in: *«it's routine», «I thought it was more restrictive», «I have my dialysis time»* and *«I anticipate to have fu*n (during the handling time)» even if *«it is painful»* and *«it is dialysis that organizes my life»*.

Satisfaction with care

- Dependence on the team

Patients are satisfied with the information received from the pre-dialysis stage. They mention the attentiveness and availability of the teams, well-organized follow-up in a climate of trust which *«removes any doubt»* about the choice of technique. They know the members of the PD team which facilitates *«acclimatization»* to dialysis and consider the relationship with this team to be good to excellent.

- Prvate nurse

The patients interviewed are independent but all benefited, at their request, from support by a private nurse, from a few weeks to a few months, at the initiation of dialysis. The nursing intervention mainly concerned clinical monitoring of hydration status, management of «entries and exits», monitoring of emergence, but very little handling. Patients all report greatly appreciating this «invaluable help» experienced as a *«heartwarming presence at the start»* that *«takes away the anxieties»*.

Sleep disorder, interference and pain intensity

The participants all reported an absence of pain and restful sleep, in both APD and CAPD.

Suggestions for improvement

Patients would like to *«demystify the word dialysis»*. But according to them, only a *«witness»* patient can do it, *«I couldn't imagine what a catheter in the stomach could be»...*

Despite explanations of the different stages of dialysis, a specific meeting with people on peritoneal dialysis (or hemodialysis) is necessary to *«explain the process to other patients»* because one always *«has the impression of discovering things when 'we start dialysis'. It would be nice to improve visual aids and practical demonstrations and to be able to benefit from testimonials from «real patients»*.

DISCUSSION

The description of the day-to-day experience of kidney disease and PD treatment, based on patients' accounts, made it possible to assess and analyze the impact of this technique on their quality of life.

PD brings rapid improvement in health, both physical and emotional, as has already been shown in different studies that have used other self-assessment tools like SF-36, EQ- 5D and KDQOL [3,11]. The patients noticed the disappearance of the symptoms felt before dialysis and were able to quickly resume their usual activities. The emotional shock was especially present when the illness was announced. The choice of the dialysis tehcnique was mentioned as a difficult decision despite satisfactory information and support from the healthcare team. The period of pre-dialysis is a stressful stage, loaded with emotions. Decision making depends on a rational input of knowledge but mainly on the values, preferences and emotions of the patient [12, 13]. Starting replacement therapy is awareness of the chronicity of the disease; An adaptation process then takes place, sometimes long, so that the patient accepts both his disease in a new form and

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the associated treatment. As various patient testimonials point out, all techniques must be offered and the objective is to «find a balance in life» [14].

While PD allows rapid improvement in health and physical abilities, patients regret that it does not dispense with dietary restrictions, especially in sodium intake. This “regime” is considered to be an essential problem, the non-compliance of which has, moreover, a direct clinical repercussion.

Patients are satisfied with the technique they chose, however the acceptance process is a step-by-step process, as is the integration of PD into daily life. After an adjustment period, dialysis is perceived as a routine, an automatic process and allows the patient to regain a social, family and professional life. The ability to adapt dialysis to lifestyle is a major characteristic of home dialysis [13,15,16]: reduced mobilty, feeling of freedom, autonomy and independence linked to greater flexibility in schedules and treatment, allowing the patient to continue their activities, keep their jobs and travels. Peritoneal dialysis allows patients to implement their own treatment at home, in an environment conducive to comfort and well-being [11]. However, it has been shown that the patient can quickly become weary and feel overwhelmed by the care. He will then feel an invasion of dialysis in his daily life and his quality of life will be degraded [12,13,15]. If psychosocial factors play an important role in the choice of a home dialysis modality, they are also major causes of discontinuation of treatment [17, 18]. The patient must then benefit from optimal and continuous support [13, 15,16] through listening, availability and empathy from the PD teams.

The use of a private nurse, without any preconceptions about the patient’s age, social or cognitive level, can offer an appropriate transition period at the start of dialysis and has shown its interest in our center.

Individualized and personalized support is necessary [15,19] and recourse to patients already in PD should be offered. The expression of their daily life is appreciated through their testimonies, but their participation in more practical demonstrations with a focus on the catheter desired.

In order to keep patients in home modalities and improve their quality of life, it would be interesting to assess the impact of relaxing treatment goals and of prescribing flexibility.

LIMITS

The narrative interview method made it possible to meet our objective and analyze the themes we wanted to study. Patients felt listened to and appreciated the interest in their quality of life.
Our sample, although small, is representative of the patients in our center, mostly males and of extreme ages. It is possible that our results cannot be transposed to all PD centers in France, even if this technique is, in general, chosen by patients who benefit from good family support and a higher level of education. Our results are not currently generalizable; it would be necessary to carry out this kind of interview on a larger scale and on a more diverse population. In addition, it was necessary to adapt certain responses concerning the environment and the social impact of PD to the context of the current health crisis due to COVID-19 pandemic.

CONCLUSION

Quality of life is an important factor to take into account when choosing a renal replacement technique. This choice must be individualized and take into account psychosocial factors. Although PD is associated with many benefits, it can be seen as a burden, and referring a patient to a home technique without considering his concerns can negatively impact its quality of life. Understanding the expectations and wishes of patients is important for caregivers, as commitment and adherence to treatment depend on them. These aspects therefore have an impact on clinical outcomes.

Narrative interviewing is an effective method that allows clinicians to collect the story, to understand the patient's perspective, and integrate it into practice. The intervention of a patient partner reassures the patient and allows the sharing of difficult experiences. This method for assessing quality of life, which is certainly too time-consuming to be offered systematically, could be used to check the quality of care for our patients.

CONFLICT OF INTEREST

The authors declare not having any conflict of interest for this publication.

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