Cogitare Enfermagem

ORIGINAL ARTICLE

LIFE EXPERIENCES IN THE TRANSITION OF THE DIALYSIS MODALITY: FROM HEMODIALYSIS TO PERITONEAL DIALYSIS

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ABSTRACT
Objective: To describe the experience of the patients transitioning from haemodialysis to peritoneal dialysis.
Method: A phenomenological and qualitative study conducted with nine semi-structured interviews between September 2017 and May 2018. Inclusion criteria: Autonomy for peritoneal dialysis, change of substitutive renal therapy, and minimum permanence of two months in the previous and new renal therapies. Exclusion criteria: Home haemodialysis and psychic or cognitive impairment. A deductive-inductive codification paradigm revealed five main categories.
Results: The transition denoted separation from life depending on others and experimenting life changes, as well as adjustments to manage home therapy.
Conclusion: The experience mobilized resources to acquire a fluent and integrative identity, with a role being re-born characterized by personal satisfaction and responsibility in self-care.

DESCRIPTORS: Life-Changing Events; Transition Care; Renal Dialysis; Qualitative Research; Nursing Care.

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EXPERIENCIAS DE VIDA EN LA TRANSICIÓN DE MODALIDAD DIALÍTICA: DE HEMODIÁLISIS A DIÁLISIS PERITONEAL

RESUMO
Objetivo: describir la experiencia de los pacientes que transitan de hemodiálisis a diálisis peritoneal.
Método: estudio cualitativo fenomenológico con nueve entrevistas semiestructuradas, entre septiembre de 2017 a mayo de 2018. Criterios de inclusión: autonomía para la diálisis peritoneal, cambio de terapia renal sustitutiva y permanencia mínima de dos meses en la antigua y nueva terapia renal. Criterios de exclusión: hemodiálisis domiciliaria y deterioro psíquico o cognitivo. Un paradigma de codificación deductivo-inductivo reveló cinco categorías principales.
Resultados: la transición denotó separarse de una vida dependiente de terceros y experimentar cambios de vida, y ajustes para gestionar la terapia domiciliaria.
Conclusión: la experiencia vivida movilizó recursos para adquirir una identidad integradora fluida, renaciendo un rol caracterizado por satisfacción personal y responsabilidad con el autocuidado.

DESCRITORES: Acontecimientos que Cambian la Vida; Cuidado de Transición; Diálisis Renal; Investigación Cualitativa; Atención de Enfermería.

EXPERIÊNCIAS DE VIDA NA TRANSIÇÃO DE MODALIDADE DIALÍTICA: DA HEMODIÁLISE PARA A DIÁLISE PERITONEAL

RESUMEN:
Objetivo: descrever a experiência de pacientes que fazem a transição da hemodiálise para a diálise peritoneal.
Método: estudo fenomenológico e qualitativo, com nove entrevistas semiestruturadas, de setembro de 2017 a maio de 2018. Critérios de inclusão: autonomia para diálise peritoneal, troca de modalidade da terapia de substituição renal e permanência mínima de dois meses na antiga e na nova terapia renal. Critérios de exclusão: hemodiálise domiciliar e comprometimento mental ou cognitivo. Um paradigma de codificação dedutivo-indutivo revelou cinco categorias principais.
Resultados: a transição denota a possibilidade de abandonar a dependência de terceiros e experimentar mudanças na vida, realizando ajustes para gerenciar a terapia domiciliar.
Conclusão: a experiência vivida mobilizou recursos para adquirir uma identidade integradora fluida, assumindo um papel caracterizado pela satisfação e responsabilidade pessoal com o autocuidado.

DESCRIPTORES: Acontecimentos que Mudam a Vida; Cuidados de Transição; Diálise Renal; Pesquisa Qualitativa; Cuidados de Enfermagem.

INTRODUCTION

Chronic Kidney Disease is the progressive and irreversible loss of the renal function, which, in its advanced phase, leads to a Substitutive Renal Treatment with haemodialysis, peritoneal dialysis, or renal transplantation[1].

According to the Spanish registry of renal patients[2], in 2018, 54.7% of the patients with prevalence of Advanced Chronic Kidney Disease received a functioning renal transplantation in contrast to 45.3% who stayed on dialysis, the proportion of patients on haemodialysis (40.3%) being higher than on peritoneal dialysis (5.0%).

It is common to favour the assisted dialysis techniques in detriment of the home modality, whether due to the urgent arrival of patients to haemodialysis or to the deficiencies in the prescription and performance of peritoneal dialysis in many hospital centres[3]. This situation denies the patients the opportunity to explore other dialysis options; in fact, the studies demonstrate that, if the person's decision on the treatment choice is respected, a similar percentage chooses hospital and home techniques[3,4], which is in consonance with certain legal referents which protect the patients' right to choose their treatments[5].

The main causes for the change from haemodialysis to peritoneal dialysis are heart disease, difficulty in vascular access, and the patient's preference[6]; nevertheless, the life experiences of a person are unique, and it is not indistinct to face the individual to one therapy or the other[7]. Peritoneal dialysis offers greater autonomy, preservation of the renal function, and a better conciliation of the working and family roles; however, entering a home dialysis program implies a high level of self-care and responsibility, conditions which not all the patients are able to fulfil[8].

Facing a dialysis therapy generates doubts and fears in the patients, who must make adjustments and mobilize energies to attain a healthy transition[9]; it also supposes a great challenge and a clinical dilemma for the professional, especially when it is not an option that the patient desires, making this transition a problematic experience[10].

In the research approach, the reference adopted was Meleis' theory of transitions[10,11], which conceptualizes the transition as a passage where the person moves from on life state to another. In this journey, the person experiments profound life changes, creates new meanings and perceptions when faced with reality and, by means of mastering new knowledge and abilities, reformulates their behavioural pattern to recover their balanced state[10,11].

Human responses to the transition are conditioned by factors which promote or limit a healthy progress; this patterns, called process and result indicators, guide the Nursing therapy since they allow valuing the knowledge the person possesses about the transition, as well as the resources with which they handle the situation; process indicators like feeling connected, interacting, being-in-place, development of confidence and coping; however, the result indicators refer to the degree of mastery of the person in relation to the abilities and conducts available to attain a fluid and integrative identity[11].

The bibliographic review did not reveal any research study with a qualitative approach on the transition of the dialysis modality. Understanding the life experience of the patients who transition from haemodialysis to peritoneal dialysis rescuing their own narratives allows identifying critical points susceptible to improvement in the care practice, as well as empowering the patients to favour their self-care, minimizing the impact of the transition on their lives, hence the importance of investigating new aspects related with this process by means of research studies.

This scenario sets out the following research questions: How do patients with Advanced Chronic Kidney Disease live the transition from haemodialysis to peritoneal dialysis?; Which are the main changes they experiment?, and How do they integrate the

new renal therapy into their lives?; therefore, this study aims at describing the experience of the patients transitioning from haemodialysis to peritoneal dialysis.

METHOD

This is a qualitative study with a phenomenological approach, conducted from September 2017 to May 2018 with a universe composed of patients with Advanced Chronic Kidney Disease undergoing haemodialysis. The inclusion criteria were the following: autonomy for the peritoneal technique, change from haemodialysis to peritoneal dialysis, and minimum permanence of 2 months in the previous and new renal therapies. The exclusion criteria were the following: home haemodialysis and psychic or cognitive impairment.

15 patients were recruited in the Nursing consultation by convenience sample, after a process where information was given on the purpose and development of the study. No participants refused to participate.

Data was collected through semi-structured interviews and field notes. The interviews had an informal character, although there was a previous selection of questions by means of a guiding script which was submitted to a pilot test with two respondents to profile and reformulate not clarifying questions and introduce new ones. The interviews were started with an open question: How was your experience with peritoneal dialysis?, to then redirect the participants' statements to the questions which were set out, but always offering freedom of expression.

A 45-60 minute-long interview was conducted with each respondent in their homes, without the participation of any third party. The interviews were recorded and transcribed, the transcriptions being returned to obtain the participants' confirmation, until reaching the data saturation point, for a final sample of nine respondents (Table 1).

Table 1 - Sociodemographic characteristics of the respondents. Oviedo, Spain, 2018

Respondents	Gender	Age	Marital status	Work situation
Antonio	Male	71 years old	Married	Retiree
Jesús	Male	76 years old	Widower	Retiree
Blas	Male	52 years old	Married	Retiree
Cristina	Female	61 years old	Married	Housewife
Sonia	Female	68 years old	Widow	Retiree
Olaya	Female	46 years old	Married	Working
Ángel	Male	74 years old	Married	Retiree
Arturo	Male	75 years old	Married	Retiree
Oliver	Male	54 years old	Married	Retiree

Source: The author

The analytical strategy was based on content analysis by means of a paradigm of deductive-inductive coding which was made up of five stages: 1) Elaboration of the conceptual framework with an initial list of codes extracted from the bibliographic review on the life experiences of the patients undergoing dialysis; 2) Thorough reading of each interview; 3) Segmentation of the respondents' discourse with a relevant meaning for the research questions; 4) Process of deductive-inductive coding, where the a priori codes of the conceptual framework were applied to each segment; and 5) Grouping of the codes in categories, establishing thematic axis in which the life experience of the participants were articulated. The MAXQDA software was used as support in the analytical process.

Approval was obtained from the Clinical Research Ethics Committee (*Comité Ético de Investigación Clínica*, CEIC) under number 22/17, as well as the authorization of the Hospital centre Board of Directors. All the respondents participated freely and voluntarily, and signed the informed consent form. Their identities were preserved by using pseudonyms. The personal data and the content of the interviews were safeguarded by the lead researcher and the recordings were destroyed once the research had finished. This study comes from the article entitled "The experience during the transition from haemodialysis to peritoneal dialysis" from the 8th Ibero-American Congress on Qualitative Research of 2019[12].

RESULTS

The life experience of the transition was articulated in five main categories (Table 2).

Table 2 - Relation between categories and sub-categories. Oviedo, Spain, 2018

Categories	Sub-categories
Planning the transition	Acceptance vs. Denial
	Conscience and commitment
	Searching for/Receiving information
Peritoneal learnings	Motor abilities/Cognitive capacity
	Responsibility/Self-care
	Support network
	Process indicators
Managing life and peritoneal dialysis	Initial feeling towards peritoneal dialysis
	Adjustments in activities
	Time management
Life changes	Physical changes
	Psychic changes
	Socio-family changes
A new beginning	Mastery
	Integrative identity
	Result indicators

Source: The author

Category 1 - Planning the transition

The news of the change from haemodialysis to peritoneal dialysis supposed the critical moment which triggered the transition and was based on ambivalent feelings of fear, nervousness, or happiness when faced with the commitment of self-care.

I was very happy, although I was afraid, but I was wanting to change to peritoneal, I knew it was the best for me. (Arturo)

When the change was wanted, full acceptance was present but, in the case of those participants whose situations were imposed upon them due to health reasons, they fell into an initial renouncement, which transformed itself after preparing their minds to face the new future.

…. I had many [haemodialysis] catheters but they got infected, then they spoke about the peritoneal, and my soul fell down to my feet, I laid down for fifteen days to prepare mentally, change the chip and accept it. (Blas)

The technical information set out the benefits and risks of home dialysis in comparison with the hospital setting, and revealed the objective of a role based on dependence on others and on the possibility of returning to a less medicalized health care and, therefore, away from the identity of a sick person.

… when the doctor told me about the peritoneal, it seemed easy to me and then I realized what it implied… I was going to be able to stay at home and not to depend on the ambulance, they'd told me my health could improve. (Sonia)

On the other hand, the need emerged to expand knowledge in the view of immediate needs to gain self-confidence, which mobilized the search for information.

… they advised me on the peritoneal, but I wanted to look for more information to come prepared and see what it was that I was going to find… I could speak to others [patients on haemodialysis] who have undergone peritoneal, that helped me a lot, it took the fear away from me. (Oliver)

Category 2 - Peritoneal learnings

The training period prior to the beginning of the home therapy mobilized a proactive attitude which was key in the transition. Peritoneal dialysis was not considered a difficult therapy, but it did require the development of motor abilities and having enough cognitive capacity to remember following it systematically, as well as hygiene maintenance.

… it's easy [the peritoneal], but you have to repeat and repeat, until you remember all the steps, I found it hard to take the air out… it's very important to follow an order, and the hands must be very clean. (Ángel)

The quality of the teachings offered by the nurses promoted process indicators such as feeling connected and interacting with their support network to learn the self-management of dialysis and how to adapt it to their needs, thus establishing a process of nurse-patient interaction which revealed the connection of the participants to their reference nurses, as well as an awakening of confidence in view of the self-care demand implied by the new dialysis.

My life depends on the peritoneal, ah!, I have to do it well, that's what María [peritoneal nurse] told me, I did it because it's my health, I learned to wash my hands, to heal myself, I do all the things possible to care for myself, I have to be responsible because it's my own health. (Sonia)

The support received from the family was also an essential cornerstone to face each of the learning difficulties, as well as a driving force to overcome the first days of home

dialysis.

… I learned the peritoneal, and so did my wife, at first we did it together, she [wife] helped me because I was afraid of forgetting, besides she [wife] is the one who heals me, I cannot manage by myself. (Blas)

Category 3 - Managing life and peritoneal dialysis

Managing the beginning of the home therapy awakened feelings of fear and insecurity, although the support of the dialysis unit gave them confidence.

Ana [peritoneal nurse] called me every day to see how everything was going, that encouraged me a lot, that I was doing it right… I could also call if I needed to, that helps a lot. (Jesús)

It implied restructuring the home space to store the supplies, but no important alterations or huge expenditures were needed.

... I had to remove the two carpets and put more light in the room… (Arturo)

Similarly, it also implied restructuring the participants' lives since peritoneal dialysis required a different commitment than haemodialysis. Greater personal dedication to the therapy was revealed, which disclosed the need for making adjustments in the daily activities, as well as their ability to manage time with dialysis and life itself.

… I started changing some things in my life, of course! you have schedules for the dialysis and I want to go on with my life as much as I can… Yes! You have more freedom, but the interchange at noon limits you, but I already know how to organize myself. (Blas)

Category 4 - Life changes

The participants' physical condition improved, they felt more energy and vitality to carry out their activities, in harmony with a greater psychic well-being after the first coping moments, since they reported less anxiety and emotional exhaustion with respect to haemodialysis, with an emergence of optimism and decrease in the identity of being a sick person.

I was very happy, I came back to being who I was, I wasn't that anxious, it was mind-freeing, besides changing your life, I didn't feel sick any longer. (Ángel)

Carrying a catheter in the abdomen and the presence of liquid in the peritoneum revealed changes in physical appearance, with the emergence of answers of discomfort by the abdominal distension and the change in the way of dressing. The repercussion on self-esteem stood out in the female participants since they felt less attractive; nevertheless, as time went by they accepted the catheter as part of their bodies and their new image, thus assuming their new condition.

… now I'm very uncomfortable because I have a belly and it makes me feel bad aesthetically, but well I came to terms with the fact that it's my way of life. (Cristina)

The gain in freedom and autonomy for effective performance of peritoneal dialysis were the most noticeable concepts in the transition, which was evidenced in the desire to recover social life, travel, or planning vacations.

… my wife told me that I had improved a lot, I started to have more freedom, now I go play the game in the afternoons which I didn't felt like before. (Jesús)

Although the participants felt they were a burden to their families, family played a transcendental role and was identified as the main support during the adaptation to the transition; on the one hand, the family nucleus was freed when they saw their loved one in

better health, but they had to temporarily face an adjustment process for having to adapt their dynamics to the schedules of peritoneal dialysis.

My wife is my main support, now she's not that worried, but I think that I'm still a burden for her because she's still so behind me, that I take the medication, that I wash my hands, and of course she doesn't do other things she did before. (Arturo)

Category 5 - A new beginning

Living, functioning, and being healthier than before reflected certain mastery of the participants at the end of the transition, and was identified with the reconstruction of identity through changes in their health condition and in their behavioural pattern. The satisfaction of transcending to a new life condition was characterized by a greater level of well-being and hope for a future transplantation.

You feel different, you come back to being who you were, you feel that you're at another level, but better, ah!, I feel better, with my wife, with friends, with myself… your life changes, it was coming out of a tunnel [haemodialysis] and seeing the light [peritoneal], now it's just waiting for the transplant. (Antonio)

Initially, the participants were anguished, to later gain freedom and peace of mind, being able to integrate a new identity with new roles and responsibilities, not only as patients but also as family and social beings.

The peritoneal turns out to be a way of life, you have it so integrated in your daily routine, washing your hands, healing yourself, making the change and knowing you have to be responsible… but it leaves you margin to enjoy more time with the family, I couldn't do that with haemodialysis, I was always tired. (Olaya)

DISCUSSION

The passage of the patients in transition implied a transfer of roles from the dependence assumed in haemodialysis to the freedom obtained in peritoneal dialysis, as well as the improvement in personal well-being. This was an important feature of Meleis' theory of transitions, where the end of a transition implies that the person attains greater stability; nevertheless, it previously exposes the individuals to a higher risk of vulnerability, problematic recovery, or delayed coping[10,11].

While there are studies reporting fear for the responsibility of home dialysis[13], others notify the proportion of patients who experience the sensation of anguish regarding the beginning of dialysis (50%) or in the change of the dialysis modality (32%)[14].

On the other hand, the participants were able to gain awareness of the transition they were living, according to studies which assert that the individuals have to be aware of the change which is taking place in their lives to assume certain degree of commitment[10,11,15],

In this sense, knowledge is a tool of great value for the acceptance of a new dialysis, since the initial fear is usually related to doubts and uncertainty which dissipate after receiving adequate information, either from associations or professionals, or by contact with other people undergoing dialysis[16].

The respondents' reports stated that the role of the nurses is indispensable as the main caregivers who prepare the patients and their families for the imminent transitions, facilitating the learning process of new abilities related to the experiences of sickness and of health, this being a unique contribution of the profession to expand the conscience and the personal transformation and, therefore, to distance the patient from the identity of a

sick person[17], similarly to the disconnection phase of the theory of transitions[18].

The training on the aspects related to peritoneal dialysis awakened a dynamic attitude in the participants which favoured self-care and enriched the patient's connection with the nursing professional. The important role of the nurses has been communicated as one that provides a sensation of security to adapt the new life to the renal therapy, relieving part of the experienced fragility[19]; in the same vein, the importance is signalled of how the subject under care creates a close bond with the professional which allows expressing feelings, clarifying doubts, developing confidence, and managing changes in the daily routine[20].

The participants' interaction with their support network, especially their families, was identified as a tribute to the improvement of the general well-being which facilitated the participants' adaptation to the therapy, through the emergence of a process of trust in the other and of coping in view of the new reality[21], this being an indication of a healthy transition according to Meleis' theory of transitions[11].

Various studies[20,22] report that the fact that the patients having access to the guidance of the professionals from their homes gives them peace of mind, for them being close to their health process, thus contributing to an adequate management of peritoneal dialysis in everyday life; and this fact was evidenced by all the participants. The reorganization of the dialysis schedules to adapt them to the daily activities is reported in research studies[23-25] which evidence this adjustment as an incentive which mobilizes the individuals to integrate dialysis in their daily routines according to their behavioural guidelines and, in this way, to become self-care agents responsible for their own treatment.

The personal transformation that the participants lived during their adaptation to peritoneal dialysis as a struggle to deal with themselves when faced with the changes in their physical appearance, the ambiguous feelings generated, and how they managed to recognize themselves and become more autonomous were aspects reasserted by the participants themselves and widely discussed in other studies[7,8,19,22,24].

With respect to the socio-family dynamics, the family has been presented as a physical and emotional support for the patient as regards the renal disease, which motivates to keep struggling to overcome adversities[16], as well as an ally of the health team that watches for the recovery of the patient[20] and which was evidenced in the study by the influence exerted by the family network on the adherence to the dialysis treatment.

The participants' mastery revealed theoretical knowledge and practical abilities to manage peritoneal dialysis, as well as an adequate integration of the therapy into daily life and, therefore, an efficient performance of the new identity based on responsibility for the dialysis and for their self-care. In this sense, the studies evidence that the transition brings along the reformulation of the identity and the assumption of new behavioural patterns which lead to higher levels of satisfaction and well-being[26] and, in the same way, the end of a healthy transition is determined by the extent to which the individuals show mastery of new abilities to manage the new situation, access resources, or making adjustments for self-care[27].

In this aspect, it coincided with research studies that describe the transition, not only as a passage between two points but as a moment of reorientation and/or internal transformation which the individuals go through to incorporate the new change in their lives, by means of adapting to new roles, abilities or conducts and which, in the present study, was realized by higher levels of well-being, self-care, and integration as indicators of a healthy transition that reward the efforts for crossing personal limits, which was interpreted as a reformulated identity[11,25,27].

One of the limitations of the study is the non-generalization of the results, although certain transferability and practical applications could be assumed for the care provided in similar transition situations. Likewise, the permanence time of the participants in haemodialysis was variable, which could have distorted the experience of the transition.

CONCLUSION

The experience of the transition from haemodialysis to peritoneal dialysis revealed to be a vulnerable one which implied the development of a proactive attitude to accept, learn, and manage peritoneal dialysis with everyday life. Likewise, it confronted a process of adaptation and of role changes that denotes life changes in the physical, emotional, social, and family scopes, which resulted in higher levels of well-being and personal satisfaction and, therefore, in the acquisition of a new fluid and integrative identity.

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