

Life changes in Peritoneal Dialysis - Educating Patients for healthy transitions- the Portuguese experience

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LEARNING OBJECTIVES

- To understand the patient's experiences at the beginning of peritoneal dialysis (PD) treatment.
- To identify nursing theory of the Transition Model⁴ for facilitating patients in health/illnesses process.
- To recognize the properties of transition experience in PD patients.
- To identify the patterns of response (process and outcome indicators) in the beginning of PD treatment.
- To understand nurse's therapeutics that can be developed to educate patients for a healthy transition.

INTRODUCTION

Chronic disease presents an enormous challenge to current healthcare systems. Chronic kidney disease (CKD) a progressive and irreversible disease can lead to the need for renal replacement therapy (RRT). This paper aims to discuss patients' experiences of Peritoneal Dialysis (PD) in Portugal. In 2017, the Portuguese Society of Nephrology national data, set reported 756 prevalent patients receiving PD⁶. PD has many advantages: preserves residual renal function; greater freedom for patients to reorganize their personal time; fewer dietary restrictions and vascular access preservation. However, the demanding technique performance, strict hygiene rules, frequency and time of PD treatments can be considered disadvantageous⁷. Patients performing PD treatment face a health/illness transition, and the major goals for nurses are to prepare patients and families to facilitate the transition process, care for them during the transition and to improve their wellbeing and the quality of their lives. The Transition Theory developed by Afaf Meleis⁴ can support nurses with a framework, which can be applied in practice. This enables staff to learn from the patient experience by understanding: the nature of and responses to change; facilitating the experience and responding to its different phases; and promoting health and wellbeing prior to, during and at the end of the change event. This paper will discuss the findings of applying this theory to practice.

METHODOLOGY

To demonstrate how the Transition Theory works in practice, a qualitative research study using a phenomenological approach was used^{3,5}. The data was collected using semistructured interviews and included the following criteria:

- CKD patients who started PD in a nephrology unit in University Hospital of Coimbra, Portugal
- Time on PD between 6 months and 24 months
- Patients' consent to research.
- All ethical and legal requirements have been fulfilled

The Exclusion criteria included patients that refused participating in the research or that had no autonomy to perform PD.

The study sample originated 12 PD patients (8 male; 4 female); all married with a mean age of 49 years and one-year average time on PD treatment. Education/school levels were variable between elementary, high school and graduation. The etiology of CKD was primarily hypertension, diabetes and polycystic kidney disease. Using Colaizzi's methodology, described by Streubert and Carpenter³, we were able to conduct a qualitative analysis of the data to describe the phenomenon (Fig. 1).

Steps in Analysis	Purpose
1. Read and reread all interviews from the patients	To acquire the general feeling of experience the phenomenon "living in PD", the researcher read and reread all the interviews, while they were taped
2. Extract the significant statements	To generate information related to the experience at the beginning of PD treatment and live performing the PD. The researcher identified significant statements in the interviews
3. Formulating meanings	To construct meanings that elucidates the patients experience in PD, from the significant statements identified

4. Categorizing into clusters of themes and validating	To identify the themes that are shared to all patients in PD
5. Describing	To generate a exhaustive description of the phenomenon and a model structure
6. Returning to patients	To validate the findings
7. Incorporating findings and changes based on the patient's validations	To present a theoretical model that explains the phenomenon and reflects the experience in research

Fig. 1 - Colaizzi's Method of Analysis

The researcher interviewed patients using an interview script. The interviews were taped and transcribed verbatim which enabled the researcher to analyze and theme the findings⁷.

RESULTS

When the data was analysed, several themes emerged.

- Individuals experiences to starting PD treatment
- Facilitating and/or inhibiting conditions
- Patients' responses to PD treatment
- Experienced changes in PD
- (Re)building the day life
- Nursing care interventions in the health/illness transition process.

To help highlight how the patient's perspective led to the results, some of their own statements are detailed below according to the themes.

• "If I have to do it, I will do it"

Individual Experiences to start PD treatment

In the case of individual experiences to starting PD treatment, the personality characteristics of each patient was emphasized. In all participants, starting PD treatment was a critical event of life. This demonstrates that when patients are diagnosed with CKD and need a RRT to live, they experience several feelings and emotions such as: denial of the chronic condition; acceptance of their health status; impact of the decision on the choice of RRT and adaptation to CKD itself. For patients within the study, it appears the moment that renal failure was diagnosed it triggered the health/illness transition. For example, one person expressed that:

"The worst moment was when I recognized the diagnosis, was a bit sad. I am now more or less adapted to this, as I shall say, I'm resigned. What should I do? If it wasn't for this treatment I wouldn't still be here".

• "We create some drama around this"

Facilitating and / or inhibiting conditions

Several conditions influence the transition process when patients start PD treatment. Personal conditions are influenced by emotions, lifestyle, beliefs and knowledge acquired from family members, friends, health professionals or others patients with CKD. The family appears, as a resource, support and protection. However, this can be also inhibitive when the chronic illness situation influences all its structure, relationships and economic support. Community and Social support, work and employment, material and physical resources are also issues that can affect the experience of dialysis. The environment, information, previous experiences, or family members may be constraining factors, especially if they perceived negative experiences previously. A negative comment was from a patient who stated *"My job requires that I work a lot out of home but I have to always return home, whether I have longer vacation periods or only a few days, I have to take the machine and all the material for five to ten days or so"*.

• "I feel that this experience is very exhausting"

Patient's responses to PD treatment

There is no doubt that to perform a home dialysis modality requires a lot of time for a patient to learn how to perform the treatment safely. The interview analysis from participants permitted us to categorize the patient's responses to PD treatment by intrapersonal and interpersonal responses. Intrapersonal responses can be unfavorable and include: fear, concern; anxiety; depression; tiredness; feeling lack of freedom and discomfort. As an advantage patients experience: wellbeing; hope; dietary freedom and lack of pain.

Within the study, family and friends appeared to be a resource and offer protection but, in some cases, the patient felt excluded. In regard to peoples' professional and social domains, patient's may experience unemployment and social isolation. Figure 2 organizes the findings in regard to patient responses to PD treatment.

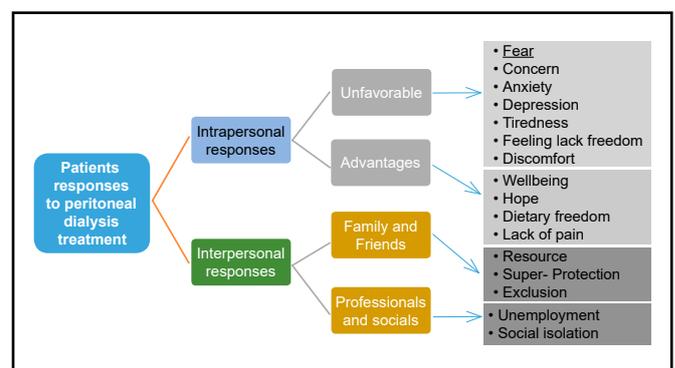


Fig. 2 - Patients responses to peritoneal dialysis treatment

A further comment from a patient was *"I think that PD gives us freedom, it gives us a certain quality, a certain quality of life. The difficulty is that whenever we move anywhere, we have to take a warehouse. If they developed some kind of computer, it would be easier; this is the frustration I see in peritoneal dialysis"*.

- “I do my treatment on time”

Experienced changes in PD

There is much evidence to show that patients need time to understand the disease and the PD treatment itself. Patterns of response in this regard are helpful to recognize indicators involved in the transition process. By analyzing the data from interviews, we could perceive the engagement required when they learn to perform treatment. People are seeking and receive support when they show concepts of self-care and acquire confidence when they comply with performing the PD. Each patient perceives their experience individually. A healthy transition process is essential for a successful therapeutic adherence. An example of this came from a patient who said -“*Look, I had to learn how to do the exit-site care, to wash my hands perfectly. And I had to learn how to do dialysis*”.

- “We need to have a schedule, rearrange our life plan”

(Re) Building the day life

Many changes and adaptations to life styles are encountered to allow for the dialysis process and it is important to identify the outcomes that subsequently occur. Information from interviews show that patients identify PD as fundamental survival. The mastery of the technique, the resourcefulness that they use and the healthy interaction allows identification of the person undertaking PD. Searching information, education and professional support help them to accept their chronic condition. Their perceived well-being and trying to adopt behaviors will empower them to live the day life without complications. PD treatment becomes part of the daily routine as a task, involving a new way of life “*It’s necessary I end up into this rhythm, that it’s a normal thing to do, it’s like going to drink a cup of coffee and read the newspaper. At this time I have to be there and it is there where I will be, doing dialysis*”.

- “The support, dedication and the way that nurse explained to me how to do dialysis”

Nursing care interventions in the health/illness transition process

Analysing the data, patients’ assumed the nurse’s interventions as a fundamental role in PD training. Nurses provide information, education, coaching and empower patients for their self-care and autonomy. The referred skills of relationship, communication, technical and scientific knowledge are essential in nursing care. Promoting transitional care, nurses liberate patients to be an active part of their health/illness transition process.

DISCUSSION

Patients undergoing PD experience a complex health/illness transition process. The critical points are the CKD diagnose and the need for RRT. Followed by, individual, family, social and professional changes which occur when they need to perform the actual dialysis . This transition can be facilitated or inhibited by conditions and complicated by the complexity of human responses. Blumental and Schwarz suggest that after the diagnosis of kidney disease, people experience a process of emotional, cognitive and behavioural changes in order to adjust to RRT, and they scope balance after the

development of coping strategies^{1,3}. The transition is a period of change with an indefinite time, as it causes suffering it needs time to be aware of all the changes. A period of adjustment is necessary. Studying patients experiences through qualitative methodology, nurses emerge in human care phenomenon³. Analyzing their experiences, we can illustrate a framework to demonstrate the need of nursing care through the experience of being on PD and understand the phenomenon of patient experience on peritoneal dialysis (Fig 3).

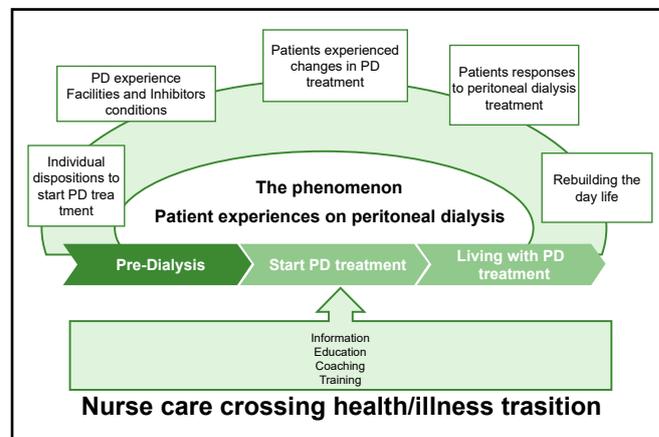


Fig. 3 – Patient experiences on peritoneal dialysis⁷

Hutchinson² states that people with CKD face multiple transitions, which can be a threat to their treatment, depending on the experience they have at the beginning. Therefore, health professionals need to be familiar with patient’s responses to the transition processes, to mobilize care and support, minimizing the emotional impact that this difficult period may have on their lives. During the pre-dialysis phase patients need information, guidance and support to choose a modality of RRT. Acceptance and adaptation to any chronic condition requires a therapeutic relationship between health professionals. Nurse’s interventions are fundamental to promote a healthy transition achieving wellbeing and quality of life. When initiated the dialysis treatment can induce a “fear” and “anxiety” moment that can influence all transition process⁷. Education, empowering and training are essential to promote a healthy experience performing the dialysis treatment. Acquiring autonomy and the ability to self-care, gives patients the necessary tools to move forward and seek for new goals in life.

CONCLUSION

Interpreting the information gathered from patients undergoing PD as it is experienced, can contribute to a better understanding of the details of this period of life for nurses wishing to improve their skills and scientific knowledge. By gathering this data we identified the need to establish and implement a **pre-dialysis nursing consultation** which incorporates the patient and his family in the PD experience process. The creation of **therapeutic groups to share experiences** and the **building of PD education programmes based on patients’ experiences** and responses can ensure that these programmes will meet future patient needs.

Patient’s experiences in the beginning of PD treatment are perceived as a process of health/illness transition, and they try to adopt a new life. Patients experience rejection, but also acceptance, decision-making and adaptation to CKD and PD

treatment. When initiating PD, many experienced a difficult period with evident emotional responses, these were mostly negative, and included comments like suffering. Family and friends support and nursing interventions can help patients to achieve a healthy transition. Nurses need to help patients to understand the disease, support and educate them for the new adaptations and new life perspectives. This integrated and individualized care when performed by nurses enables patients to feel supported with the disease and related PD treatment as a life process⁷.

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