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# EMPOWERMENT, QUALITY OF LIFE AND THE PERSONCENTERED CARE MODEL IN THE CONTEXT OF CHRONIC ILLNESS

#### Elisabete Lamy da Luz

Guest Adjunct Professor. Doctorate in Nursing.

Portugal. Instituto Politécnico de Santarém: Escola Superior de Saúde.

CIEQV-centro de Investigação em Qualidade de Vida

ORCID: https://orcid.org/0000-0002-4841-5251



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Abstract: Introduction: Person-centered care is related to Empowerment in the case of chronic illnesses. They focus on the person/family, community and decision-making processes related to promoting self-care in the management of therapeutic regimes. Person-centered care goes beyond not only most nursing models, but also current health promotion and policies.

Theoretical Framework: The concepts used in this study were mainly Empowerment.

Method: Qualitative cross-sectional study with data analysis according to grounded theory (Charmaz). 9 semi-structured interviews were carried out.

Results: the empowerment construction process was categorized through theoretical explanation: "facilitating the decision according to each person's mind" and was made up of three processes/categories: awareness of the need for change; perceive oneself as being capable of changing; deciding to change. This process consists of phases that will have to be resolved for the person to progress and are part of the nurse's intentionality when developing nursing interventions. Primary health care provides an excellent context for the application of person-centered care in chronic illness, due to its proximity to the population (McCormack & McCance (2017). Person-centered care and their needs seem to be part of a theoretical discourse on nursing, but without practical application in the area. C

Conclusion: The person-centered care model for chronic illness can give visibility to the nursing discipline, especially in obtaining health gains; having implications in terms of personal satisfaction, improved well-being, self-care and prevention of complications: particularly in preventing early deaths, reducing the number of hospitalizations.

**Keywords:** Empowerment; Chronic disease; Quality of Life, Person-Centered Care, nursing.

#### **INTRODUCTION**

The person-centered care model means a shift towards active involvement and ownership of each person's health journey. This approach recognizes people as active partners in their care, which ultimately leads to better outcomes and a better quality of life and care.

Nurses and healthcare, by combining these elements, the person-centered care model, training and education, can create a person-centered environment that helps individuals take an active role in their health, make decisions informed and working collaboratively with their healthcare team to achieve better health outcomes and improve the quality of care. With this article we aim to disseminate some results of the research we carried out and reflect on the empowerment result in the context of chronic illness and the person-centered model proposed by McCormack and McCance (2017).

#### THEORETICAL FRAMEWORK

Person-centered care model consists of the philosophy of most nursing models, but also of current health promotion and policies. It can be applied across the entire spectrum of healthcare. Recognizes the importance of individual empowerment and the role of people in their self-care regardless of the healthcare context or the nature of the illness. This model not only increases people's engagement, but also improves health outcomes by promoting the quality of healthcare.

Person-centered care focuses on the person/ family, the community and the decisionmaking processes related to the promotion of self-care in the management of therapeutic regimens. This model assumes a symmetrical relationship between the person and the nurse in the context in which professionals have knowledge and the person has experience in chronic illness. The theoretical framework of the study was anchored in the concept of a person with a chronic illness and therapeutic regimen and in its Empowerment, highlighting Meleis' transition theory, Orem's self-care and Rain's self-management, Sawin (2009), as well as the concept of Empowerment, as process and result (Rappaport, 1984; Gibson, 1991; Labonte, 1994; Perkins, 1995; Aujoulat et al., 2006; Tengland, 2007). The research was carried out in 2015 in the context of the doctorate in nursing. A cross-sectional study was carried out with 271 participants of both sexes, aged between 18 and 65 years and with chronic diseases, in which we characterized their level of Empowerment and identified factors related to this result. In the 2nd phase, 65 people with a high level of Empowerment were identified through the application of the individual Empowerment scale (Luz, 2017). Of the 65 people with chronic illness, we selected those who showed the highest level of Empowerment and carried out 9 interviews; which allowed us to deepen the identification of the personal and contextual factors of the participants that contribute to individual Empowerment and understand the construction of the process from the participants, developing a qualitative study.

#### **METHOD**

#### KIND OF STUDY

Descriptive cross-sectional qualitative study.

#### STUDY DESIGN

In the first part, it was decided to identify and develop the individual Empowerment scale and apply it in the CSP, in the ACES functional units. At this stage we created and validated the scale and from it we identified the people who had the highest values on the scale, that is, they were the most qualified. Subsequently, we selected nine users with the highest level of Empowerment and who agreed to carry out semi-structured interviews in a location of their choice (home or functional unit where the questionnaire was administered). We opted for the guidance of Grounded Theory (Charmaz, 2014) for data analysis.

#### THEORETICAL SAMPLE

Participants in the qualitative study were selected from the sample of 271 subjects according to their level of Empowerment. We identified 68 people with a high level of Empowerment, which was defined by applying a Likert-type scale from 1 to 4 values, corresponding to 25% of the sample, above 3.58. Participants were contacted considering, in descending order, the level of Empowerment; nine agreed to carry out the semi-structured interview. This was considered the theoretical sample because it guided the researcher on the path he needed to take to obtain explanatory data for the categories considering the conceptual and theoretical development of the topic.

#### **DATA COLLECTION**

Data collection took place from July to October 2015 through semi-structured interviews, which were carried out in a location chosen by the participants and previously scheduled with the researcher. They were recorded and transcribed. Thus, six interviews take place at home, two at the health unit and one at the workplace.

#### **DATA ANALYSIS**

The analysis of the nine interviews was carried out according to the Grounded Theory method proposed by Charmaz (2014).

#### **RESULTS AND DISCUSSION**

### TOM AKE THE DECISION EASIER ACCORDING TO EACH PERSON'S MIND

The process of "Facilitating the decision according to each person's mind" is made up of phases and explains the decision process according to individuality and what is understood during this process. The person has the ability to act in synergy with the world and the potential to manage and guide change. Awareness of the need for change will be the first step, characterized by the following indicators: Pre-awareness: Individual Factors: Attitudes (people and health professionals); Empowerment facilitating environment. Pre-awareness corresponds to in which the person already expresses openness to initiating change; There may be a confrontation with the clinical diagnosis and the need to start treatment, which will last for life. It can be a phase of shock with reality, but also, and often, the first contact with health professionals. Individual factors correspond to indicators that reflect the person's perception of the severity of their illness and their reaction to the diagnosis; each person reacts and "responds" according to the meaning attributed to the severity of the disease, which conditions awareness of the disease and treatments. People's attitudes may be characterized by flexibility in managing the therapeutic regimen, taking responsibility for managing it, and need for time. It is important for nurses to give people time to integrate the complexity of their regime and to be available to answer questions. Nurses' attitudes must promote and facilitate the person's internal dialogue, promoting different types knowledge, namely knowing how to mobilize and knowing how to transfer, creating a relational environment that facilitates critical reflection and self-knowledge. Awareness is a crucial step towards the integration of the therapeutic regime into the person's identity, and it is important for the nurse to facilitate awareness of the need to change for people with a chronic illness. Promoting reflection on their beliefs and values about the disease, their fears, about decisions and, above all, understanding whether the person feels capable of changing and providing information considering their need.

Perceiving oneself as being capable of changing will be the next stage, in which the person becomes aware of their internal power. This perception depends on a set of conditions that translate into the following indicators:

- Personal attributes of management style of the therapeutic regimen predominantly Responsible;
- Support or help from family and health professionals.

Family, friends and neighbors are the main support in managing the therapeutic regimen, especially in terms of the pharmacological regimen. Fun, humor, "forgetting about the illness" and friends are strategies that correspond to emotion-focused coping mechanisms in order to find ways to deal well with the negative emotions they face, which may take longer to resolve. use of problemcoping strategies. Professional focused support is highly valued and the "continuity" of the same professionals over time acquires the meaning of "being known", increasing the feeling of security. Being able to expose your anxieties and needs to professionals and feel confident in them is very important to promote self-knowledge and Empowerment.

The person will have to become aware of the need for change, this will be the first step towards later perceiving themselves as capable of changing and then deciding to change. This stage consists of integrating the therapeutic regimen and developing a fluid identity and mastery which is translated, in this study, by the following indicators:

- Do everything so well that it has become a routine;
- Make changes and achieve them;
- Maintain balance;
- (Con)living with chronic illness.

These three sub-processes occur when a person with a chronic illness is confronted with the diagnosis, at which point the nurse assumes the role of facilitator of the decision, considering the individuality of the human being. Raising awareness among people with chronic illness regarding their role is a very important step towards change, being the first without which change will not materialize.

However, not all people with chronic illness achieve this awareness. When it happens, the person commits to themselves and becomes increasingly involved, establishing goals and objectives, feeling "empowered". When a person feels that they have the power to change, they are actually prepared to do so, but may not have decided yet. It is then up to the nurse to establish a relationship of trust and mutual respect based on the meaning that people give to the problems posed by their chronic illness and their goals. The guiding thread of the nurse's intention will depend on the nature of the help that the person with a chronic illness needs. When a person with a chronic illness decides to change, it is up to the nurse to look at the present capabilities so that this change can come to fruition, (re) building identity and providing security; The professional assumes the role of facilitator of skills and competencies that allow the person to manage their therapeutic regimen. When a person really feels "empowered" and decides to change, they can achieve their goals and objectives.

This process is not easy, neither for the person with a chronic illness nor for the nurses, whose significant role was not recognized by the people who participated in the study. Seven

participants even mentioned that there was no contact or relationship with the nurses. Only one of the participants, who is followed in the APDP, mentions support and interventions from nurses, but in conjunction with medical clinical activities, based on monitoring of bodily processes, such as weight assessment, capillary blood glucose and teaching standard. It is important to understand why the most "empowered" people do not perceive nurses as a resource.

#### **DISCUSSION**

The theoretical explanation of the process "Facilitating Decisions According to Each Person's Head" means that the intentionality of therapeutic nursing interventions consists of supporting and promoting Empowerment, autonomy and responsibility in accordance with each person's individuality. This process of "Facilitating the Decision according to "each person's mind" is made up of phases that correspond to steps that will have to be resolved, on the part of the person to move forward, are part of the nurses' intentionality when developing therapies of nursing. Intentionality based exclusively on the acquisition of instrumental skills and adherence often fails in the face of necessary decision-making in health matters (Bastos, 2012). The development of the competence of "feeling empowered" is a challenge for nursing, because creating environments that promote growth from a "Rogerian" perspective allows both to grow and the encounter, presence and therapeutic relationship acquire a meaning promoting **Empowerment** being that, increases health gains for people with chronic illnesses.

We consider that primary health care provides an excellent context for the application of a model centered on people with chronic illness due to its proximity to the population, as mentioned by McCormack,

McCance (2017). However, in this study, we found that none of the participants mentioned the nurse as a resource or support in managing the therapeutic regimen at the PHC level, they did not attribute a meaning to it. The care model centered on the person and their needs seems to be part of a theoretical discourse of the nursing discipline, but without an effective translation of knowledge into the clinic.

#### **CONCLUSION**

**Implementing** the person-centered healthcare model in the context of practice may lead to empowerment as a result. Characterized by an individualized approach, as it considers the unique needs, preferences and objectives of each person in the care plans and strategies. This personalization empowers, recognizing each person's individuality and involving people in shared decision-making. Promoting a feeling of autonomy. Care plans are carried out together, considering people's lifestyle and preferences; This collaborative effort allows you to take ownership of your care and therapeutic journey. Person-centered care places more responsibility on the patient to actively participate in their care. This shift from a passive to an active role can lead to increased confidence and a sense of control. When people feel that their choices and opinions are valued, they are more likely to feel empowered in their healthcare journey.

This model also promotes improved communication because they encourage open and honest communication between professionals and people. This exchange of information allows them to express concerns, ask questions and be more proactive in managing their health.

Along the way, people experience the benefits of the model and see improvements in their health, they are more likely to commit even more and feel empowered to continue to effectively manage their chronic illness.

When we consider empowerment as a result, it involves observing tangible changes and results in the person's behavior, mentality and well-being. It is an ongoing process that means a shift towards active involvement and ownership of each person's health journey. This approach recognizes people as active partners in their care.

The person-centered care model is characterized by the authors as empowering; Therefore, its application at the level of nursing interventions and simultaneous evaluation of the Empowerment result could give visibility to nursing, especially in obtaining health gains; having implications in terms of person satisfaction, improvement of well-being, self-care, quality of life, and prevention of complications: particularly in the prevention of premature deaths, reduction in the number of hospitalizations.

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