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ADAPTATION MODEL IN A CONTROLLED CLINICAL TRIAL INVOLVING FAMILY CAREGIVERS OF CHRONIC PATIENTS

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ABSTRACT

Objective: to elaborate the conceptual and theoretical-empirical structure, based on the application of Roy's Adaptation model, to guide the development of a controlled clinical trial aimed at assessing the effectiveness of a nursing intervention program to promote the adaptation of family caregivers with caregiver role strain.

Method: theoretical study. The conceptual structure was developed in three phases: development of a comprehensive understanding of the conceptual model, literature review and construction of the conceptual and theoretical-empirical structure itself.

Results: the application process demonstrated its consistency in the design of an intervention program for family caregivers of chronic patients, to be tested in a controlled clinical trial. The indicators of adaptation were the reduced score on the caregiver tension scale and the increased perception of wellbeing and quality of life.

Conclusion: Roy's model serves as an important guide for nursing research intended to test nursing interventions that favor the wellbeing of family caregivers.

DESCRIPTORS: Caregivers. Nursing. Nursing theory. Chronic disease.

MODELO DE ADAPTAÇÃO EM UM ENSAIO CLÍNICO CONTROLADO COM CUIDADORES FAMILIARES DE PESSOAS COM DOENÇAS CRÔNICAS

RESUMO

Objetivo: elaborar a estrutura conceitual e teórico-empírica, a partir da aplicação do modelo de Adaptação de Roy, para nortear o desenvolvimento de um ensaio clinico controlado que avaliará a efetividade de um programa de intervenção de enfermagem para promover a adaptação de cuidadores familiares com tensão do papel de cuidador.

Método: estudo teórico. A estrutura conceitual foi desenvolvida seguindo três passos: o desenvolvimento de uma compreensão abrangente do modelo conceitual, a revisão da literatura e a construção da estrutura conceitual e teórico-empírica, propriamente dita.

Resultados: o processo de aplicação mostrou-se consistente no delineamento de um programa de intervenção para cuidadores familiares de pessoas com doenças crônicas, a ser testado num ensaio clínico controlado. Os indicadores de adaptação foram a diminuição da pontuação na escala de tensão do papel de cuidador e o aumento da percepção de bem-estar e qualidade de vida.

Conclusão: o modelo de Roy configura-se como um guia importante para a pesquisa de enfermagem que pretende testar intervenções de enfermagem que favoreçam o bem-estar de cuidadores familiares.

DESCRITORES: Cuidadores. Enfermagem. Teoria de enfermagem. Doença crônica.

MODELO DE ADAPTACIÓN EN UN ENSAYO CLINICO CONTROLADO CON CUIDADORES FAMILIARES DE PERSONAS CON ENFERMEDADES CRÓNICAS

RESUMEN

Objetivo: elaborar el marco conceptual-teórica-empírico, a partir de la aplicación del modelo de Adaptación de Roy, para guiar un ensayo clínico controlado que evaluará la efectividad de un programa de intervención de enfermería para promover la adaptación de cuidadores familiares con cansancio del rol de cuidador.

Método: estudio teórico. La estructura conceptual teórica empírica fue desarrollada siguiendo tres pasos: desarrollo de una comprensión amplia del modelo conceptual, revisión de la literatura y construcción del marco conceptual-teórica-empírica.

Resultados: la aplicación de la teoría fue consistente con el diseño de un programa de intervención para cuidadores familiares, a ser evaluado en un ensayo clínico controlado. Los indicadores de adaptación fueron la disminución en la puntuación de la escala cansancio del rol de cuidador y el aumento de la percepción de bienestar y calidad de vida.

Conclusión: el modelo de Roy es una guía importante para la investigación en enfermería que pretende evaluar intervenciones de enfermería que promuevan el bienestar de los cuidadores familiares.

DESCRIPTORES: Cuidadores. Enfermería. Teoría de Enfermería. Enfermedad crónica.

INTRODUCTION

In the 21st century, chronic conditions represent one of the main challenges in the health area. The number of adults diagnosed with chronic diseases continues to increase around the world. Many of them, at some point in the natural history of their illness, will probably need a family caregiver to provide care due to the limitations they may experience in their physical, mental or cognitive functioning.

Family caregivers organize and participate in medical consultations, participate in treatment decisions, coordinate care and services, ensure that food and shelter needs are met, help with daily tasks such as dressing, bathing and administering medications, as well as managing financial problems.[1] All of this makes the caregiver a vulnerable person who requires nursing care and attention. That explains the importance of this concern about the development of specific interventions that promote the well-being of family caregivers, especially those who experience strain in their caregiving role.

On the other hand, at present, the nursing has a wide and acknowledged spectrum of models and theories to guide research and care. Nevertheless, there are few studies that use these models or theories to develop interventions for caregivers of people with chronic conditions.

In order to contribute to the advancement of nursing, the studies should be based on theoretical and conceptual models within their area of study.[2] Therefore, this theoretical study aimed to elaborate the conceptual-theoretical-empirical (C-T-E) structure, departing from the application of Roy's Adaptation model, to guide the development of a clinical trial that will evaluate the effectiveness of a nursing intervention program to promote the adaptation of family caregivers with strain to the caregiver role. To achieve this goal, three steps were taken:[2] I) developing a comprehensive understanding of the conceptual model and its guidelines for research; II) literature review on the use of the model as a basis for research and III) construction and description of the C-T-E structure. These three components, conceptual-theoretical-empirical (C-T-E), are articulated as foundations for the empirical research.

The conceptual component is the most abstract and deals with generic propositions involving the main concepts of interest; the theoretical component, less abstract than the conceptual component, deals with specific concepts deriving from the conceptual model that focus on a particular research question; the empirical component, the most concrete of the three, seeks to identify the ways in which the data will be collected and the analyses necessary to make sense of the data and to draw conclusions about the theory that has been generated or tested.[2]

It is important to point out that the elaboration of the C-T-E is important for nursing because it permits structuring its own body of knowledge, it provides a reference framework that informs the nurses who work in the field of research or care to family caregivers of people with chronic diseases, on how to observe and interpret the phenomena of interest to the profession.

RESULTS

Roy's adaptation model

The main concept of the model is adaptation, understood as the process and result by which sensitive and thinking people, as individuals or groups, use consciousness and choice to create human and environmental integration. The human person is a holistic adaptation system, with components that function as a unit with a purpose. The environment, in turn, is seen as all the conditions, circumstances and influences that affect or permeate the development and behavior of the adaptive human system, particularly considering the person and the resources of the earth. Adaptive responses promote survival, growth, reproduction, mastery and transformations between the human being and the environment, and fulfilling the purpose of life is reflected in becoming integrated and complete. Thus, health in the adaptation model is defined as a state and a process of being and becoming an integrated human being; and the lack of integration represents a lack of health.

The following are the main components of the Adaptation Model.[3]

Stimuli: constitute the entry into the system and are classified as focal, contextual and residual. The focal stimulus is described as an internal or external stimulus more present in the consciousness of the individual or group. Contextual stimuli are all other stimuli present in the situation that affect or contribute to influence the focal stimulus, without being the center of attention or energy, but these factors affect the way the person deals with the focal stimulus. Residual stimuli are environmental factors, inside or beyond human systems, whose effects on the situation are unclear or cannot be validated. When their effects are known, residual stimuli become contextual stimuli.

Coping processes: Inborn and acquired coping processes are categorized into two major subsystems, the regulator and the cognator. The regulatory subsystem is a type of basic coping process that responds to stimuli that originate externally or internally through neural, chemical, and endocrine coping channels. In relation to the cognator subsystem, it responds through four cognitive-emotional channels: perception and information processing, learning, judgment and emotion.

Adaptive modes: in the model, four adaptive modes are described as categories in which individuals' behaviors can be observed.

- Physiological function mode: includes physical and physiological mode. It comprises nine subdimensions and five basic needs (oxygenation, nutrition, elimination, activity and rest and protection); and four complex processes (perception, fluids and electrolytes, acid-base balance, neurological function and endocrine function).
- Self-concept mode: includes behaviors related to the personal aspect of human systems. It refers to the adaptability of individuals and groups in modes of self-concept and image identity.
- Role function mode: corresponds to the knowledge category about the roles of people. It is related to the effectiveness of adaptation, considering the roles that people play in relation to others.
- Interdependence mode: explains the behavior of interdependence relations. For any relationship, the mode of interdependence helps to describe purpose, structure and development. Each relationship of interdependence exists for some purpose and, through these relationships, people continue to grow as individuals and contribute to society. Relationships of interdependence involve the willingness and ability to give to others and accept from them all that they can offer, such as love, respect, value, education, knowledge, skills, commitments, material possessions, time, and talents.
- The level of adaptation: it represents the situation of the processes of life. The level of adaptation affects the individual's ability to respond positively to a situation. There are three levels: integrated, compensated and committed life processes.
- Integrated: refers to the structure and functions of life processes, working as a whole to meet human needs.
- Compensatory: at this level, the regulatory and cognator coping subsystems have been activated to respond to threats or challenges from integrated processes.
- Compromised: occurs when the above processes are insufficient, generating an adaptation problem.

- Behaviors: the outputs of the systems are categorized into adaptive responses and ineffective responses. Adaptive responses promote a person's integrity. Integrity is shown behaviorally when a person is able to achieve goals in terms of survival, growth, reproduction and mastery. Ineffective responses do not support these goals.

In line with the Adaptation model, the nursing professionals are interested in the person-environment interactions that promote maximum human development and well-being. The target of nursing is to promote individuals' adaptation in their five modes (physiological function, self-concept, role function and interdependence), contributing to their health, quality of life and dignified death.

Family caregivers from the perspective of Roy's adaptation model

According to the model, the different stimuli, whether focal, contextual or residual, trigger the systems of regulatory and cognitive coping, triggering behaviors that, in turn, will define the level of adaptation to the role of caregiver. In the family caregivers, the main focal stimulus is the responsibility to give care to the family members with chronic illness who depend partially or totally on the caregivers to meet their needs. Focal stimulus is responsible for activating the available coping mechanisms of family caregivers to seek physical and psychological resources to cope with this responsibility.

Contextual stimuli that contribute to the effects of focal stimuli on the family caregivers' situation include: sex, race, kinship, relationship, care demands, stressful life events derived from care, as well as social support.[4]

Studies have shown that women caregivers suffer a greater burden than male caregivers.[5-6] In addition, when women are solely responsible for caring, they may experience feelings of guilt over not caring enough.[7]

In one study, the authors reported that female caregivers and young adults in general reported having had more negative experiences related to care than male caregivers and spouses, respectively.[8] Caring wives were the least likely to report positive experiences deriving from care.[9] Results from a systematic review showed that female caregivers reported more psychiatric symptoms than male ones.[9] Comparisons between caregivers and non-caregivers suggest that caregivers' experience increased psychiatric morbidity due to care delivery. In addition, women are at a higher risk of psychiatric morbidity than men.[9]

With regard to other social and psychosocial variables involved in family caregiver adjustment, there is evidence to suggest that African-American caregivers experience less stress,[10-11] obtain more gratification[10-11] for caring, and have higher levels of mental health when compared to white caregivers.[12] Family caregivers who do not have a good relationship with the care recipient report more strain.[13]

Demand for care refers to direct and indirect care arising from the illness of the care recipient which the family caregiver needs to attend to, involving hours of care, amount of care, supervision of daily needs,[14] and financial issues.[15] Stressful life events are physical and/or psychological experiences that may represent significant changes in people's lives.[16] The literature shows that high demands for care and stressful life events deriving from care are related to the increased perception of burden[17] and psychological distress among family caregivers.[18]

Social support is a multidimensional concept associated with the health of individuals. For family caregivers, social support is a protection factor against the perceived burden,[19-20] besides being related to the reduction of negative care outcomes.[21]

Given the lack of consensus among the different authors regarding the conceptual and operational definition of social support, to design the intervention program to be tested in the controlled clinical trial, it was defined as social resources[22] involving any information, whether spoken or not, and/or material assistance and protection that people perceive to be available and which are effectively provided by other persons and/or groups with whom there are systematic contacts and which result in positive emotional effects and/or behaviors.[23] Based on the above, it is proposed that social support of the family caregiver moderates the intensity of the focal stimulus.

On the other hand, and considering that the effect of social roles on the well-being of family caregivers of people with chronic conditions is not yet clear, it is proposed that social roles are a residual stimulus. In the context of family caregivers, the social role is defined as the responsibilities or functions beyond their role as caregiver, towards other people in other aspects of life, such as the role of worker, parent or volunteer.[4]

With regard to family caregivers, the results of the studies that deal with the possible effects of having multiple roles diverge. One study found that additional roles in caregiving did not increase the stress levels of women caring for family members.[24] The authors suggested that family caregivers with multiple roles, such as being a mother and being employed, could experience higher levels of well-being than those with lesser roles, besides being associated with a better state of health. Female caregivers could even reduce stress when they had other roles besides family caregiver.[24]

One study found that spending more time on the job did not affect the caregiver's stress outcome.[25] Caregivers who cared for a person with a mental disability experienced significantly less stress when they spent more hours involved in their job.[25]

In contrast, in another study, it was evidenced that stress related to the care for sick parents was aggravated when female caregivers were also employed and had at least one child of up to 25 years old at home.[26] Supporting these findings, other authors found that caregivers who took care of children while taking care of relatives with cancer were particularly prone to experience psychological distress and greater difficulty in finding meaning in the role of caregiver for a person with cancer.[7]

The environmental stimuli of the family caregiver are processed by the regulatory and cognitive subsystems that act in the adaptive modes. It is emphasized that the regulatory subsystem is particularly relevant in family caregivers, as the continuous exposure to stimuli that require adaptation may activate mechanisms that involve the deregulation of the neuroendocrine-immunological axis, including the autonomic nervous system and the hypothalamic-pituitary-adrenal axis, leading to the deregulation or deterioration of organic functions.[28]

As the adaptive modes are intertwined, environmental stimuli can manifest in all of them. This means that an adaptive or ineffective response of family caregivers may suggest changes in several of their adaptive modes (physiological function, self-concept, role function and interdependence). These changes determine the caregivers' level of adjustment.

The physiological function mode is the means by which the caregiver responds to stimuli as a physical being. The self-concept mode refers to the caregiver's self-concept. The role function mode involves how the caregiver responds to stimuli in relation to the roles he or she plays in society and their performance. The interdependence mode is defined as the close relationships between the caregiver and other people. These relationships involve the willingness and the abilities to love, respect, and value others.

The ineffective responses of the family caregiver include, in the physiological mode: decreased immune function,[29] increased cardiovascular reactivity,[30] increased blood pressure, disorders[31] and worsening of sleep quality,[29,32] weight loss or gain,[33] loss of appetite[34] and fatigue.[35] In the self-concept mode: symptoms of depression,[36] anxiety,[35] emotional stress,[36] somatization,[37] low self-esteem,[38] constant worry, feelings of uncertainty,[39] anger, guilt,[40] resentments, sadness,[35] feeling of frustration,[41-42] of burden,[43-44] feeling of lack of control over one's own life,[45] among others. In the role function mode: role conflict,[9] dissatisfaction with caregiver role.[46] In the interdependence mode, the ineffective responses can be low satisfaction with life,[47] family conflicts[44,48] and isolation.[49]

As seen, the family caregiver's adaptation to the care for his relative with chronic illness is a complex process involving internal and external factors that influence their responses and levels of adaptation. Adaptation is the observed outcome of changes in the physiological function, self-concept, role function and interdependence modes, which allow the caregiver to experience well-being. Figure 1 represents the concept adopted here for the adaptation of family caregivers with chronic diseases according to Roy's model.[5]

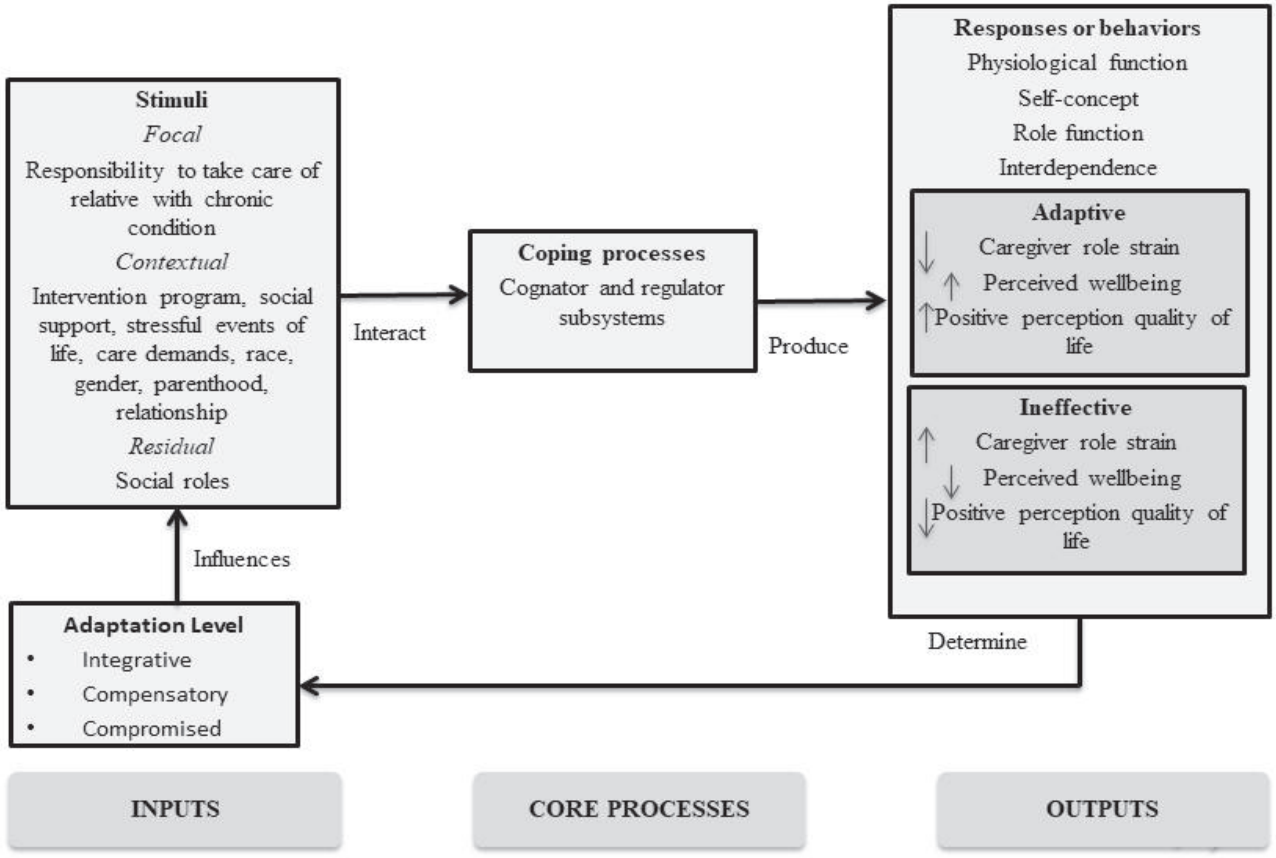

Figure 1 – Adaptation of family caregivers according to Roy's model

Literature about intervention studies using Roy

In the literature, there are studies that have used Roy's Adaptation Model to develop the research.[50-51] Nevertheless, despite its validity, to guide the design or to explain the effects of the interventions,[52-53] only one intervention study was found that involved family caregivers of adults with chronic conditions, with a quasi-experimental, "before and after" design, which evaluated the effects of an intervention based on an information leaflet for caregivers of people with kidney failure on hemodialysis.[54] Based on a literature review and expert advice, the structure and content of the questionnaire and leaflet were developed. The sample of 30 people was non-probabilistic. After the pre-test, the caregivers received the leaflet. The post-test evaluation was performed one week after the pre-test. The author reported statistically significant findings on improved caregiver knowledge after the intervention. The global pre-test score was 50.35 and the post-test score 86.25. The variance analysis did not show a correlation between the demographic variables selected and the variable post-test knowledge.[54] Also, the author did not mention how the adaptation model was applied or operated within the research.

Conceptual-theoretical-empirical structure of the research

The conceptual-theoretical-empirical (C-T-E) structure to guide the clinical essay that will assess the effectiveness of a nursing intervention program to promote the adaptation of Family caregivers to people with chronic conditions with caregiver role strain was elaborated deductively,[4] moving from the more generic conceptual model to the empirical indicators, being the more concrete elements of the structure. The C-T-E structure proposed is displayed in Figure 2.

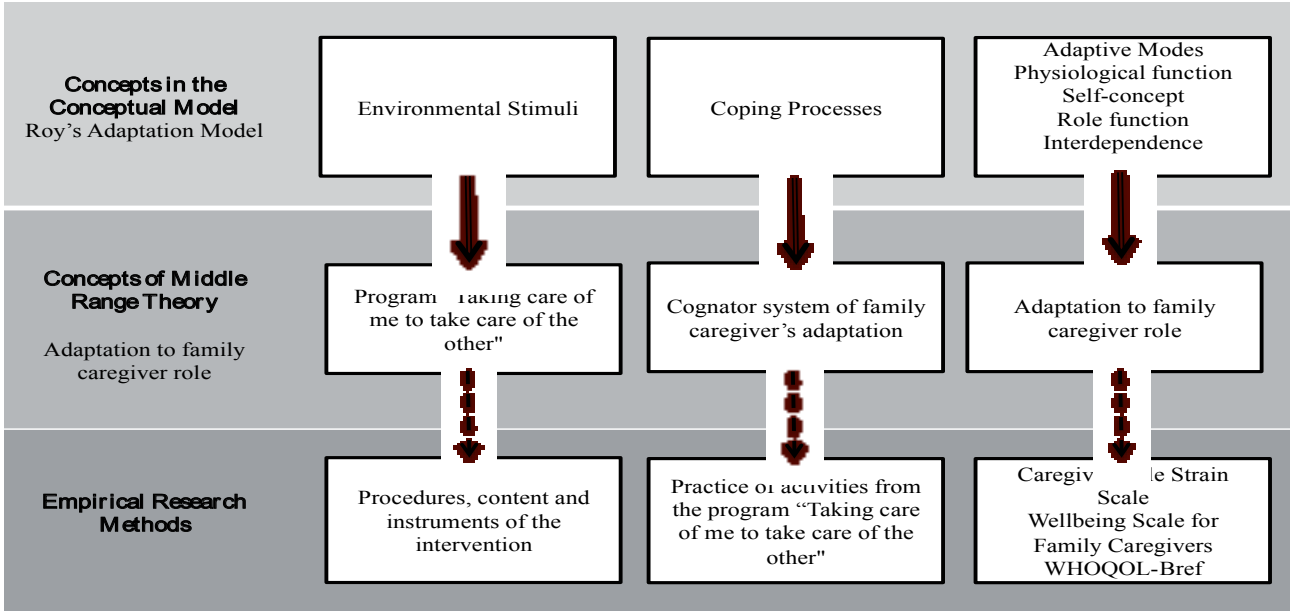

Figure 2 – Conceptual-theoretical-empirical (C-T-E) structure diagram proposed for the research

Based on Roy's model, the following propositions were derived for the research:

- Taking responsibility for the care of a family member with chronic illness (focal stimulus) is an experience that affects both coping - cognator and regulator -subsystems.
- The adaptation of the family caregiver is sensitive to the manipulation of contextual stimuli.
- All adaptive modes are interrelated, so that everyone will be affected in case of family caregivers with caregiver role strain and everyone will be integrated into the adaptation.
- A nursing intervention program for the promotion of the caregiver's adaptation is a contextual stimulus that interacts with other contextual stimuli, affects the focal stimulus and activates the coping mechanisms of the caregiver with caregiver role strain towards the compensatory level, relieving the caregiver role strain and improving the well-being and quality of life.
- The nurse, through the intervention program, promotes the adaptation by supporting the change of perceptions, the construction of knowledge, the development of skills, and the encouragement of the use of problem solving strategies.

According to the medium-range theory, the concept of environmental stimuli of the Adaptation model corresponds to the "intervention program for caregiver adaptation". Assuming that this program will promote the caregiver's adaptation, it is defined as a contextual stimulus. In the more concrete sphere, which corresponds to the research methods, this component is represented by the content, procedures and instruments used in the intervention (Figure 2).

The concept of coping processes of the Adaptation Model is represented at the level of the medium-range theory by the cognator subsystem of family caregiver adaptation (Figure 2), defined as the ability of the caregiver to change perceptions related to their experience as caregiver, as well as the ability to gain new knowledge, develop skills and apply them in daily situations. At the level of the empirical research methods, this concept is represented by the caregiver's reports (Figure 2).

The concept of adaptation modes in the Adaptation model is operated as an adaptation to the role of family caregiver according to the medium-range theory (Figure 2). The adaptation to the role of family caregiver is defined by the family caregivers' responses resulting from their taking responsibility for the care of a family member with chronic illness. These responses, when it comes to empirical research, can be observed by the diagno-

sis of caregiver role strain, by the nursing outcome caregiver wellbeing and by the perceived quality of life (WHOQol-Bref) (Figure 2).

CONCLUSION

Through this theoretical study, we were able to show the application of Roy's Adaptation Model to guide the development of a controlled clinical trial that will evaluate the effectiveness of a nursing intervention program to promote the adaptation of family caregivers with caregiver role strain, who take care of a loved one with chronic conditions. This model was chosen because it supports the promotion of the caregivers' adaptation to their caregiver role, in addition to guiding the focus of nursing research and practice.

The model permitted outlining an explanatory theory of the impact of care on the family caregiver's adaptation. The Family caregiver adaptation theory derived from Roy's conceptual model allows us to understand the impact of care responsibility on the family caregiver, as well as to provide a framework for testing the effectiveness of the intervention program in a controlled clinical trial. It should be emphasized that exploring the stimuli related to the caregiver role allowed us to advance in the understanding of the complex and multifactorial nature of the adaptation process to this role in the family caregiver.

We hope that the description of the application of a conceptual model in the nursing research presented here will be useful for other researchers to design their research, develop interventions and interpret their findings from a nursing perspective. The findings of this theoretical study contribute to the body of knowledge of the nursing discipline by showing that the Adaptation Model is sufficiently robust to support and structure an empirical study.

Finally, this study shows how the Adaptation model can be used to guide an intervention study in family caregivers of people with chronic diseases. Roy's model is useful in guiding the process of evaluating the adaptation of family caregivers to situations involving the care for a loved one with a chronic condition. Also, it serves as an important guide for nursing research that intends to test nursing interventions that favor the well-being of this group of people.

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