

Indicators of the applicability of nursing instructions in the daily lives of alzheimer patient caregivers

INDICATIVOS DE APLICABILIDADE DAS ORIENTAÇÕES DE ENFERMAGEM NO COTIDIANO DE CUIDADORES DE PORTADORES DE ALZHEIMER

INDICATIVO DE APLICABILIDAD DE LAS ORIENTACIONES DEL CUIDADO EN LO COTIDIANO DE LOS CUIDADORES DE LOS PORTADORES DE ALZHEIMER

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ABSTRACT

We aimed to describe the instructions that Alzheimer patient caregivers receive before they participating in the Neuro-geriatrics Center; analyze the applicability of the instructions received at the Neuro-geriatrics Center in everyday home care; and identify the coping and adaptation mechanisms found in these caregivers. We adopted a qualitative approach, in this descriptive-exploratory case study. The chosen technique for data collection was the semi-structured interview. Subjects were 15 caregivers seen at a Federal Hospital in Rio de Janeiro. Data analysis was performed using thematic content analysis, and three categories were obtained: Instructions received before participating in the Neuro-geriatrics Center; Instructions received at the Neuro-geriatrics Center; Coping and adaptation mechanisms within the context of family care. It is concluded that the coping mechanisms are used to adapt to overload situations, which can be relieved through the educational and emotional support received in the orientation groups.

KEY WORDS

Caregivers.
Alzheimer disease.
Health of the elderly.
Geriatric nursing.

RESUMO

Objetivamos descrever a orientação recebida pelo cuidador do portador de Alzheimer antes de sua participação no Pólo de Neurogeriatria; analisar a aplicabilidade das orientações recebidas no Pólo de Neurogeriatria no cotidiano do cuidado domiciliar; e identificar os mecanismos de enfrentamento e adaptação encontrados nesses cuidadores. Adotamos uma abordagem qualitativa, do tipo estudo de caso, descritivo-exploratório. Como técnica de coleta dos dados, utilizamos a entrevista semi-estruturada. Os sujeitos foram 15 cuidadores atendidos num Hospital Federal do Rio de Janeiro. Para tratamento dos dados, optou-se pela análise temática de conteúdo, obtendo-se três categorias: Orientações recebidas antes da participação no Pólo de Neurogeriatria; Orientações recebidas no Pólo de Neurogeriatria; Mecanismos de enfrentamento e adaptação no contexto do cuidado familiar. Concluiu-se que os mecanismos de enfrentamento são utilizados para a adaptação à situação de sobrecarga, podendo ser amenizada pelo apoio educativo e emocional recebido nos grupos de orientação.

DESCRIPTORIOS

Cuidadores.
Doença de Alzheimer.
Saúde do idoso.
Enfermagem geriátrica.

RESUMEN

Objetivamos describir la orientación recibida por el cuidador del portador de Alzheimer, antes de su participación en el Polo de Neurogeriatria; analizar la aplicabilidad de las orientaciones recibidas en el Polo de Neurogeriatria en lo cotidiano del cuidado domiciliar; e identificar los mecanismos de enfrentamiento y adaptación encontrados en los cuidadores. Adoptamos un abordaje cualitativo, del tipo estudio de caso, descriptivo y exploratorio. Como técnica de recolección de datos utilizamos la entrevista semiestructurada, los sujetos fueron 15 cuidadores atendidos en un Hospital Federal de Río de Janeiro. Para tratamiento de los datos, se optó por el análisis de contenido, del tipo temático, obteniéndose tres categorías: Orientaciones recibidas antes de la participación en el Polo de Neurogeriatria; Orientaciones recibidas en el Polo de Neurogeriatria; Mecanismos de enfrentamiento y adaptación en el contexto del cuidado familiar. Se concluye que los mecanismos de enfrentamiento son utilizados para adaptarse a las situaciones de sobrecarga, la que puede ser amenizada por el apoyo educativo y emocional recibido en los grupos de orientación.

DESCRIPTORIOS

Cuidadores.
Enfermedad del Alzheimer.
Salud del anciano.
Enfermería geriátrica.

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INTRODUCTION

The increase of the aging population all around the world also increases in direct proportion, the relevance of healthcare attention, not only in the physical realm, but also in regards to the mental status of the population of 65 years of age and older. From this point on, afflictions common to elderly people emerge, and one of the most devastating for family members is dementia, such as Alzheimer's. The impact of the diagnosis for them can be overwhelming due to their lack of knowledge of the disease, what to do, how to react, how to understand the affected person, and above all how to discern their own feelings concerning their caregiving role⁽¹⁻⁴⁾.

Literature reveals that the nurse plays an important role in the development and application of such orientations to caregivers⁽⁵⁻⁹⁾. However, this study will focus on the following objective: the relationship between the instructions caregivers receive in the orientation groups coordinated by the nurse and their applicability in the daily life of the elderly person with Alzheimer's.

We understand that caregivers must be familiarized with the disease's stages the characteristics of each one of them, and the care that is needed at each stage in accordance with their everyday reality⁽¹⁰⁾. It is important for caregivers to learn and understand that the patient with Alzheimer's capacity to perform any activity will decrease day after day, as he continually loses his cognitive functions. Hence, dealing with the elderly patient who develops Alzheimer's requires not only information, but also caregiving solidarity⁽¹¹⁾.

Bearing that in mind, we observed the need to develop ways of helping the caregiver adapt to this *new* reality that creates so many critical moments; this observation led us to Callista Roy's Adaptation Theory and the grounds to explain direct care to the family caregiver, and the indirect care to the elderly patient with Alzheimer's. The theory presents the concept of adaptation as the guiding axis of the Nursing practice, which considers the person as an open system, undergoing continuous changes, and attempting to adjust to reality. The concept employs either inherent or acquired adaptive mechanisms towards this end, which are part of the person's cognitor's subsystem, that is, stimulus that individuals receive in their life context that will positively or negatively reinforce their physical or mental health status⁽¹²⁾.

We therefore formulated the question: what is the perception that people who provide care to elderly Alzheimer's patients have concerning received instructions and their applicability to the elderly patient's daily caregiving? Focusing on the family caregiver's assimilation of the instruction process, the following objectives were outlined: describe how Alzheimer's patient's caregivers were instructed

prior to their participation in the Neurogeriatrics Center; analyze the applicability of the instructions received at the Neurogeriatrics Center to everyday home care; and identify the confrontation and adaptation mechanisms found in Alzheimer's elderly patients' caregivers.

METHOD

This research adopted the descriptive study qualitative approach, using a case study-based method. The semi-structured interview was comprised of open and semi-open questions and was used for the generation of data regarding individual characteristics; kinship to the client; client's follow-up time; knowledge of dementia; knowledge about the received instruction; place where instruction was given; and whether or not the received instruction regarding dementia assisted them to better care for their family member.

For the organization and refinement of reports, this study chose to use the thematic analysis, one of the ways to refine data in the content analysis process. Therefore, the operationalization of the work followed the literal trans-

cription phases of the recordings, floating reading, codification of reference units (RU), organization of RU frequencies into synthesis tables, RU discrimination into thematic categories, and designation of content emergent categories.

Three categories were defined in the data classification process: instruction received prior to the participation in the Neurogeriatrics Center; instruction received at the Neurogeriatrics Center; and confrontation and adaptation mechanisms in the family context. The declarations are referred to with the use of pseudonyms, such as knowledge, patience, honesty, confidence, humility, hope, and courage, according to the caregiving ingredients found in a study⁽¹²⁾.

The chosen scene was the Lagoa Hospital, located in the southern area of the municipality of Rio de Janeiro, and more specifically the Neurogeriatrics Center that functions as the hospital's laboratory; the center proposes an alternative assistance model grounded on the healthcare needs of the population⁽¹³⁾. The center makes two types of services available: one service assists approximately 200 elderly patients in multi-professional consultations and inter-consultations; the second, in its turn, provides day center assistance for 15 elderly patients with dementia of the Alzheimer Type in moderate or initial stages of the disease, previously selected in the ambulatory care center, who had a caregiver and who were able to travel to and from the institution and benefit from the support, stimulation, and cognitive rehabilitation activities.

Inclusion criteria of the subjects were: be family caregivers of elderly patients with dementia of the Alzheimer type; attend the Neurogeriatrics Center on a weekly basis;

The caregivers must be familiarized with the disease's stages the characteristics of each one of them, and the care that is needed at each stage in accordance with their everyday reality.

and agree to take part in the study. There were no subject exclusion criteria, since all participants in the study decided to participate in the research.

We highlight that the study was approved by the Ethics Committee in Research of the Lagoa Hospital, under Legal Order number 08/2005, in accordance with the precepts of Resolution 196/96 of the National Health Council, safeguarding the ethical rights of caregivers during the entire process, up to the final signature of the Term of Free and Informed Agreement.

DATA ANALYSIS AND DISCUSSION

Instruction received prior to the participation in the Neurogeriatrics Center

In Brazil, dementia and its treatment, instruction, and elderly patient/caregiver support practices are not at the levels they should be; this status may result in unfavorable outcomes, such as domestic violence situations, physical and psychological abuse, and financial indiscretion, among others⁽¹⁴⁾.

The only thing I was told by the doctor was that the disease was incurable, that she could develop memory lapses, and that I should not leave her on her own, and that the disease had a worsening trend; now, as for how to take care of her and the phases of the disease, he did not say a word [...] he gave me the caregiver manual so that I could read and understand the disease (Courage).

The Associations of Friends and Relatives with Alzheimer's⁽¹⁵⁻¹⁶⁾ are the authors of some publications and take part in the production of available texts aimed at layman family members; the published works basically follow the perspective of manuals and written experience, initially made available in the North American culture. Among the definitions of Dementia of the Alzheimer Type we can find *a degenerative disease that slowly and progressively destroys brain cells, affecting cognitive and social functions, as well as the personality*⁽¹⁵⁾. Therefore, technical-scientific terms are incorporated with common sense⁽¹⁷⁾, as can be seen in caregivers' statements below:

I understood it as a brain deficiency; it's like a machine in short circuit, which slowly collapses. This is how I understand it, a deficiency that attacks the brain and starts destroying everything you know, everything you learned (Knowledge).

I thought dementia was related to crazy people! (Honesty).

The subjects' statements point to an adherence to the privatist assistance model that essentially considers that the cure is only achieved by means of clinical-biological knowledge⁽¹³⁾, revealing information on Alzheimer's disease as being irreversible and progressive, with possible alterations of personality, yet scarcely dealing with a way to tackle this problem, since it is incurable.

As such, it is quite relevant to undertake discussions regarding the findings elaborated by the alternative assistance model that takes into account the caregivers' individual needs, and that approach them as singular agents that need to be heard and have their needs addressed, as well as a need to be provided with instruction⁽¹³⁾. We highlight that the instruction activities performed at the Neurogeriatrics Center from the caregiver standpoint attempt to cope with problematic situations, taking into account the common knowledge and the caregiver's experience in his reality, so that they can be potentially applicable to the elderly patient, as we'll present in the next category^(7, 10).

The understanding and the applicability of instructions at the Neurogeriatrics Center

The major purpose of the Neurogeriatrics Center is to integrally assist elderly patients with dementia. The work is performed by an interdisciplinary team that employs the elderly patient-family binomial in individual consultations, inter-consultations, neuropsychological assessment, caregiver training and individual family instruction, a support group aimed at family members, and therapeutic workshops for cognitive rehabilitation.

It was here that I came to know what the disease was, and each one of its phases; if I weren't here, I would have gotten sick again (Courage).

There's not a single day that I leave here without learning something [...] here I learned to be patient at repetitions and oblivion [...] the good thing about the group is that sometimes someone has already undergone what I'm undergoing now, and thus one helps the other [...] when I'm not able to come, I miss it very much, this should never end! (Confidence).

Sometimes she grabs food with dirty hands; before the group, I used to say that she could not do that because her hands were dirty, and my words generated a huge argument; here I learned how to go around this type of situation, trying to find ways of dealing with her (Knowledge).

Therefore, the assistance model applied at the Neurogeriatrics Center reveals positive aspects in the perspective of caregivers. Despite the low number of enrolled patients, 15 caregivers and their respective loved ones afflicted with Alzheimer's, this total amount of 30 people are assisted by a team comprised of one nurse, one phonoaudiologist, one social worker, one nursing assistant, and one massotherapist, all of them together responsible for all weekly activities and the multi-professional ambulatory care center.

The elderly patients perform activities in therapeutic workshops, divided into two groups: the more preserved (initial phase of disease) and the less preserved (moderate phase). These activities take place two times a week, for a period of 2 hours, with 50 minutes dedicated to each activity (word workshop, body workshop, garden workshop,

beauty workshop, game workshop, and memory workshop). The participation of elderly patients provides caregivers with the opportunity to offer some healthcare and welfare assistance; they reported that they feel good about seeing the patients joining the activities.

The participants in the Neurogeriatrics Center, together with the professional team, prepare a snack for the last 20 minutes. This activity is aimed at promoting encounters with others, socialization, and organization of the group, a period when monthly activities can be discussed and a time that promotes a plural and cozy environment^(7,10-11).

Caregivers develop conjoint activities in the group, regardless of the phase of the disease. They alternate two activities: the instruction group, which provides support and stimulates encounters and sharing of knowledge, thus strengthening the group's mutual apprenticeship in order to better adapt to their concrete reality; the other group aims at strengthening caregivers' self-esteem and emphasizing the need to take care of themselves first, so that they are capable of taking care of others^(7,10-11).

We are aware that the cost benefit of such type of assistance model must be taken into account. Studies point out that alternative services offer elderly patients and their families the possibility of preventing precocious institutionalization, hospital admittance, and family conflicts⁽¹⁸⁾. In this study, caregivers indicated that their participation in the Neurogeriatrics Center was quite positive, as professionals provided them with knowledge and better ability to care for elderly patients at home. However, the small number of clients assisted, among so many that need this type of assistance, mostly due to problem of distance and transport, and the necessary financial support for caregivers to continue the training process, are identified by them as negative aspects.

Therefore, the creation of systematized nursing care was necessary, prioritizing those needs related to daily living activities and prevention of incapacities and complications as educational activities offered in the group, taking maximum advantage of their participation and integrating the Neurogeriatrics Center into their domestic realities.

The instructions helped me fix the type of food she eats, and also bath care; today I take care of her money and I also learned to be very, very patient [...] you have to understand that she does not do things on purpose (Honesty).

Here I learned how to take care of mom; for instance, in homecare-related activities, taking care with the rugs, bathroom rails, and I also learned that the disease presents ups and downs (Hope).

When I receive instruction, I know how to apply it. There are moments in which it's quite the opposite, it happens, and I have to come to someone for help (Humility).

As such, the group was a space for the acquisition of knowledge and abilities by caregivers, so that they could

apply new skills throughout the disease period. The group also received instruction in care adaptation processes and the increasing dependence status of the elderly patient, gave family members the tools for practical care, and encouraged caregivers to take care of his/her own health and self-esteem.

All through the interviewing process we realized that the caregiving experience is also perceived as a donation that encompasses not only a feeling of professional and human duty, but also a responsibility for "doing one's best" for elderly people. Hence, responsibility, effort, and donation are part of the lives of these caregivers, who even in the midst of so many difficulties are comforted in knowing that they are offering them a worthy old age by providing care that goes beyond the technicism, a kind of care that involves attention, good spirit, a good relationship, security, and endearment⁽¹⁰⁻¹¹⁾.

Thus, this alternative assistance model applies light, relational, shelter-based, bond-related skills that produce solutions and create stronger degrees of autonomy in the way people live their lives⁽¹³⁾. In short, when common spaces between clients and professionals are built, and when people's objective and subjective issues are valued, we potentiate the understanding and the applicability of instructional processes in the clients' every day life.

Confrontation and adaptation mechanisms in the family care context

The activities performed by the care giver can lead to psychological and physical unbalance, causing him to display negative feelings, such as anguish, guilt, role inversion, rage, and aggressiveness⁽²⁾. The following content exemplifies the feelings brought about in the care giver:

I could never imagine mom would acquire this disease; I keep thinking on what is going to happen to her, and I get so scared. But I will manage (weeping) [...] facing it till the end, because I want to give her a worthy old age, because she sacrificed a lot for me [...] I know that the day will come when she will not remember me anymore, or even reject me (weeping) because you just can't think straight and know that that food dish in front of you is yours to eat, and you don't know what that is for [...] come on...that hurts, hurts a lot; I'm forcefully learning and forceful learning is very difficult [...] you get so discouraged, but I'll keep moving! (Confidence).

Family members can also feel quite limited, experiencing feelings of despair, anger and frustration that alternate with their guilt in *not doing enough* for a beloved relative⁽⁵⁻⁸⁾.

My most important learned lesson is to live today and take good care of this day, without thinking about what can happen (Hope).

When I arrived here, I was desperate, because I had never taken care of a person with Alzheimer's [...] it is quite rewarding for me to take her to the doctor and to hear him saying she's very well cared for [...] (tears in the eyes) this is very rewarding! (Humility).

In this sense, the changes that take place in caregivers' lives assault their feelings, significantly altering their everyday lives and activities. As the disease progresses, some family members alienate themselves from social-family life environments due to prejudices, feelings of guilt, and lack of knowledge of Alzheimer's disease. There is an emotional and activity overload that transforms the lives of those who are committed to the caregiving task.

In an attempt to graphically represent an approximation of Callista Roy's theory (Figure 1), we observed that the stimulus the caregiver receives, such as the work over-

load, lack of leisure time, financial difficulties, restricted personal time, lack of work shifts with other people, inadequate rest, not having anyone to share problems with, job abandonment, family abandonment, and lack of physical and emotional support, among others, can generate consequences and impacts on their lives, such as stress, anxiety, fatigue, emotional instability, irritability, impoverishment, lower self-esteem, isolation, and broken relationships. All these factors can affect both the physical and mental health, according to all defense mechanisms acquired for the care giving adaptation process toward elderly patients.

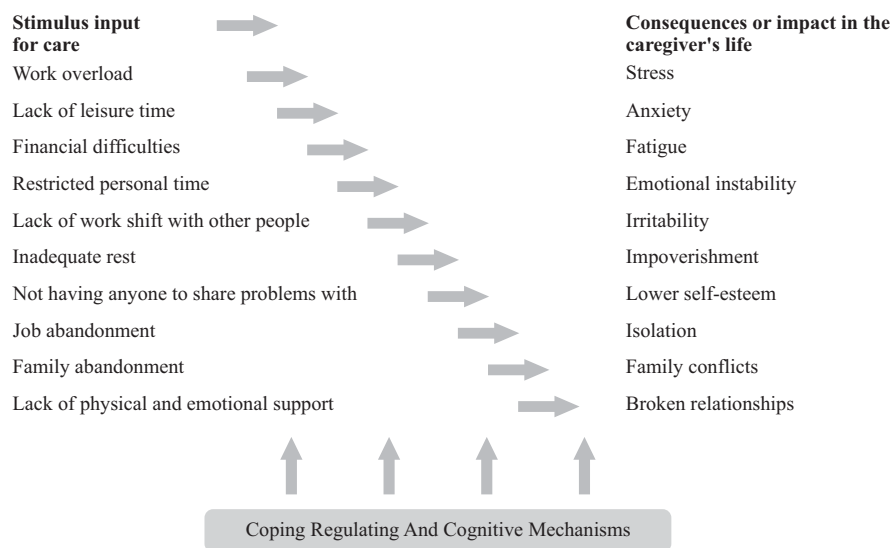


Figure 1 - Application of Callista Roy's Adaptation Theory for caregiving processes toward elderly patients with Alzheimer's - Rio de Janeiro - 2008.

Thus, whenever we provide care givers with instructions that allow them to have access to knowledge and applicable abilities for their daily reality, we stimulate the adaptation of regulatory confrontation mechanisms that are necessary for the act of caring for elderly patients with dementia. Nonetheless, the group's thematic discussions must stem from experienced situations so that they are valued and addressed from the subjects' standpoint; from this point on, instruction is conjointly planned by the group in order to guarantee its applicability to the caregivers' everyday reality.

FINAL CONSIDERATIONS

As per the understanding of the disease, caregivers seem to have personal and distinctive comprehension of the dementia process in elderly patients, according to their cultural level and the length of time since joining the Neurogeriatrics Center activities. The comprehension of the disease process progressively improves as they increasingly participate in the Center's meetings. The instruction on the disease is performed through group dynamics, which facilitates adherence to, and better understanding of, the

process. We can infer that the Neurogeriatrics's parlance, its educational methodology, and the didactic resources it employs in workshops using the body, cognitive games, art-therapy, socialization among care givers, and walking around together lead them to interact with professionals, thus facilitating the comprehension of the disease and all pertinent care issues.

Therefore, the family group is guided by the nurse, and it begins with the problematization (problem-based) method, generating a theme for each discussion between caregivers and professionals. This teaching-caring method is of high value to the caregiving subject regarding his doubts about the disease and care practices, motivating him to participate in the discussions and favoring his learning through the problematization. Some caregivers reported that in medical consultations before they were part of the Center, instructions were superficially passed on, showing no concern for their comprehension of the information given, leaving them with questions and doubts and with no adequate response to their level of understanding.

We also verified that this learning process, as well as its applicability, is a continuous procedure. All of them reported

that each meeting they take part in brings clarifications toward the way they should apply such care: i.e. food, bath, medication, domestic security. It is important to highlight that these lessons received in the meetings are not only restricted to physical care; there is also a focus on the therapeutic relationship.

In terms of the confrontation mechanisms for the adaptation to this critical situation, they pointed to financial difficulties, overload arising from the responsibility of caring without being able to shift care to other caregivers, thus leaving them with very little time for their own self-care, sacrificing their resting, leisure, social life, family life, and affective time. The strongest impact reported by caregivers in this context is the risk of getting sick, mostly those that are associated with stress, which can generate emotional instability, anxiety, depression, and eventual loss of emotional control.

Caregivers also need help and follow-up, as they feel quite lonely and carry quite a heavy work burden. The Neurogeriatrics Center is a place in which they are able to share the impacts of this life context. In this place and time they experience solidarity with other caregivers who experience the same problems, and are offered useful instruction. These actions favor the elaboration of mechanisms and strategies that strengthen them toward the confrontation and better adaptation to this reality.

As such, we consider the Neurogeriatrics Center as a reference for these caregivers, aiming at strengthening their

confrontation mechanisms in their daily assistance activities with elderly patients afflicted with Alzheimer's. In these meetings, they feel sheltered, comforted, strengthened, and encouraged to render care based on affectivity, valuing the elderly person in his physical, mental, social, cultural, and spiritual dimensions.

We believe that the exposed theme highlights the importance of the creation of Neurogeriatrics Centers, as well as the role of the nurse, pointing out the need to create other centers in the public healthcare system, taking into account the population's ever-growing aging process. In the caregiving practice, educational strategies applied in family groups by means of the problematization method shed light on the active participation of subjects, as well as on the validation of their needs and desires, thus generating the subjects' interest and favoring awareness, motivation, and future transformation. In the teaching field, we still lack professional backgrounds aimed at the formation of human resources that are able to both deal with elderly patients and prepare family caregivers. We hope nursing programs will consider the results of this study as a contemporary need. As per the research, we understand that the study is feasible towards future applications of Callista Roy's adaptation model, focusing on the reduction of caregivers' stress during the implementation of the confrontation mechanisms; in doing this, we will be able to provide caregivers with physical and mental health assistance, welfare and comfort.

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