

Behavioral changes of elderly with Alzheimer's Disease and the burden of care for the caregiver

Mudanças de comportamento em idosos com Doença de Alzheimer e sobrecarga para o cuidador
Cambios en el comportamiento de las personas mayores con enfermedad de Alzheimer y la carga para el cuidador

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ABSTRACT

Objective: Identify key behavior changes in elderly with Alzheimer's Disease, and distinctions on the burden of care imposed on the caregiver. **Method:** Research process was guided by Grounded Theory using semi structured interviews as primary technique for data collection with twenty five caregivers of elderly with Alzheimer's Disease. **Results:** Compromised safety due to contact with fire and wandering behavior, was reported by 80% of the caregivers. Half of the elderly receiving care provided by the participants required constant supervision and protection. **Conclusion:** Behavioral changes of elderly with Alzheimer's Disease have emotional impact, result in stressful situations, and affect caregivers' quality of life. Compromised safety resulted in overload of functions, suffering and fear to participant caregivers. Among the implications to nurses is the demand for partnership geared towards protective care planning, aimed at managing behavior changes.

Keywords: Aged; Nursing; Alzheimer's Disease; Caregivers; Family.

RESUMO

Objetivo: Identificar principais mudanças comportamentais em idosos com Doença de Alzheimer e distinções na sobrecarga imposta ao cuidador. **Métodos:** Pesquisa guiada pela Teoria Fundamentada nos Dados utilizando entrevista semiestruturada como a principal técnica de coleta dos dados, junto a vinte e cinco cuidadores de idosos com Doença de Alzheimer. **Resultados:** Segurança comprometida por contato com fogo, fugas e saídas desacompanhadas foi destacada por 80% dos cuidadores. Metade dos idosos sob os cuidados dos participantes requeriam supervisão e proteção constantes. **Conclusão:** Mudanças comportamentais em idosos com Doença de Alzheimer tem impacto emocional e resultam em situações estressantes, comprometendo a qualidade de vida dos cuidadores. Segurança comprometida significou sobrecarga de funções, sofrimento e medo para os cuidadores participantes. Dentre as implicações para as enfermeiras está demanda por parceria direcionada ao planejamento de cuidado protetor, para manejar mudanças comportamentais.

Palavras-chave: Idoso; Enfermagem; Doença de Alzheimer; Cuidadores; Família.

RESUMEN

Objetivo: Identificar principales cambios en comportamiento de personas mayores con Enfermedad de Alzheimer y distinciones en la carga de los cuidadores. **Método:** El proceso de investigación se guió por la Teoría Fundamentada en los Datos usando entrevistas semiestructuradas como la principal técnica de colección de datos, con veinte cinco cuidadores de personas mayores con Enfermedad de Alzheimer. **Resultados:** Comprometimiento de la seguridad, debido a contacto con fuego y salir solo, fue reportado por 80% de los cuidadores. Metade de las personas mayores recibiendo atención prestada por los participantes requiere constante supervisión y protección. **Conclusión:** Cambios en comportamiento de personas con Enfermedad de Alzheimer impactam emociones, provocam situaciones de estrés y comprometen la calidad de vida de los cuidadores. Riesgos para la seguridad se tradujo en la sobrecarga de funciones, sufrimiento y temor de los cuidadores participantes. Entre implicaciones para las enfermeras esta la demanda de una asociación orientada a la planificación de una de una atención protectora, con el objetivo de manejar cambios en el comportamiento.

Palabras clave: Anciano; Enfermería; Enfermedad de Alzheimer; Cuidadores; Familia.

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INTRODUCTION

For the first time in mankind people 60 years old and over are going to outnumber children under 14 years old, corresponding, respectively, 22.1% and 19.6% of the world's population¹. For the year 2020 Brazil, the largest country in size and number of residents in Latin America, is expected to have 29.8% of people over 60 years old, with 40.7 million people at 80 years old and over². A population change that brings up different types of dementia, led by Alzheimer's Disease³ to the attention of policy makers, health care providers and researchers as it joins the rank of top health issues in the country. Currently affecting near 35.6 million older individuals, numbers are expected to increase up to 65.4 million by 2030 and to 115.5 million by 2050⁴.

Alzheimer's Disease is primarily a degenerative cerebral syndrome, of unknown etiology, with particular neuropathological and neurochemical components, that goes beyond the biology of aging and unfolds into social change in culturally established roles, interferes in the individual's and in his family life. A condition that dramatically alters previous levels of autonomy and independence, and results in important changes and severe limitations to perform instrumental and basic Activities of Daily Life (ADLs)^{4,5} Thus, caring for an ill family member configures a multidimensional responsibility and challenge. New social demands include coping resources need to be adopted by the affected and impacted family⁶.

Behavior changes of elderly with Alzheimer's Disease impact family caregivers' lives, and result in emotional distress, suffering, sadness, burn out, stressful situations, and affect quality of life⁷. However, qualitative distinctions on how and to what extent these impact and interact on the caregiver's life has not yet been extensively studied.

The literature published between 2012 and 2014 in PubMed and Biblioteca Virtual em Saúde - BVS databases was reviewed and 154 articles selected, in order to examine and enlist behavior symptoms and changes, in elderly with Alzheimer's Disease and related caregivers' experiences. Most publications focused on reporting from one to three related behavior changes, indicated some sort of burden on the caregivers' but made no reference to distinctions on the resulting interaction effect. Thus, in the outset of the study any item on behavior change or aspect related people with dementia of the Alzheimer's type found in the reviewed health literature, were compiled and enlisted to ensure comprehensiveness. A total of 26 alterations in behavior, specifically related to individuals with Alzheimer's Disease were identified, compiled, and then sorted into domains to introduce the scope of documented changes that may affect the experience of caregiving. The voices of the caregiver's data were compared and contrasted with the enlisted items and aspects on the literature, this paper presents distinctions on the types of alterations experienced, with emphasis on the burden of care imposed on the caregiver's life.

METHODS

Part of a doctoral dissertation aimed at increasing the body of knowledge on Alzheimer's Disease and the burden of care imposed on the caregiver this paper focuses on individual's key behavior changes, and distinctions on the resulting impact. Study conducted under the light of the Symbolic Interactionism (SI)⁸, based upon three premises: the human being acts in relation to things based on their meanings to him; these meanings come from the individual social interpretation established with other people; and such meanings are manipulated and modified through an interpretative process used by the individual to deal with encountered situations and things encountered. In the perspective of the SI, and within the scope of this study, meaning would emerge from the interaction process among, participant caregivers, individuals with Alzheimer's Disease and the environment. Thus, under the light of the SI, the best suited method, selected to guide data collection, treatment and analysis procedures became the Grounded Theory (GT)⁹, developed in the 1960s by two North American social scientists, Barney Glaser and Anselm Strauss.

Although the word "theory" name may generate some sort of confusion at first, GT is a complex, rigorous and detailed research method in which a close and continuous relationship is kept along data collection, analysis and eventual resulting theory. Translating reality beyond the reunion of a series of concepts based on experience or speculation, the key characteristic in GT is data based concepts, constant comparison and contrast, that provide a better understanding and a sound guide for action and interventions⁹ in clinical and social nursing practice.

Participants were twenty five caregivers of elderly individuals with Alzheimer's Disease, outpatients at the Center for Alzheimer's Disease and other Mental Disorders of Old Age, of the Institute of Psychiatry of the Federal University of Rio de Janeiro - CDA/IPUB/UFRJ. Inclusion criteria were to be an informal caregiver of an elderly person who had probable diagnosis of Alzheimer's Disease documented in the medical record, verbally confirmed by participant. Were excluded formal caregivers; and caregivers with diagnosis of depression or dementia.

Eligible caregivers who accepted to participate in the study signed an approved informed consent in two copies, one kept by the participant and one by researcher, as part of the research protocol analyzed and approved by two Institutional Review Boards - IRBs. The Ethics and Research Committee (CEP) of the Ana Nery School of Nursing (EEAN) and Institute for Health Care San Francisco of Assis (HESFA) and the CEP of the Institute of Psychiatry at the Federal University of Rio de Janeiro (IPUB/UFRJ), respectively under the protocol n^o 117/10 of the 03/02/ 2011 and under the report n^o 75 - Liv.3-11 of 27/04/11.

To build a participant voiced database on behavior changes, semi structured interviews with caregivers were recorded in

MP3 audio files, followed by immediate transcription, accuracy check, line numbering and initial free coding. Along with simultaneous data analysis, with constant comparison and contrast, researcher's sensitivity, empirical reality theoretical sampling, and indicating memos were critical in supporting more advanced waves of the coding process to ensure concept development and density^{9,10}.

Participant accounts advanced coding and in depth analysis evidenced that most behavior changes enlisted in the published literature were robust for the interviewed group. However, wandering was highlighted as the key unanticipated behavior. The close interaction of behavior changes, in particular wandering, and its effect on caregivers' lives brought in a more refined understanding of meanings, distinctions, and gave rise to the dense, core category "compromised safety".

RESULTS

The 25 interviewed caregivers of a person with Alzheimer's Disease were mostly women (76%), married (52%), with children (68%), in the age group between 50 and 60 years old (48%), had completed college, (52%), had a professional occupation with an average of 8 hours' work daily, (52%), were daughters (56%), Catholic, (64%) resided in the same household (64%), and had been caring for the person with Alzheimer's Disease, on average, from 5 to 7 years (28%).

The number of hours dedicated daily to the care of the elderly person with Alzheimer's Disease corresponded to 32% exclusively seven days a week; 24% from two to four days a week; and 8% up to four days a week. The number of daily hours participant caregivers dedicated to care were reported by 12% up to four hours; 8% from six to eight hours; 4% up to twelve hours, and 12% did not specify the number of hours dedicated.

Compromised safety was pointed out as the main concern and represented 23% of total behavior alterations to the elderly with Alzheimer's Disease. Reported by 80% of the caregivers, it was described through accounts on episodes of contact with fire, for the risk of explosion and burns, and of wandering or going out unaccompanied, for the risk of getting lost, as illustrated in the excerpts here presented.

Compromised safety: contact with fire, risk of explosion, and burns

Compromised safety is described in a composite format with the risk, the context, and the result as illustrated by accounts codes 7 and 20.

[...] Another thing is fire, we even put the stove out there, as we were afraid of her burning things by leaving the pan on the stove, forgetting [...] on one occasion, she went out and left the milk to boil [...] and the milk dried up completely. It's dangerous. Then, we are going through a rather difficult time [...]. (Code 7)

[...] We unplugged the stove, so that it had no electricity, no matches and no lighter. The stove is automatic. (Code 7)

[...] There was a day when I arrived and saw, she had taken the dog's food, put it in the pan and fried it. I was worried [...] she can't stay on her own [...] I could send her to a nursing home, but I am not going to do this [...] She has forgotten the gas on and, since then, we made sure she would not stay on her own [...] if I hire a caregiver, it is because I need. (Code 20)

Compromised safety: escape

Wandering is described through the emotional word of "disappeared", the context of how dangerous the house is, and the sense of responsibility at stake, exemplified by the accounts codes 8 and 13.

[...] She disappeared twice. We hid the key so she couldn't go out [...] she lived in a house that had two floors and she threw herself out of the second floor window [...] she needs someone by her side [...]. (Code 8)

[...] Because I feel responsible for her. If she leaves the house I'm terrified [...]. (Code 13)

Compromised safety: going out unaccompanied

Going out unaccompanied is not safe anymore. The elderly former and current self, and the reasoning for current protection needs, illustrated by the accounts codes 7, 13 and 17.

[...] A car already hit her in the middle of the street, she has already crossed the fast lane [...] my sister and I learned of it [...] Our concern is that she will leave and never come back. [Dizemos] a nossa mãe que "nossa preocupação principal é que você deve entender que precisamos cuidar de você, por onde anda, o que está fazendo." The greatest concern [is to say] "Mom, you have to understand that we need to care for you, we worry about you, whereabouts you are, what you are doing" [...] Nowadays I see my mother differently. My mother, today, is not like that anymore (tears). She is not like that anymore more friendly. Today I do not know why, but she touched my hair, tided it up, there are times that, you understand, she cares. (Code 7)

[...] One of the reasons I have stayed with her is because beforehand she left and didn't know how to get back. (Code 13)

[...] She needs someone to go out with her [...] it is a question of constant attention. It concerns me most [...] the fact that she needs someone with her, to go out [...] we have to keep the key. (Code 17)

With progress of the Alzheimer's Disease within the home context, participant caregivers' resources, care demands and activities, dynamic interactions that are constantly (co) modified; unfold into an increasing accumulation of functions, responsibilities and involvement of the caregiver; and generate overload and fatigue. Reports indicate that protection and safety were core issues when compared and contrasted in context with 12 other areas or types of main care activities performed by the caregiver, grouped as feeding, domestic activities, medical assistance, social stimulation and open air activities of the elderly person with Alzheimer's Disease.

Such distinction was also evidenced in numbers. Behavior changes that compromised safety accounted for 50% of the reports on the sometimes unanticipated, but often the most demanding care need, that generates tension and requires constant supervision and attention from the caregiver.

DISCUSSION

The caregiver who is responsible for the care of an older individual with Alzheimer's Disease, faces extensive demands of his own physical and mental health, personal time and major changes in lifestyle. As the older person's instrumental and survival ADLs become compromised over time, the new lived situation takes up more complex demands on the individual who takes up the comprehensiveness of care. Thus, once the caregiver's way of living is modified based on the needs of the person being cared for¹¹, the dyad dynamics is affected.

Changes on caregiver's life may become a burden of multidimensional order that is, physical, emotional, financial, and also interferes on social relationships and leisure^{12,13}. And, when the caregiver takes up the mission of caring for the older adult, with no proper break or rest time, situations of burnout and overload often take place¹⁴.

There is also a direct relation between caregiver overload and being a woman caregiver. Women have a number of ongoing social roles such as of mother, wife, housewife, and so, including professional work, and taking up older parents' care responsibilities¹⁵.

Questions related to the safety of the elderly with Alzheimer's Disease required specific care and supervision from the study caregivers, causing an overload of functions, in addition to suffering and feelings of concern and fear.

In such events, the care provided by the caregiver results in demands such as the development of skills, strategies, and competences in order to make it possible to manage changing situations on a day-to-day basis. Enlisted study paradigm strategy examples were to hide the keys such that the elderly person does not leave the house; unplug the cooker from the electric outlet; hide matches and lighters; share the care with other members of the family and/or with a formal caregiver; institutionalize the elderly person in a Long-Stay Institution for the Elderly or *Nursing Home*; convince and talk to the elderly person about questions that involve risks and to fully assume

the role of caregiver with the function of constant supervision, all of which, in turn, require (re)organization of home routine for all family residents and visitors.

The alterations relating to the compromised safety of the elderly person with Alzheimer's Disease demanded from the caregiver, protective strategies with modified interactions from the previously experienced in earlier phases of life. Interactions with consequences of emotional repercussions for the caregiver, such as the reported changes in the standard relationship between the caregiver and the elderly person. The caregivers' reports constantly compared and contrasted the behavior of the elderly person before and after Alzheimer's Disease set in and the inversion of roles, such as father/son; husband/wife. A care that brings along challenges that, are not only of physical overburdening, but also of affective overload. In such environment, caregiver coping demanded and resulted in mobilization of personal, intrinsic resources intuitively designed within their own, newly reinstated dynamics of care.

Alzheimer's Disease changes the caregiver's way of living and the living with, due to needed, required or even imposed objective adaptations in his daily living, with subjective repercussions of emotional (re)organization.

A study¹⁶ on the management of behavior problems in Alzheimer's Disease indicated that pharmacological and non-pharmacological interventions are needed, factoring in the individuals involved and the biological, psychological, psychosocial and environmental aspects. The presence of neuropsychiatric and psychological symptoms can express some sort of patient need, such as pain, anger, sadness, or even fear of some sort. The lack of ability of individuals with Alzheimer's Disease to recognize their own needs or express them to the caregivers may result in behavior change manifestation¹⁶.

Thus, nurses working with these individuals in dyads are required to recognize and acknowledge caregivers' specific demands so that informative, educational and tailored nursing care that acknowledges and accounts for the elderly with Alzheimer's Disease reactions and attitudes as well. It is critical that the nurse skillfully manages assessment techniques, and verifies if specific behavioral changes of the individual with Alzheimer's Disease is bringing in pain, suffering for the caregiver, with subsequent work to identify, classify and assess caregiver's strategies in place. Next, comes the demand to learn, tailor and teach alternative intervention techniques and management strategies based on the dyad care needs brought in by the caregiver.

CONCLUSION

Safety related behavior issues involving individuals with Alzheimer's Disease were those with the greatest impact on the caregiver's life and were brought into perspective as multidimensional overload and fatigue to the caregiver's life, in particular emotional and affective. Under the light of the Symbolic Interactionism, the compromised safety of the elderly with Alzheimer's

Disease symbolized for the caregivers, representative, significant and subjective memories, tailored for and by the individual, closely related to the elderly who they used to live with and with whom they live now.

To reach and meet the demands expressed by the caregivers, requires from health care providers to interpret and recognize them as mediating tools to guide and move nursing care planning actions, taking the caregiver as the caring highly demanded protagonist in the life and safety of the elderly person with Alzheimer's Disease at home.

The team built by the dyad patient-caregiver demand nurse, closely supported, partnership. Professional encounters are to be geared to support, listen, inform, propose, plan, monitor and assess strategies aimed at managing care and behavior changes of the individual with Alzheimer's Disease, in particular those involving risks to safety. A limitation of the study was not to monitor the longitudinal behavior changes in the elderly with Alzheimer's Disease in relation to compromised safety. Such monitoring is a recommendation for future studies, which could enable verification on the potential increase or decrease of caregiver burden, in context of the frequency and mode on how changes may occur.

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