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Original Article

Self-care to elderly after cerebrovascular accident: caregiver and academics experiences

Autocuidado a idosos pós-acidente vascular encefálico: vivências do cuidador e de acadêmicos

Autocuidado a ancianos después del accidente cerebrovascular: experiencias del cuidador y académicos

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Objective: understand the experiences of the caregiver and multidisciplinary health academics toward the development of self-care at home for elderly after cerebrovascular accident. **Methods:** qualitative study with the use of semi-structured interviews with six caregivers and eight academics whose data were analyzed in the light of the Phenomenology. **Results:** three categories emerged: living with the challenges and limitations imposed on the caregiver and on the person being cared; the professional being and the technic conservatism; the multidisciplinary team at home: experiences with the caregiver and the person being cared. **Conclusion:** caregivers of elderly who went through cerebrovascular accident need more support and guidance for conducting home care, they need a plan of care to facilitate and encourage self-care, minimizing the burden incurred to the caregiver. Multidisciplinary academics displayed a technical view. This demonstrates the need for change in academic education with more focus on a holistic and humanistic view of care.
Descriptors: Aged; Stroke; Self Care; Caregivers; Patient Care Team; Nursing.

Objetivo: compreender as vivências do cuidador e de acadêmicos multiprofissionais da saúde para o desenvolvimento do autocuidado ao idoso pós Acidente Vascular Encefálico no domicílio. **Métodos**: estudo qualitativo, utilizaram-se entrevistas semiestruturadas com seis cuidadores e oito acadêmicos, cujos dados foram analisados à luz da Fenomenologia. **Resultados:** emergiram três categorias: convivendo com os desafios e as limitações impostas ao cuidador e ao ser cuidado; o ser profissional e o conservadorismo tecnicista; a equipe multiprofissional no domicílio: vivências com o ser cuidado e seu cuidador. **Conclusão**: apreendeu-se que os cuidadores de idosos pós Acidente Vascular Encefálico precisam de mais apoio e orientação para a realização dos cuidados no domicílio, um plano de cuidados para facilitar e estimular o autocuidado, minimizando a sobrecarga do cuidador. Os acadêmicos multiprofissionais mostraram uma visão tecnicista, evidenciando-se a necessidade de mudança na formação acadêmica, com foco na visão holística e humanística do cuidado.
Descritores: Idoso; Acidente Vascular Cerebral; Autocuidado; Cuidadores; Equipe de Assistência ao Paciente; Enfermagem.

Objetivo: comprender las experiencias del cuidador y académicas multidisciplinarios de la salud para el desarrollo de autocuidado a ancianos después del accidente cerebrovascular en hogar. **Métodos**: estudio cualitativo, se utilizaron entrevistas semiestructuradas con seis cuidadores y ocho académicos, cuyos datos fueron analizados a la luz de la Fenomenología. **Resultados**: tres categorías emergieron: viviendo con los rectos y las limitaciones impuestas al cuidador y al ser cuidado; el ser profesional y el conservadurismo tecnicista; el equipo multidisciplinar en el hogar: experiencias con el ser cuidado y su cuidador. **Conclusión**: aprehendió que los cuidadores de ancianos después del accidente cerebrovascular necesitan de más apoyo y orientación para la realización de cuidados en el hogar, un plan de atención para facilitar y estimular el autocuidado, minimizando la sobrecarga del cuidador. Los académicos multiprofesionales señalaron visión tecnicista, evidenciándose necesidad de cambios Necesidad en la formación académica, basada en la atención humanista e integral.
Descriptores: Anciano; Accidente Cerebrovascular; Autocuidado; Cuidadores; Grupo de Atención al Paciente; Enfermería.

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Introduction

The inversion of the Brazilian age pyramid has made the country to figure among the world ranking of countries with the largest populations of elderly. The proportion of elderly is expected to increase from 5% to 10% between 2000 and 2020. Life expectancy of men will reach 70 years and women, 76. By 2050, 38 million Brazilians, or 18% of the population will be over 65 years[1]. Due to this inversion of curves, non-transmissible chronic diseases, especially cerebrovascular accident, are also expected to increase[2].

Currently, cerebrovascular accident is considered the third major cause of death among elderly and leads many of those that experience it to the need for care, which is frequently possible only at home[3].

The elderly person that suffers cerebrovascular accident may have significant changes in his/her style and quality of life, leading to changes in the family circle and, thus, creating doubts regarding sequelae, recovery and how to respond to this reality. By the moment of discharge, the person with sequels and his/her families face a new and unexpected situation that causes changes in family dynamics. Thus, it is necessary to consider the wants and needs of these people in order to prepare them for home care[4].

The changes brought about by this illness generate crises and stress in face of the breakdown of family routine, changes of roles, increased financial costs, feelings of uncertainty in the administration of care, and increased workload[5].

While engaging in activities to promote recovery of the elderly, caregivers may find themselves facing a grueling routine and experiencing feelings of frustration when they meet difficulty to achieve positive results. In many cases, caregivers end up performing activities that the elderly would be able to execute and this prevents the development of self-care and independence[6].

Thus, the care for elderly affected by cerebrovascular accident sequelae requires a broader approach, with a view of the person and his/her reality and establishing a comprehensive care that contemplates biopsychosocial and spiritual dimensions, health promotion and disease prevention. With this approach, aggravating factors for the development of the disease are expected to be minimized, taking into account their social impact in the life of the patient and his/her family[6].

In relation to overloading, health professionals must plan and implement actions to guide caregivers regarding the realization of inherent care activities. The team of health professionals deals with a complex therapy routine that aims at the interaction between the team and the people involved in the administration of care[4].

This process, therefore, consists in the continuity, coordination and interaction of the multidisciplinary team, which is extremely important since it favors the exchange of knowledge needed to provide a comprehensive and highly-qualified care to elderly that suffered cerebrovascular accident. It is, therefore, the team's role to encourage the development of self-care. This makes patients active and sharers in the process of care, contributing to the improvement of their quality of life[7].

Due to increased incidence of cerebrovascular accident among elderly population, there is a clear need for strengthening strategies to consolidate networks of support with participation of the caregiver and the multidisciplinary team.

In this study, Phenomenology was adopted in order to search for the experiences of participants, who were academics from the fields of nursing, nutrition, physiotherapy and pharmacy and also caregivers of elderly who have suffered cerebrovascular accident. The understanding of their statements aims to identify the household routine, in order to capture the demands of the caregiver, the patient, and the multidisciplinary team for this type of care.

The present research aimed to understand the experiences of caregivers and of multidisciplinary

health academics when it comes to the development of self-care at home to elderly after cerebrovascular accident.

Method

This was a qualitative study on the slope of Phenomenology in the light of Merleau Ponty that focuses primarily on the understanding of experienced phenomena from the perspective of individuals themselves[8].

We used the semi-structured interview technique and speeches were recorded in MP4 players. Interviews were conducted in households when respondents were the caregivers of elderly. In the case of academics that make up the teams, interviews were accomplished in the undergraduate institution. Interviews were done from December 2014 through March 2015. A form was also applied for characterization of social aspects of the caregivers.

A guiding question was used to approach participants. In the case of academics of the multidisciplinary team the question was: talk about your experience with the elderly with sequels of cerebrovascular accident and with caregivers in the household regarding the development of self-care. In the case of caregivers: talk about your experience in the day-to-day activities with the elder who has passed through cerebrovascular accident and the development of self-care.

Participants were identified by letters C (caregiver) and A (academic) followed by Arabic numerals, following the sequence of interviews to ensure anonymity.

The number of participants cannot be defined *a priori* in qualitative research because it depends on the quality of information collected. The aim, in phenomenological research, is not to generalize the results, but to present the experience exposed in the statements[9].

In this study, three stages of the Phenomenology were followed to analyze the statements of participants: description, reduction and comprehension. The phenomenological description is the experience that the subject lives, and the researcher must capture the essence of it without changing its real meaning[10].

Phenomenological reduction was performed in sequence. This is the moment to select what is part of the consciousness of the individual and what is only supposed by him/her. Thus, the technique for carrying out the phenomenological reduction is called imaginative variation which is evident when the researcher puts himself in the place of the individual and makes reflections on the significant parts of the description[10].

The last moment called phenomenological understanding is the intent to structure the expressions of the individual in the researcher's own expressions, facilitating this way the understanding of its searches, but always in conjunction with interpretation of the real experience[10].

The research project was approved by the Research Ethics Committee of the Federal University of Alfenas-MG, Brazil, under Opinion Nº 923.976. Participants of this study consisted in six caregivers of elderly patients with cerebrovascular accident sequelae and eight multidisciplinary academics who make up the home care team to these patients. They were informed about the study objectives, anonymity, and that the resulting data will be published in academia. After accepting to participate as volunteers, all signed the consent form.

Results

Six caregivers were interviewed, all female, aged predominantly between 41 and 60 years. Regarding marital status, two were single, three married and one divorced. All live in their own house, two reported living with one to three people, and four of them live with four to seven people.

Regarding education level of respondents, two reported having not completed elementary school, two completed elementary school, one completed

high school and one had superior education, including postgraduate degree.

Regarding monthly family income, two caregivers reported an income equivalent to one minimum wage, three reported an income between one and three minimum wages, and one caregiver reported an income between six and nine minimum wages. Concerning individual income, one caregiver informed having no income, one informed one minimum wage, three informed to have an income between one and three minimum wages and one had income between three and six minimum wages.

In addition to caregivers, eight academics of multidisciplinary health teams that make up an Extension Project were interviewed, three from the nursing course, three from pharmacy and two from physiotherapy.

After interviews, the three phases of phenomenology were proceeded: a transcript of the speech in its entirety, the reduction followed by a meticulous reading where essential parts of the description emphasizing the study participant's consciousness in relation to the phenomenon were selected. And finally, the phase of understanding was proceeded, which consists in the interpretation of speeches and alignment of such with their real meaning.

From the analysis of core of sense, two categories were created: living with the challenges and limitations imposed on the caregiver and on the person being cared, and the multidisciplinary team at home: experiences with the caregiver and the person being cared.

Living with the challenges and limitations imposed on the caregiver and on the person being cared

This category concerns the experiences of caregivers of elderly with cerebrovascular accident sequelae and it was manifested by impotence, need for help, psycho-emotional imbalance, difficulty of acceptance by the dependent person and increase of self-care deficit.

Participant caregivers of elderly with cerebrovascular accident sequelae highlighted the difficulty in adapting to the limitations of the dependent person and the persons' own acceptance of the disease: *... It was quite hard ... I had to adapt. Adapt the home. Adapt even the issue of family, because we had a routine of life, and with time, we ended up limited to the issue of self-care because it is not easy. There are some who have chronic degenerative disease that depend on us for everything. Then, you need a person to assist you twenty-four hours a day, because you alone are not able to take care of all, and not even the caregiver can do this. So it's not easy, it was difficult to adapt, it was hard for herself to accept. Acceptance of the diaper was hard for her and it was hard for me. I think it affects the mind, a lot, the issue of dependency, being dependent on the other* (C1).

In their statements about their experiences in daily life with elderly with cerebrovascular accident sequelae, caregivers mentioned different degrees of dependence on: *At first she could eat with her own hand with great difficulty, but still she could do it. Sometimes, she would stain her clothes, the table cloth, then she stopped eating with her own hand, we would feed her, then later she stopped eating mushy food, food had to be blended, and finally she would depend on tube feeding. So this whole process is very painful, both for the patient and for the person who is taking care of her* (C1). *She helps a lot, she can comb her hair with one hand. She passes lipstick, you can see that she is using makeup, she makes it with her hand* (C2).

Despite the limitations to daily activities of the elderly with cerebrovascular accident sequelae, caregivers encourage the development of self-care as noted in the speeches: *At home, she does not give me almost any trouble, she helps me sometimes. She helps me to make a desert, dipping the wafer ... Feijoada, like she did Sunday, I bring her here, I work on the stove, she will say and guide me ... she picks beans ... to help her to exercise her hand* (C2). *He can brush his teeth with his hand. We teach how to brush, moving the left hand, eating with his left hand, putting on and removing shoes. He picks the ball up in hand, he takes perhaps a weight, opens the door, we try to develop him, to move* (C6).

The multidisciplinary team at home: experiences with the caregiver and the person being cared

Regarding the experiences of multidisciplinary academics in home visits to elderly with sequels after cerebrovascular accident and his/her caregiver, it is apprehended that these were restricted to professional techniques, still falling short of holistic look to the patient and his/her caregiver, as it is unveiled in the statements: *... The guidelines passed are referent to the lower limb, it's stretching, hiking, biking he does every day; Regarding hand, we work with the small ball, with flexion, extension, force with the leg and joint mobilization at shoulders* (A1). *We delivered some tips about pharmacy, drug interactions, how to administer the drug orally, recommended not to take it with milk, not take it with coffee, not take it with coca, but always take it with water, if there was any interference with food; As we needed to do it, we ended up managing to organize it* (A2). *I learned to develop techniques I studied in college, and put them into practice, I would go to measure vital signs; I helped her with her medications, teaching the right hours to take it* (A5).

In addition to a technical exposition, statements did not show interrelationship between multidisciplinary academics, for a better development in the plan of care for the customer and his/her caregiver.

Although some statements are turned toward specific procedures of each professional field, some academics stressed the importance of self-care for the elderly, as they are expressed in the quotes below: *Then I began to perform exercises of amplitude of motion, move fingers, facial rhyme, motor coordination, functional exercises so that his daughter would let him try to eat by himself, drink water by himself, hold the glass by himself* (A7). *The caregiver said that he would do a mess when trying to eat, and I would incentive her to have a little more patience because this was due to the disease, for her to let him do things a little by himself, drink water by himself* (A7). *We guided them to do physical exercise; he used to ride a bike, so we were always encouraging this activity. With respect to walking, he would always do a longer way to go to the bakery and we always encouraged that, and recommended him to have preference for light periods and not dark to avoid the risk of accidents* (A8).

It was possible to learn that there were some statements from academics regarding the need for care toward the caregiver: *We also worked with the caregiver because she was quite overwhelmed, we would do some stretching with her and guidelines for her to leave on weekends to distract, we measured her blood pressure and guided her about the medications because she was also hypertensive* (A7). *We approached not only him, but also his wife. So we did the same guidelines for her, regarding feeding habits, even issues related to the furniture disposition in the house such as remove carpets in order to prevent accidents* (A8).

The importance of prevention against injuries during administration of care was also emphasized by academics: *With time he went to the wheelchair and we guided the family as the change of decubitus, because whether he was in the chair or in the bed, thus I was always recommending them to monitor if there was some kind of ulcer on bony prominences* (A7). *We gave instructions on changing habits in the case of smoking, use of alcohol and physical activity. The issue of food as well, we instructed to have a reduced intake of salt, use natural seasonings and avoid processed and prepared spices as well as intake vegetables and fruits. He always said he liked fried food, so always discouraged these, we followed his laboratory tests every three months, on triglycerides, cholesterol in order to follow-up this reduction and the issue of adherence to treatment which, at times, he adhered very well and would take medications correctly* (A8).

Discussion

The experiences stated by caregivers in the present study unveiled a difficulty to acceptance by the person in face of his/her dependence caused by sequelae of cerebrovascular accident and increased self-care deficit, reiterating the importance of family support and the need for adaptations in the home environment, so to improve the quality of life of both the elder and his/her family.

The limitations of the person cared at home can entail severe and profound arrangements in intra-family dynamic organization. Thus, the caregiver and the family of the person sequelae of cerebrovascular accident experience various changes in their lifestyle,

both socially and personally[11].

The caregiver says that when faced with the difficulties of non-communicable chronic disease feel helpless and impotent in carrying out the action of care, for in the majority of cases, elderly need continuous attention, causing a bio-pyscoemotional wear to the caregiver and the need for help.

Depending on the difficulty for development of activities of daily living by the elderly, according to the degree of dependence, this may trigger a burden to the caregiver[12]. This overload leads to progressive loss of energy, which generates occupational fatigue and hence the imbalance in the process of health and disease. So, there is a need to monitor not only the person with sequelae of cerebrovascular accident, but also his/her caregiver[13].

In order to minimize the caregiver burden, this must encourage self-care at home, what also provides positive aspects in the quality of life of the elder, in the sense that the elder develops independence, seeking greater autonomy, also reflecting on the positive aspects of his/her self-image[14].

We observed, through the statements of multidisciplinary academics, the importance of support to the elderly and their caregivers with respect to creating a plan of care, one to be drafted with the help of a multidisciplinary team of health. Regarding home visits made by them, it was observed that there is a real need for interaction between these, to strengthen the performance of self-care by both the caregiver and the person being cared.

Thus, an individualized self-care plan has to be based on the reality of the elderly person with cerebrovascular accident sequelae and must be drawn up together with him, the caregiver and the multidisciplinary team in order to provide a more humanized care and proactive rehabilitation. As a model, health professionals can follow the strategies of the 5 "A"s (assessment, advising, agreement, assistance and accompaniment) aimed at supported self-care that provides a better approach to the elderly person with cerebrovascular accident sequelae, especially when the approach is employed for physical and social rehabilitation[15].

The view of the multidisciplinary team should be inclined also toward the caregiver, in order to improve the quality of life of this, and the promotion of the elderly maintenance at home, which reduces difficulties in caring and greater satisfaction of the caregiver while performing activities[16].

The multidisciplinary health team should observe the person with cerebrovascular accident sequelae based on its temporality, that is to say, overcome logical thinking and see beyond what is shown. It is necessary that they pay attention to these factors that improve the well-being of these people in the home environment, in order to plan appropriate interventions to minimize and prevent future injuries. There is need to implement educative programs, aimed at families and caregivers of dependent people in order to prepare them to face the cerebrovascular accident sequelae based. It is important to invest in training of caregivers, which is a way to improve the autonomy of elderly, reduce the burden on caregivers and reduce family conflicts[17].

In this study, despite multidisciplinary academics having managed to build a bond with elderly with cerebrovascular accident sequelae and his/her caregiver at home, they showed a technical view and this hinders the development of an effective plan of care.

Training of professionals must be focused on the model of completeness which depicts an enlarged view of the person in order to allow more humanized actions and practices in health[18].

There is need for integration among professionals of the multidisciplinary team, so that the model that is one of dehumanized attention, fragmented, focused on individual biological recovery and rigid division of labor, may not be perpetuated. Thus, the professional team should participate in the reconstruction of a health care model based on the principles of the Unified Health System, which requires availability, commitment and responsibility

towards the population[19].

The quest for rapprochement between health services and instances forming professionals with superior education, by implementing the National Curriculum Guidelines of Undergraduate Courses, may facilitate changes in the design and professional profile, graduated professionals targeted to provide comprehensive care of individuals, families, social groups and communities[20].

Final Considerations

From the interviews with both caregivers and multidisciplinary academics, we can understand that incentive for development of self-care in home concerning activities of daily living in among their experiences with elderly with cerebrovascular accident sequelae.

However, caregivers of elderly need support for dealing with care at home. They often have no guidance for its realization, once they express impotence in the face of increased self-care deficit by the elderly person. They report that the limitations of the dependent brought to everyday life a great overload of activities and responsibilities, both of physical and emotional nature.

Regarding the experiences stated by multidisciplinary academics, it was also observed that they still understand the excellence in customer and family service through a technical view, which opposes the model advocated by Family Health Strategy which emphasizes a holistic and humanistic view of care at home.

However, search for interaction between multidisciplinary academics, caregivers and the ones receiving the care was observed in the statements of the academics. In the intersection was possible to apprehend situations of evaluation, advice, assistance, monitoring and agreement, considered fundamental to proactive and shared assistance, as well to the humanization of health care.

The results of this study emphasize the importance of valuing the actions of multidisciplinary health professionals in the Plan of Assistance at home for the elderly after cerebrovascular accident, both turned toward the cared person as well as to the caregiver; and the implementation of strategic actions in the academic training of health professionals on the team's view, the orchestration and harmony of knowledge focused on the customer, in the human being and not in the sickness and/or in the technique. These results may subsidize new studies that will contribute to feed back the knowledge and holistic foundation for humanized care in the assistance of elderly.

Collaborations

Nascimento MGG and Martins PCF contributed to the conception, collection of field data, analysis/data interpretation and writing of the article. Resck ZMR contributed to the conception, advising at every stage. Dázio EMR and Terra FS contributed to final approval of the version to be published.

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