







DEVELOPMENT OF PERSONAL SKILLS OF THE FAMILY CAREGIVERS IN THE HOSPITALIZATION OF PEOPLE WITH STROKE

DESENVOLVIMENTO DE HABILIDADES PESSOAIS DO CUIDADOR FAMILIAR NA HOSPITALIZAÇÃO DE PESSOAS COM ACIDENTE VASCULAR CEREBRAL

DESARROLLO DE HABILIDADES PERSONALES DEL CUIDADOR FAMILIAR EN LA HOSPITALIZACIÓN DE PERSONAS CON ACCIDENTE VASCULAR CEREBRAL

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ABSTRACT

Objective: to understand the development of personal skills of family members of people with stroke in the hospital, from the perspective of health promotion. **Method:** action-participant research, with a qualitative approach, based on Paulo Freire's research itinerary, which foresees the investigation procedure of the themes and the analytical process in its stages (thematic investigation, coding/decoding, and critical unveiling). The study was carried out in four culture circles, with 16 caregivers, in a public hospital care unit for people with stroke. **Results:** three predominant themes were unveiled: family relationship, being a caregiver and empowerment/autonomy, identifying the weaknesses and challenges found in the context of care in the hospital environment, highlighting the insecurity of family members in becoming a caregiver and facing care in transition to the home environment, difficulties in developing autonomy and conflicts generated in family relationships. **Conclusion:** professional practices centered on biological issues are distant from health-promoting actions and the skills necessary for family members to provide care after hospital discharge are not developed. These results can contribute to the reflection of the multi-professional team in directing educational strategies to the family caregiver, ensuring the safe transition of care.

Keywords: Caregivers; Health Promotion; Stroke; Hospital Care; Aptitude; Delivery of Health Care; Patient Care Team; Family Relations; Personal Autonomy.

RESUMO

Objetivo: compreender o desenvolvimento de habilidades pessoais dos familiares de pessoas com acidente vascular cerebral no âmbito hospitalar, na perspectiva da promoção da saúde. **Método:** pesquisa ação-participante, de abordagem qualitativa, fundamentada no itinerário de pesquisa de Paulo Freire, que prevê em suas etapas (investigação temática, codificação/descodificação e desvelamento crítico) o procedimento de investigação dos temas e o processo analítico. O estudo foi operacionalizado em quatro círculos de cultura, com 16 cuidadoras, em uma unidade hospitalar pública de cuidados às pessoas com acidente vascular cerebral. **Resultados:** foram desveladas três temáticas predominantes: relação familiar, ser cuidador e empoderamento/autonomia, sendo identificadas as fragilidades e desafios encontrados no contexto do cuidado no ambiente hospitalar, destacando-se a insegurança dos familiares no tornar-se cuidador e frente aos cuidados na transição para o ambiente domiciliar, dificuldades no desenvolvimento de autonomia e os conflitos gerados nas relações familiares. **Conclusão:** as práticas profissionais centralizadas nas questões biológicas distanciam-se de ações promotoras de saúde e, dessa forma, não são desenvolvidas as habilidades necessárias para os familiares realizarem o cuidado após a alta hospitalar. Esses resultados podem contribuir para reflexão da equipe multiprofissional no direcionamento de estratégias educativas ao cuidador familiar, garantindo a transição segura do cuidado.

Palavras-chave: Cuidadores; Promoção da Saúde; Acidente Vascular Cerebral; Assistência Hospitalar; Aptidão; Assistência à Saúde; Equipe de Assistência ao Paciente; Relações Familiares; Autonomia Pessoal.

RESUMEN

Objetivo: comprender el desarrollo de las habilidades personales de los familiares de las personas con accidente vascular cerebral en el hospital, desde la perspectiva de la promoción de la salud. **Método:** investigación acción-participante, con enfoque cualitativo, a partir del itinerario de investigación de Paulo Freire, que prevé en sus etapas (investigación temática, codificación / decodificación y develación crítica) el procedimiento de investigación de los temas y el proceso analítico. El estudio se llevó a cabo en cuatro círculos culturales, con 16 cuidadores, en una unidad de atención hospitalaria pública para personas con accidente vascular cerebral. **Resultados:** se develaron tres temas predominantes: relación familiar, ser cuidador y empoderamiento / autonomía, identificando las debilidades y desafíos encontrados en el contexto del cuidado en el ámbito hospitalario, destacando la inseguridad de los familiares para convertirse en cuidador en la transición al entorno familiar, dificultades para desarrollar la autonomía y conflictos generados en las relaciones familiares. **Conclusión:** las prácticas profesionales centradas en temas biológicos están alejadas de las acciones promotoras de la salud y, por lo tanto, no se

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desarrollan las habilidades necesarias para que los familiares brinden cuidados después del alta hospitalaria. Estos resultados pueden contribuir a la reflexión del equipo multiprofesional en la dirección de estrategias educativas al cuidador familiar, garantizando la transición segura del cuidado.

Palabras clave: Cuidadores; Promoción de la Salud; Accidente Cerebrovascular; Aptitud; Grupo de Atención al Paciente; Atención Hospitalaria; Prestación de Atención de Salud; Relaciones Familiares; Autonomía Personal.

INTRODUCTION

The decrease in birth rates and the increase in life expectancy made a change in the world age pyramid. This demographic transition culminates in the predominance of older people and social demands generated by social inequality, especially in developing countries, such as Brazil. Among these challenges, we highlight the increase in chronic non-communicable diseases (NCDs), together with the intensification of needs in health services and challenging managers involved in this scenario, for public policies that respond to these urgencies.^{1,2}

Stroke (CVA) stands out among NCDs, with a high rate of deaths and responsible for a high number of hospitalizations in adults and older adults.³ It is the disease that most disables people, given that one in four people in the world will suffer a stroke, a cause of great concern for the health area.⁴ This epidemiological context showed the need for effective action by health care networks, enabling care at all levels of care, and a line of care was instituted specifically to stroke in the Brazilian health system.⁵

This disease causes a series of repercussions on the survivor, such as physical sequelae and functional incapacity, generating dependence to perform basic activities of daily living.⁶ In the hospital, there is support by the multi-professional team meeting the limitations, especially of the Nursing team. However, in the transition to the home, it is usually the family that takes the place of the main provider of care, facing a new and challenging situation, with abundant demands.⁷

The need to involve the family in the guidelines has been increasingly discussed aiming to stimulate the motivation for coping and involving these individuals, including promoting autonomy.⁸ When caring for a stroke survivor, we need to provide support, including the training of care to be provided outside the hospital environment, to give adequate care, considering that continuity of fragile care can lead to complications or readmissions.⁹ Also, these actions can improve the quality of life of the patients' family caregivers and prevent them from getting sick too. Therefore, favoring the reintegra-

tion of the person with stroke in the community and supporting the caregiver should be an objective initiated during hospitalization.^{7,9}

Due to the increase in people with stroke, changes need to occur in health care practices to achieve comprehensive care, enabling the positive interference of indicators related to this chronic disease.¹⁰ In this sense, as a new *modus operandi*, the health promotion arises to overcome biological care in the health-disease process, understood as the process of training individuals and the community, to act in improving the quality of life and considering the influence of social determinants of health. It is developed through five fields of action: healthy public policies, creation of favorable environments, reinforcement of community action, development of personal skills, and reorientation of health services.¹¹

Although in the hospital environment - where curative and preventive care for the disease predominates - health promotion actions are hidden. In the case of stroke, the axis of the development of the personal skills of family caregivers has great relevance. This field of action is based on dissemination, information, health education, intensifying vital skills, promoting empowerment for care, and seeking improvement in living conditions.¹¹ The caregiver plays a fundamental role, giving continuity to care, given that the isolated performance of health professionals does not meet the demands of the person who survived the disease. Although there is knowledge of the importance of the caregiver, there is a fragile consideration of their participation in health practices. In this sense, the development of training is urgent to encourage family caregivers to have autonomy for care after hospital discharge, aiming at the zeal for the well-being of the family, developing healthy practices, and more control for coping with NCDs.¹²

The adequacy and reorientation of services in search of a health-promoting practice becomes essential for the continuity of care in a qualified and safe manner, including in environments that provide highly complex services.¹³ Some movements have started in this direction, with emphasis on the international network Health Promoting Hospital (HPH), created in Europe, which develops the movement to implement strategies for health promotion in hospital care.¹⁴ In Brazil, despite the National Health Promotion Policy (*Política Nacional de Promoção da Saúde*) reaffirming the importance of these actions, they are timid and need advances.¹⁵

Considering these notes, the debate about the skills development of family caregivers of people with NCDs,

whose focus is health education, needs to be built beyond healthy lifestyles, given the reduced scientific production on the subject, including in tertiary care environments. In this scenario, advancing health-promoting practices that incorporate the needs and limitations of the person with stroke and their caregivers constitutes a challenge to be overcome by health teams.¹⁶ As a possibility for expanding the frontiers of the professionals' performance, we highlight the reference of educator Paulo Freire, who based on a liberating pedagogical proposal contributes to the practical construction of knowledge and encourages individuals to change their reality in an emancipatory way and the search for autonomy, in line with the precepts of health promotion.¹⁷

Given these considerations, this study aimed to understand the development of personal skills of family members of people with stroke in the hospital, from the perspective of health promotion.

METHOD

This is a study with a qualitative approach, of the action-participant type, in which the data are contextualized based on the reality of the participants. It is based on Paulo Freire's research itinerary, which consists of a liberating methodological proposal. This method is based on three dialectically interconnected steps, which can occur simultaneously: thematic investigation; encoding and decoding; and critical unveiling. These moments are operationalized in cultural circles, which are characterized by a group of people who experience the same limited situation and, based on collective dialogue, seek to transform their contexts.¹⁷

This method enhances and sensitizes the conscience, the full exercise of autonomy, and stimulates participation as a form of empowerment and emancipation of individuals, in line with the precepts of health promotion.¹⁷ It is considered opportune in carrying out educational work, with a view to the development of personal skills of caregivers of people with stroke in the hospital environment.

The study was carried out in a public hospital in the state of *Santa Catarina*, in the southern region of Brazil. The individuals affected by the stroke are treated at a specialized unit, the Integral Stroke Unit (*U-AVC Integral*). The team consists of professionals from Medicine, Nursing, Physiotherapy, Speech Therapy, Psychology, Occupational Therapy, and Social Assistance. The approach to the family considers the daily routines and the participation of these people in the groups of care-

givers, which occur weekly. It is a time when a professional discusses the stroke with families.

To participate in the study, the following inclusion criteria were established: being a family caregiver of individuals hospitalized at the *U-AVC Integral* and being present at the unit for at least 48 hours. We adopted the following exclusion criteria: being a formal caregiver and being a family caregiver of a person who was not hospitalized due to stroke. Sixteen caregivers participated in the study during the meetings, responsible for the individuals hospitalized at the *U-AVC*. However, the group of participants did not remain the same during the meetings. Paulo Freire's research itinerary considers that culture circles can occur with a reduced number of participants and, considering that it is an active methodological strategy, it also allows a horizontal relationship between the researcher and the study participants.¹⁷ Contact with the participants, for the research, was carried out through visits to the rooms of hospitalized people, presentation of the research, and objective, in addition to the delivery of an invitation to family members.

The research mediator is linked to the Laboratory for Research in Nursing and Health Promotion (*Laboratório de Pesquisa em Enfermagem e Promoção da Saúde*), at the *Universidade Federal de Santa Catarina*. The discussions of this group are permeated by active methodologies, such as action-participant research and the use of Paulo Freire's research method in various academic studies. The stages were developed in four meetings that took place in the same week, with an average duration of 90 minutes, in April 2018. All meetings were held in a classroom of the Teaching Department of the hospital. Initially, the research mediator applied a guide to collect the socioeconomic information of all participants and asked each one to fill in items that included: age, gender, occupation, marital status, and educational level. The dialogues developed at the meetings were audio-recorded and later transcribed for analysis.

In the thematic investigation, some guiding questions were asked to the group: *How do you feel as a caregiver? What are the biggest challenges to empower yourself as a caregiver? What are the greatest facilities/potentialities to empower and promote the health of people with stroke?* The mediator brought to the group a concept of empowerment based on the ideals of the Ottawa Charter. To make this stage operational, the family caregivers reflected together and used images from magazines and cards to express their perceptions collectively. The answers were placed on posters corresponding to the questions asked, resulting in 40 generating themes.

In the second roundtable, there was the participation of new caregivers and the mediator took printed cards with the 40 themes investigated and urged them to do a re-reading, providing reflection and critical deepening, to proceed with the following phases. Of the 40 themes investigated, family caregivers identified significant themes and, according to Paulo Freire's Itinerary, participants codified three relevant themes.

In the following two roundtables, the themes raised by the group of participants were discussed. The mediator stimulated encoding and decoding by showing the participants videos to enhance the debate related to the theme. Furthermore, some questions were asked for the group (*what can I do to make my family more involved in care? How can I empower myself to promote the health of my family member with stroke?*), Leading to reflection about their worldviews and enabling the search for possibilities for the transformation of their contexts.

Paulo Freire's research itinerary allowed family caregivers to participate in the investigation, discerning their leading roles in care routines, during the hospital stroke scenario. In the last culture roundtable, we could reach critical unveiling, perceived by words and positions that reflected a collective thought, meeting Paulo Freire's method.

The caregiving participants analyzed the encoded and decoded themes (data) as the most relevant and that should be unveiled in the culture roundtable. For the analysis of the data, the themes that contained the records of the dialogues related to the three generating themes discussed were read, promoting the necessary care skills and critical unveiling, according to Paulo Freire's approach.

The research started after the opinion of the participating hospital and approval of the project by the Research Ethics Committee of the *Universidade Federal de Santa Catarina CEP/UFSC* following Resolution 466/12 of the National Health Council. After being clarified, it was explained and delivered and the signature of all participants was requested to start the data collection. Following the ethical precepts of the research, the names of the participants were replaced, identifying them with alphabetic letters.

RESULTS

The family caregiver's profile was characterized based on sociodemographic data. Sixteen caregivers participated in the study during the meetings, all were

female. During the meetings, new participants emerged, which led the researcher to resume the initial discussions so that the themes could continue.

The age of family caregivers ranged between 22 and 69 years old. Eight participants were housewives, five were unemployed at the time of the study and the other three were employed.

Also, regarding the type of bond with the person affected by a stroke, all participants were from the family sphere, with a predominance of daughters, represented by nine caregivers. Five were partners (wives or girlfriends), one was a granddaughter and the other was a cousin of the hospitalized person. The education of six participants was incomplete elementary school, four finished high schools, three with complete higher education, two with complete elementary school, and one with technical level.

The length of stay in the *U-AVC Integral* ranged from two to 15 days. Regarding the demand for care, five participants stated that they did not share the assignment with other family members, while the other 11, at some point, could share the role of care with other people in the family.

We reproduced the generating themes and encodings on posters to organize and facilitate the stages of Paulo Freire's research itinerary. The group identified 40 themes (Table 1) and codified them into three main themes, indicated by the participants: family relationship, being a caregiver, and empowerment/autonomy.

The culture roundtables unfolded from the dialogues related to the difficulties and facilities found in the hospital, concerning the development of personal skills of the family caregiver with the person with stroke. The discussions provided reflections on the care process, expanding the understanding of the reality and inevitability of coping with the situation experienced, and to specific issues of skills for the care with food, hygiene, and activities of daily living, but in an expanded perspective of promoting the health of these family members. The themes developed during the research itinerary are described below.

Family Relationship

Family conflicts were an issue present in all meetings. Experiencing the burden of care together with the lack of support from the family, proved to be an important point to be discussed, as it has direct interference in the care of the hospitalized person due to stroke. We

Table 1 - Themes encoded, decoded, and unveiled in culture roundtables

Themes	Encoded, decoded, and unveiled
1. Need for support from family members	Family Relationship
2. Do not bring worries to the person with stroke	
3. Lack of family recognition of the caregiver's effort	
4. Family unity	
5. Making family decisions	
6. Dealing with the person's stroke problems (stubbornness)	
7. Family organization	
8. Network of friends as support	
9. Family awareness of care	
10. Psychological support for family members	
11. Obligation to care for women	
12. Impatience with family members	
13. Do not make the relative sad with conflicts	
14. Support the family member with stroke	
15. Concern about discharge	
16. Participation of care	
17. Difficulties in the bath	
18. Doctors' follow up	
19. "This is not how I wanted to retire"	
20. Importance of caregiver	
21. Weakened to care	
22. "We help as we can"	
23. Little difficulty	
24. Care falls to those who do not work	
25. Terrified to care	
26. Caring for those who care	
27. Healthy eating	
28. "I don't even want to think about the after"	
29. The good mood of the team helps	Empowerment/Autonomy
30. Financial issue	
31. House structure - mobility	
32. Caregivers can assist the multiprofessional team	
33. Relief moments for the family favor care	
34. Avoid dependence on Nursing for all care	
35. Caring for other people without caregivers	
36. Friendship bonds with other caregivers	
37. Acquire knowledge to make decisions	
38. The person with a stroke also needs to take care of himself	
39. Support from the medical and Nursing staff favors care	
40. Learn from this experience	

Source: research data, 2018.

noted that difficult family relationships had already occurred before the scope of care. However, it became something more uncomfortable and evident, as it implied the lack of co-participation for the responsibilities of caring.

We were never able to sit down to talk, even when we were little. Now, at home, we are in four [brothers]. Everyone made an excuse, like the other times my mom got sick. Because I'm leaning, they think I don't have to take care of my life. I have a back problem, in the eyes, but I'm here (A).

Family caregivers reflected on the absence of men in the tasks of care and why they do not feel responsible for the division of tasks during hospitalization, with the obligation falling on women:

I find male children interesting. They think they are under no obligation (B).

And it doesn't matter if the family is small or large. I have only one brother, but the problems are the same (C).

The family members' anxieties were proportional to the level of dependence of the person with a stroke. While some had difficulties in feeding (for example, in the occurrence of dysphagia), others were only restricted to the bed and dependent for all basic activities of daily living. Thus, the schedule for hospital discharge and return home-generated stress and more anxiety in family caregivers, who would have to perform the function with dependent people.

The financial issue and home adaptation in terms of the structure were also a challenge for care. It was already evident in the speeches thoughts about the materials needed to buy after the discharge of the most weakened people, such as the use of diapers or other devices.

The difficulty for me is the use of things at home. Bathroom, doors [...] Because I think that there is no room for a wheelchair in the doors. For me, this is the biggest challenge. It also involves financial issues. How much will you spend? (B).

Being a caregiver

In this theme, the course of the discussions considers a new condition established in the lives of the participants, including the perception of the burden of caring for their families with stroke and also seeking to understand its importance in the hospitalization and home care process.

I feel useful because I think that if I'm on his side, the improvement will be faster. And it is my obligation [...] I am his wife (A).

For some participants, the responsibility for care is described as a burden and feeling of obligation. Generally, this feeling was raised by the caregivers, who also brought their previous health problems and their demands for self-care, added to the little collaboration of family members in the tasks of care.

I am already a certain age, difficult to get down, spinal problems. He's a big, tall, heavy man. Children come only on weekends because they can't always come, they work. I stayed four days in a row until his daughter arrived. I was broken, at home, I looked at the wall and cried because I felt exhausted, alone. We are no longer old (B).

I lost my job because I missed taking care of my mother. My sister also left the job (D).

The change in the participants' family routine was visualized due to the new assignment of "becoming" caregivers, as new demands were added to their daily obligations, such as care for the home and children. In addition to the need to develop skills for care, this new work overload and overlapping of functions appear in the testimonies of the caregivers, showing anxiety, fear, and anguish related to hospital discharge and when realizing their limits for basic care on the day morning. Some participants had already experienced care at other times, with family or friends. In this way, they also carried some of their experiences, but dealt with their limitations:

For me, the difficult thing is to take him to the bath, to go to the bathroom, because he is very big, tall, heavy. He doesn't feel the left part. I do the rest (A).

In the hospital environment, although they were experiencing more psychological tension, some participants described care as a pleasurable activity, in which they felt motivated and acted on the feeling of empathy, sometimes even helping neighbors who needed help and who were without caregivers at the moment.

Empowerment and Autonomy

During the roundtables, the participants showed their anguish regarding the scarcity of information re-

garding the prognosis of the disease and difficulty in understanding the team's statements about the situation of the family member with stroke. They expressed difficulty in communicating with their family members and believed they did not have the emotional conditions to start a conversation related to possible sequelae and their afflictions with hospitalization. Thus, they expected more clearly from the team, including the involvement of the family member, so that they could be aware of their health situation:

He told me: I don't want them to lie. We have always been very open to conversation. [...] The right thing was to have a professional arrive and give the news (B).

Regarding the work provided by the multi-professional team, the reported credibility and security were collective. The quality of the assistance, the good humor of the team, and the certification of the institution's work were items related to the positive points. Also, some participants identified that the team experiences work overload and reports that they sometimes avoid asking for help from Nursing professionals, seeking to do it alone and without guidance. This was mentioned in the execution of basic activities, such as assistance with food, hygiene, and mobility.

During discussions in cultural circles, when approached about preparing for de-hospitalization, caregivers expressed the need to pay attention to their anxieties, especially for the demands they will find in the home environment.

I told the girl [team professional]: you are going to give a lecture to take care of them, but you have to do it directly to the people who are taking care because they are weaker than they are. They will not know how to take care. Here you know that anything you press there [bell] and the "nurse" comes (E).

When the researcher asked about the knowledge of basic care to be put into practice after discharge, the team was not mentioned for developing skills for these tasks. We noticed that the search for understanding care activities, sometimes, occurred from the observation of routines.

When I took care of my mother-in-law, she had diabetes and applied insulin. I always paid attention, because at home I was going to have to do it. Like here, I pay close attention. If you need to, we know. So, that's it, I will learn if I need to use it (D).

The obstacles common to the participants have exposed during the circles and the statements reinforce that the development of skills for care occurs without guidance from the team to do so. In the end, they said that they missed moments of dialogue so that they could expose their wishes to the professionals of the stroke unit.

As an action-participant research method, the data collected and the continuity of the meetings are directed based on the demands that emerge in the roundtables. We understand that there was a predominance of themes related to the obstacles and facilities found for caregivers to develop skills and autonomy to feel able to care.

DISCUSSION

The sociodemographic characteristics of the participants in this study are similar to those found in family caregivers from other studies¹⁸⁻²¹, with a predominance of female people, with no employment relationship, and with the degree of kinship divided between those who are daughters and those who are spouses of people who experience a stroke. This reinforces the historically constructed standard that the natural function of providing care is attributed to women, as a generous, charitable, and socially imposed action.

In the process of illness of a family member, especially in the chronic condition, all the others are affected. This stressful event produces an imbalance in their ability to function normally, implying a process of family reorganization due to the need for support in patient care.²²

People who assume this role can express a feeling of obligation, starting to have restrictions in their lives^{23,24}, since, in the specificity of caring for a family member, ambivalent feelings emerge, which are characterized by satisfaction, generosity, affection, and love, as well as overload, suffering, uncertainty, and stress.²²

The study showed different perceptions of care, observed in anguished statements by the caregivers of more disabled people. This data corroborates other studies that showed caregivers overloaded in the routine of physically disabled people, as in this situation the demand for care increases.^{19,20} Physical barriers in the home environment show a relevant problem after a stroke, and an aggravating quality of caregiver's life²⁰, which also worsens in situations where there are unfavorable socioeconomic conditions and low level of educational background.²¹

The ability to exercise care is closely linked to some characteristics: a) encouragement in the participation of care, for the development of skills; b) family caregiver - professional in an empathetic relationship, active listening, and information that ensures knowledge and awareness of the situation; c) trust between family and multi-professional team, including space for sharing decisions; d) valuing the role of the family and enabling empowerment for care.²⁵

For home care to be carried out safely and confidently by family caregivers, even during hospitalization, a hospital discharge program needs to be initiated, according to the needs and limitations of the person with a stroke. In the logic of overcoming the biomedical model, a scientific tool that should be adopted by the interprofessional team is health education practices, which aim to improve the quality of life and care.²⁶

In this sense, in the transition from hospital to home, it is essential to structure the health system in networks, articulated at all levels of care for the continuity of care. However, despite the international and national consensus on the importance of the policy to fight chronic diseases, the implementation of the stroke care line is still far from being a reality in public health in Brazil.^{27,28}

The study data show that there is incipience in the reorientation of health services. The Ottawa Charter reaffirms that the development of personal skills can enhance the autonomy of people and communities, for positive changes in their environment and health.¹¹ There is hardly a safe transition to the home if these actions are not promoted in the hospital environment.

The Health Promoting Hospital movement advocates health-promoting actions that encompass the scenario involved, organization of the institution, communities, health staff, people, and their families. Also, it raises the awareness of family members so that, in the health process, they become an active partnership, with joint decision making.¹⁴

Developed countries have included informal caregivers in their public policies, recognizing their social representativeness and projection for an increase in this group in the coming years, with economic implications. For example, in New Zealand, the Caregivers Action Plan was developed, which sets out criteria for funding, support and resources and financing for informal caregivers.²⁹

The crisis caused by illness can become an opportunity to readjust standards that are weakened regarding the relationship and dialogue between the health team and the person/family caregiver, projecting the quality

of life of the family as a whole. The hospital is essential in its healing practices; however, after situations such as stroke, it is the first place where families and professionals relate.³⁰ Thus, it is important that there is space for health-promoting actions, developing personal skills, and autonomy for the adequate continuity of care.

Based on the care practices included in this study, there is a departure from the ideals of health promotion in the hospital environment. In the critical unveiling of the research, we can observe a limit for family caregivers to understand how to deal with situations related to care, away from health professionals. The development of personal skills, as a precept for health promotion^{3,11}, was observed with weaknesses in hospitalization and identified in conflicting family relationships, in the urgency of a new assignment without preparation, and difficulties for the development of autonomy. Although it was not our focus of the study, primary health care teams were not cited as expected support for families. After hospital discharge and family conflicts, they can become a limit for the quality of care, especially when the person with a stroke returns home.

The study rescues the possibility for action in the hospital environment, given that the development of skills and health promotion are little worked in this area, being strengthened by the action-participant methodology and that can be extended to other themes, in addition to stroke. Unequal perceptions of care are considered a limit of this research, due to the different situations identified in people hospitalized with a stroke and, in some situations, the recent experience as caregivers. We believe that the development of studies after hospital discharge, involving other points in the care network, may show different results than those found in the institutional context and assist in the identification of possible obstacles to the effectiveness of the caregiver's health promotion actions after discharge.

CONCLUSION

Hospital discharge was characterized as a situation of apprehension to family caregivers, including the need to adapt to structural issues at home, economic aspects with increased costs for care, the overload of a new assignment entrusted, and the abdication of their desires. Intensified in hospitalization, family conflicts hurt the dynamics of relationships and become limits for sharing care.

Also, practices centered on the health and disease process do not conceive the participation of the family

caregiver, which results in a mere executor of tasks developed without instruction, culminating in the fragility of the preparation for discharge. Health-promoting actions developed by the multi-professional team were not evident in the participants' statements. This data refers to the paradigm of the curative model and with a focus on the disease, moving away from the ideals of the Health Promoting Hospitals movement. When resuming the objective of this study, we understood that the development of personal skills of family members of people with stroke is not carried out in the hospital and this group is not inserted in the care practices aimed at health promotion.

The data refer to new thinking about professional practice, considering the development of personal skills as a possible strategy for health promotion, even at the time of hospitalization. Thus, identifying the main needs of caregivers and ensuring a safe transition to the home is an important role to be played by Nursing professionals and can be reflected in the scope of their actions.

REFERENCES

- Malta DC, Bernal RTI, Lima MG, Araújo SSC, Silva MMA, Freitas MIF, *et al.* Doenças crônicas não transmissíveis e a utilização de serviços de saúde: análise da Pesquisa Nacional de Saúde no Brasil. *Rev Saúde Pública.* 2017[cited 2020 Nov 05];51(Supl. 1):S1-10. Available from: https://www.scielo.br/pdf/rsp/v51s1/pt_0034-8910-rsp-S1518-87872017051000090.pdf
- Miranda GMD, Mendes ACG, Silva ALA. Desafios das políticas públicas no cenário de transição demográfica e mudanças sociais no Brasil. *Interface (Botucatu).* 2017[cited 2020 Aug 5];21(61):309-20. Available from: <https://www.scielo.br/pdf/icse/v21n61/1807-5762-icse-1807-576220160136.pdf>
- Maniva SJCF, Carvalho ZMF, Gomes RKG, Carvalho REFL, Barbosa XL, Freitas CHA. Tecnologias educativas para educação em saúde no acidente vascular cerebral: revisão integrativa. *Rev Bras Enferm.* 2018[cited 2020 July 10];71(Supl. 4):S1724-31. Available from: https://www.scielo.br/pdf/reben/v71s4/pt_0034-7167-reben-71-s4-1724.pdf
- World Stroke Organization. World stroke campaign. 2018[cited 2020 June 16]. Available from: <https://www.world-stroke.org/world-stroke-day-campaign>
- Ministério da Saúde (BR). Linha de Cuidado do Acidente Vascular Cerebral (AVC) no adulto. Brasília: Ministério da Saúde; 2020[cited 2021 Mar 25]. Available from: http://189.28.128.100/dab/docs/portaladab/publicacoes/LC_AVC_no_adulto.pdf
- Avezum Á, Costa Filho FF, Pieri A, Martins SO, Marin-Neto JA. Stroke in Latin America: burden of disease and opportunities for prevention. *Glob Heart.* 2015[cited 2020 Aug 11];10(4):323-31. Available from: <https://pubmed.ncbi.nlm.nih.gov/26014650/>
- Bellato R, Araújo LFS, Dolina JD, Musquim CA, Corrêa GHLST. Experiência familiar de cuidado na situação crônica. *Rev Esc Enferm USP.* 2016[cited 2020 Aug 11];50(n. esp.):81-8. Available from: https://www.scielo.br/pdf/reeusp/v50nspe/pt_0080-6234-reeusp-50-esp-0081.pdf
- Fernandes CS, Angelo M. Cuidadores familiares: o que eles necessitam? Uma revisão integrativa. *Rev Esc Enferm USP.* 2016[cited 2020 June 18];50(4):675-82. Available from: https://www.scielo.br/pdf/reeusp/v50n4/pt_0080-6234-reeusp-50-04-0675.pdf
- Walton MK. Supporting family caregivers: Communicating with family caregivers. *Am J Nurs.* 2011[cited 2020 Sept 17];111(12):47-53. Available from: https://journals.lww.com/ajnonline/Fulltext/2011/12000/Supporting_Family_Caregivers_Communicating_with.27.aspx
- Ministério da Saúde (BR). Diretrizes de atenção à reabilitação da pessoa com acidente vascular cerebral. Brasília: Ministério da Saúde; 2013[cited 2021 Mar 25]. Available from: https://bvsms.saude.gov.br/bvs/publicacoes/diretrizes_atencao_reabilitacao_acidente_vascular_cerebral.pdf
- World Health Organization. The Ottawa Charter For Health Promotion. Ottawa: WHO; 1986[cited 2020 July 02]. Available from: <https://www.who.int/healthpromotion/conferences/previous/ottawa/en/>
- Siqueira R, Loureiro M, Frota O, Ferreira Júnior M. Prática de educação em saúde na visão dos cuidadores informais em cuidados continuados integrados. *Rev Enferm UFPE on line.* 2017[cited 2021 Mar 25];11(8):3079-86. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/110212>
- Silva MAMP, Pinheiro AKB, Souza AMA, Moreira ACA. Promoção da saúde em ambientes hospitalares. *Rev Bras Enferm.* 2011[cited 2021 Mar 25];64(3):596-9. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672011000300027&lng=en
- World Health Organization. International Network of Health Promoting Hospitals and Health Services. The New Haven Recommendations. New Haven, EUA: WHO; 2016[cited 2020 May 14]. Available from: <https://planetree.org/wp-content/uploads/2016/09/2016-New-Haven-Recommendations.pdf>
- Ministério da Saúde (BR). Portaria nº 2.446, de 11 de novembro de 2014. Política Nacional de Promoção da Saúde. Brasília: MS; 2014[cited 2020 May 14]. Available from: http://bvsms.saude.gov.br/bvs/saudelegis/gm/2014/prt2446_11_11_2014.html
- Yeung EHL, Szeto A, Richardson D, Lai SH, Lim E, Cameron JI. The experiences and needs of Chinese-Canadian stroke survivors and family caregivers as they re-integrate into the community. *Heal Soc Care Community.* 2015[cited 2020 July 15];23(5):523-31. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12164>
- Freire P. *Pedagogia do oprimido.* 65ª ed. São Paulo: Paz e Terra; 2018.
- Folle AD, Shimizu HE, Naves JOS. Representação social da doença de Alzheimer para familiares cuidadores: desgastante e gratificante. *Rev Esc Enferm USP.* 2016[cited 2020 July 08];50(1):79-85. Available from: https://www.scielo.br/pdf/reeusp/v50n1/pt_0080-6234-reeusp-50-01-0081.pdf

19. Longacre ML, Valdmanis VG, Handorf EA, Fang CY. Work Impact and Emotional Stress Among Informal Caregivers for Older Adults. *J Gerontol B Psychol Sci Soc Sci*. 2017[cited 2020 July 22];72(3):522-31. Available from: <https://academic.oup.com/psychogerontology/article/72/3/522/2631929>
20. Pucciarelli G, Vellone E, Savini S, Simeone S, Ausili D, Alvaro R, *et al*. Roles of Changing Physical Function and Caregiver Burden on Quality of Life in Stroke. *Stroke*. 2017[cited 2020 Aug 28];48(3):733-9. Available from: <https://www.ahajournals.org/doi/10.1161/STROKEAHA.116.014989>
21. Totsika V, Hastings RP, Vagenas D. Informal caregivers of people with an intellectual disability in England: health, quality of life and impact of caring. *Heal Soc Care Community*. 2017[cited 2020 June 17];25(3):951-61. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12393>
22. Reis RD, Pereira EC, Pereira MIM, Soane AMNC, Silva JV. Significados, para os familiares, de conviver com um idoso com sequelas de Acidente Vascular Cerebral (AVC). *Interface (Botucatu)*. 2017[cited 2020 Sept 11];21(62):641-50. Available from: <https://www.scielo.br/pdf/icse/v21n62/1807-5762-icse-1807-576220160206.pdf>
23. Olivier CL, Phillips J, Roy DE. To be or not to be? A caregiver's question: the lived experience of a stroke family during the first 18 months poststroke. *Scand J Caring Sci*. 2018[cited 2020 May 19];32(1):270-9. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/scs.12458>
24. Faleiros AH, Santos CA, Martins CR, Holanda RA, Souza NLSA, Araújo CLO. Os Desafios do Cuidar: revisão bibliográfica, sobrecargas e satisfações do cuidador de idosos. *Janus*. 2015[cited 2020 May 08];(21):59-68. Available from: <http://unifatea.com.br/seer3/index.php/Janus/article/view/364/337>
25. Wahlin I. Empowerment in critical care – a concept analysis. *Scand J Caring Sci*. 2017[cited 2020 Aug 13];31(1):164-74. Available from: <https://onlinelibrary.wiley.com/doi/full/10.1111/scs.12331>
26. Oliveira EC, Ferreira WFS, Oliveira EC, Dutra DA. Cuidados pós-alta em pacientes idosos com sequelas de acidente vascular cerebral: planejamento de alta hospitalar. *Rev Saúde Desenvol*. 2017[cited 2020 Jun 08];11(9):172-97. Available from: <https://www.uninter.com/revistasaude/index.php/sauedeDesenvolvimento/article/view/785/0>
27. Galvão EL, Santos DF, Bodevan EC. Análise da rede de atenção ao acidente vascular cerebral no Vale do Jequitinhonha. *LAJBM*. 2018[cited 2020 May 23];9(2):80-7. Available from: <https://www.lajbm.com.br/index.php/journal/article/view/508>
28. Mourão AM, Vicente LCC, Chaves TS, Sant'Anna RV, Meira FC, Xavier RMB, *et al*. Perfil dos pacientes com diagnóstico de AVC atendidos em um hospital de Minas Gerais credenciado na linha de cuidados. *Rev Bras Neurol*. 2017[cited 2020 June 15];53(4):12-6. Available from: <http://docs.bvsalud.org/biblioref/2017/12/876884/rbn-534-2-perfil-dos-pacientes-com-diagnostico-de.pdf>
29. Ministry of Social Development (NZ). The New Zealand Carers' Strategy Action Plan for 2014 to 2018. New Zealand; 2014[cited 2020 May 23]. Available from: <https://www.msd.govt.nz/documents/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/carers-strategy-2014-18-update.pdf>
30. Greenwood N, Pelone F, Hassenkamp A. General practice based psychosocial interventions for supporting carers of people with dementia or stroke: a systematic review. *BMC Fam Pract*. 2016[cited 2021 Apr 12];17(3). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4714487/>

