



Acta Scientiarum. Health Sciences

ISSN: 1679-9291

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Universidade Estadual de Maringá
Brasil

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Acta Scientiarum. Health Sciences, vol. 39, núm. 1, enero-junio, 2017, pp. 65-70

Universidade Estadual de Maringá
Maringá, Brasil

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Meanings attributed by family members to the act of caring for elderly people with stroke sequels

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ABSTRACT. The objective of this study was to identify meanings that family members attribute to the act of caring for elderly individuals with stroke sequels. The participants were family members that were taking care of a senior with stroke sequels, both male and female. The sample was composed of 15 family members. The instruments used for data collection were: a questionnaire referring to the participants' personal and family profile, in addition to a semi-structured interview script. For extraction of main ideas, Bardin's content analysis was used. The categories that emerged from the 'Meaning of caring' theme were: 'A lot of love and support', 'Hard because of the person's dependence', 'Caring is not hard', 'Responsibility' and 'Role change'. The conclusion is that caring for an elderly person with stroke sequels involves a variety of aspects and situations.

Keywords: stroke, family caregivers, the elderly.

Significados para os familiares em cuidar de um idoso sequelado de AVC

RESUMO. O objetivo deste estudo foi identificar os significados para os familiares em cuidar de um idoso sequelado de AVC. Os participantes do estudo foram os familiares que cuidavam de um idoso sequelado de AVC, tanto do gênero masculino quanto do feminino. A amostra foi constituída por 15 membros familiares. Os instrumentos utilizados para a coleta de dados foram: questionário referente à caracterização pessoal e familiar dos participantes e o roteiro de entrevista semiestruturada. Para extração das ideias principais, foi utilizada a Análise de Conteúdo de Bardin. As categorias emergentes do tema 'Significado de cuidar' foram: 'Muito amor e apoio', 'Difícil pela dependência da pessoa', 'Não é difícil cuidar', 'Responsabilidade' e 'Inversão de papéis'. Conclui-se que cuidar de um idoso sequelado de AVC assume diversos aspectos e situações.

Palavras-chave: acidente vascular cerebral, cuidadores familiares, idoso.

Introduction

In Brazil, Cerebrovascular Accident (CVA), or stroke, without specification as to whether it is ischemic or hemorrhagic, is the third main cause of hospitalization and the second in number of deaths among diseases that affect the circulatory system. Of all 86,944 deaths that occurred in the country in 2010 from diseases included in this group, 19,892 resulted from strokes, which characterizes a public health problem to be fought (Indicadores de Saúde, 2010). In general, ischemic strokes are three or four times as frequent as hemorrhagic, accounting for 70 to 80% of all types of stroke (Sacco, 2007).

Both hemorrhagic and ischemic strokes lead to many incapacities. The latter include difficulties in performing everyday activities. In the elderly, they may cause serious health problems, depression, isolation and dependence; rehabilitation and family support are important to facilitate the resumption of

daily tasks and for one to regain autonomy, a vital factor to quality of life. However, obstacles hinder the preservation of this autonomy, such as lack of physical structure inside and outside the house and overprotection on the part of family members, who oftentimes treat them as disabled, putting them in an embarrassing and limiting situation, prohibiting them from performing activities that they are still capable of performing (Pedreira & Oliveira, 2012).

Pereira, Santos, Fhon, Marques and Rodrigues (2013) state that a senior's functional incapacity is not related to stroke only. It is worth highlighting that simultaneously with a stroke elderly individuals are going through a senescence process. Although aging is not an illness, structural and body function changes that occur in one's body, especially those affecting musculoskeletal, osseous and nervous systems, decrease an individual's functional capacity to execute everyday activities. Thus, the aging process contributes to intensifying losses in

functional capacity resulting from a stroke, reinforcing the need for continuous care.

This context shows a family's fundamental role to survival, support, unity, love and dedication in the course of the disease, bearing in mind that the act of caring continuously is a physical, emotional, social and spiritual burden and, thus, generates a situation of crisis that threatens the dynamics of a family environment.

Family support is vital to the provision of a quality care to an elderly person. However, providing care at home to dependent people is a hard task that can bring consequences to caregivers and families as a whole (Salgueiro & Lopes, 2010).

Dependence and lack of autonomy can be experienced in different ways throughout the vital cycle. For a child, they are seen as characteristics that are proper of their life phase. In the course of a disease, they are perceived as necessary in the period of transition to a better health. In old age, in turn, lack of autonomy and dependence are commonly negative and stressful events that lead to poor quality of life for both those who experience this condition and those who surround them (Gonçalves et al., 2013).

When providing care, caregivers end up having less time to take care of themselves, to rest and to work more, and often deprive themselves of social interaction, since people who have suffered a stroke become the central recipient of care and, consequently, of attention. This leads caregivers to readjust their daily practices to activities demanded by the evolution of the disease, thus subjecting themselves, in most cases, to a physical and emotional burden related to the intensity of the care provided (Araújo, Silva, Conceição, Santana, & Vasconcelos, 2012).

Considering the above exposed, the objective of this study is to identify the meaning family members attribute to the act of caring for an elderly relative with stroke sequels.

Methodology

The present study has a qualitative approach of exploratory, descriptive and cross-sectional type. Participants were family members caring for seniors with stroke sequels. This investigation had as scenario the city of Itajubá, comprehending its many neighborhoods, in both urban and rural areas, where elderly people with stroke sequels and their relatives resided. The sample is of lineal type and the technique used was Snowball with 15 informal caregivers. The first family was approached through direct contact made beforehand by means of

household visit in order to monitor the elderly person's health condition and family situation after he or she was discharged and sent back home after suffering an ischemic stroke. After the study was approved by the Ethics and Research Committee [*Comitê de Ética e Pesquisa*] (CEP) of Wenceslau Braz Nursing School, the research started with that family. Mentions of other family members and acquaintances happened naturally, but some seniors with stroke sequels did not meet inclusion criteria. Nevertheless, there always were mentions of new family members that were going through this very same moment of re-adaptation in the family environment. The saturation point occurred with the 15th participant, because the collected data started to repeat and no longer added new information that was relevant to the research.

Inclusion criteria were:

- Having an elderly family member with stroke sequels and who needs help with everyday activities;
- Being an informal caregiver;
- Living with the elderly person with stroke sequels, being caring for the latter directly, for at least six months. The inclusion criterion of having at least six months of experience is due to the fact that, according to Monteiro (2007), every adaptation to any new situation generally happens after the experience period;
- Being older than 18 years;
- Accepting to participate in the study by signing an informed consent form.

As for exclusion criterion, it was limited to: being an informal caregiver with impaired cognitive and communication capacity.

The present study complied with all precepts set forth by Resolution No 466/12, of December 12, 2012, of the Brazilian Ministry of Health, which addresses ethics on research involving humans (Brasil, 2012). The consubstantiated Legal Opinion that approves the conduction of the study can be found under No 889.895/2014.

Data were collected at the participants' homes. Data collection began after the study was approved by the Ethics and Research Committee of Wenceslau Braz Nursing School. The interviewee's authorization was obtained by means of the signing of an informed consent form. The interview was carried out, after prior scheduling, with each of the participants at places and on dates defined by the family members. Before the interviews were conducted, the researchers explained the objectives of the study, as well as the development of all the investigation, and all doubts were clarified. The

researchers made sure to maintain a calm and quiet environment, offering privacy and security. The interview was recorded and then transcribed.

For the interview, two instruments were used for data collection. The first one was a questionnaire referring to the caregivers' sociodemographic characteristics. The second one was a semi-structured interview script containing a guiding question.

As to data analysis strategy, the method chosen was Bardin's Content Analysis.

The different phases of content analysis are organized into three poles (Bardin, 2011).

1) Pre-analysis. It corresponds to a period of inferences, aiming at making initial ideas operational and systematizes them so as to conduct an accurate scheme for the development of successive operations, in an analysis plan.

2) Material exploration. This phase consists essentially of codification, decomposition or enumeration operations according to pre-established rules. Codification corresponds to transformation – carried out according to precise rules – of raw data in the text, transformation which through scope, aggregation and enumeration allows a representation of content or its expression; it can make the analyst see clearly the characteristics of the text;

3) Result treatment. Raw data are treated so as to be significant and valid. Simple statistical operations (percentages) or more complex ones (factorial analysis) allow for the establishment of result charts, diagrams, figures and models, which condensate and highlight information provided by the analysis.

Results and discussion

With the surveying of personal and family characteristics of the research participants, we obtained as results the prevalence of females, with 73.33%; average age of 58.20 years old (SD = 16.70); 46.67% completed high school. Main professions included: traders, housekeepers, nurse technicians and nurses with 13.33% each, and 53.33% were not retired; 60% claimed to be Catholics; 40% were daughters and time living together varied between 1 and 2 years, accounting for 33.33%. When it comes to the profile of the interviewed family members, 53.33% were members of an extended family; regarding family income, 26.66% earned 3 to 4 minimum wages, and 86.66% lived in their own houses.

From the explored theme, 'caring for a senior with stroke sequels', the following categories emerged (Table 1).

Table 1. Categories related to the aspect of caring.

Care	Frequency
A lot of love and support	5
Hard due to the person's dependence	4
Caring is not hard	4
Responsibility	2
Role change	2

About the aspect of caring, the ideas that emerged were that caring is performed with 'a lot of love and support', 'it is hard due to the person's dependence', 'caring is not hard', 'responsibility' and 'role change'.

In the 'a lot of love and support' category it was possible to observe that caring for others enables one's transformation, greater affinity and love. This perception is clear in the reports below:

[...] My love and affinity for her grew stronger, it moves us. (P9).

[...] Taking care of him is a pleasure [...] I do it with love. (P15).

It is relevant to say that some family members directly involved in the care seek to apply themselves to it and provide the elderly ways for them to cope with the disease. When they make this care effort, generosity, affection and love come into play and, at some moments in life, the one who cares makes the other his own existence.

It is possible to see that the act of caring brings people closer, increasing affinity, which establishes complicity ties, even though difficulties are evident. The gesture of caring causes in the one who cares a feeling of pleasure or even reward for all that has been showed and experienced before in their marital life.

It is believed that the emotional involvement enabled by marital ties is so deep that it justifies the intensity of support, love, mutual interaction, and this makes family caregivers do their best to the benefit of others.

Oftentimes, spouses find themselves all alone in the provision of this care, because children see the responsibility of caring for each other as their parents' responsibility, due to the commitment involved in a marital relationship (Maria, Sônia, Maria, Maria, & Ellen, 2013).

The recovery process of a patient that suffered a stroke should be valued and endowed with meaning. Beyond its power of keeping one alive, the act of caring reveals the zeal and dedication of people who, during this process, build, rebuild, write and rewrite a new story every day (Morales, Toneloto, Martini, & Adesto, 2009).

Despite care actions being marked by love and support, they can also be hard due to the person's dependence. This difficulty is evident in the participants' speeches below:

[...] It's really hard because of the person's dependence. (P1).

[...] The person's life is completely transformed and they start to depend on other people to take care of them. (P1).

[...] He lives because of us and we live because of him. (P3).

[...] Your family is shaken by the patient's dependence. (P12).

Dependence is an incessant routine in the life of an ill senior and this causes a social transformation that shakes a family's foundations. Face that, it is important that one finds new ways to a fair and adequate assistance, thus preventing the provided care from overburdening the one who cares. In this way, it is necessary that both parties reorganize and readapt to the continuous journey of care to be provided.

Pedreira and Oliveira (2012) state that formal support is of fundamental importance, mainly if we consider the elderly individual's level of dependence, one of the factors perceived as meaningful to the overburdening of caregivers. Among the latter, the ones that most frequently referred to overload were those with severely dependent seniors. Thus, formal support programs should be encouraged, prioritizing families whose elderly members have greater dependence, in order to assist family caregivers and elderly relatives in this adaptive process.

It is possible to observe that caring for a dependent person changes a caregiver's lifestyle due to all needs presented by the dependent one. Recreational and social activities end up being changed as a consequence of care activities and demands from the recipient of the care and the caregiver's constant presence. Family caregivers, in addition to good physical conditions, need to have emotional control and ability to care for the elderly individual without neglecting other tasks, whether domestic or work-related; otherwise, they will feel overburdened and have their physical and mental health compromised, especially if they are going through the aging process (Nardi, Santos, Oliveira, & Sawada, 2012).

Even though care actions are hindered by a person's dependence, some participants reported that caring is not hard and this was seen in the speeches:

[...] Caring is not hard. (P2).

[...] Taking care of him is normal. (P12).

Care is an inherent situation of every human being and this can raise innumerable conflicting feelings in family members who live with and take care of elderly people who have suffered a stroke, which involves reward and gratitude along with distress, doubts, anger and others.

It is worth noting that a family that cultivates peace, love, hope, in which there is emotional support, social interaction, spirituality and dialogue, reorganization becomes something pleasant, in addition to less stressful and maddening. And when we are faced with an elderly family member who falls ill, we are soon led to care for them so they regain their autonomy and take responsibility for taking care of themselves partially or fully.

Informal caregivers manage to incorporate into their practices different principles that contribute to a senior's wellbeing. This rescue of household care gives a new meaning to the house environment; once so connected to suffering, it becomes a positive space for growth and personal satisfaction, with strategies that allow all parties involved face crises and stressful situations (Vieira, Fialho, Freitas & Jorge, 2011). Care means responsibility and, by taking such a responsibility, these caregivers become vulnerable to impacts deriving from stress. And while facing this stage, they waive part of their lives in order to work towards re-establishing the quality of life of the elderly being and the family's inner balance. This is clear in the following reports.

[...] Living together and caring for them mean that the responsibility is yours. (P2).

[...] You have to think about the other. (P3).

Caregivers have many expectations concerning the care they are providing, thus denoting distress for not knowing if what they are doing is satisfying the elderly and their family, considering that all attention is going to the one being cared for.

Fernandes and Garcia (2009) report that the experience of taking responsibility for dependent elderly individuals has been manifested by family caregivers as an exhausting and stressful task, due to emotional involvement and because there is the transformation of a former relationship of reciprocity to one of dependence, in which caregivers, when performing activities related to a senior's physical and psychosocial wellbeing, are subject to restrictions in relation to their own lives.

Montezuma, Freitas and Monteiro (2008) evidence that feeling responsible for the elderly person who is dependent means committing to take care of him or her in general. It is known that from the moment a person becomes totally dependent, he or she begins to need a range of care actions that

should be carried out by someone capable of dedicating their time and waive many things in an attempt to meet these needs.

Every caregiver takes on this role when the patient that needs someone to perform for him the care that, before the stroke, was his duty. Engaging in tasks that are fundamental to the patient's everyday life, caregivers are of great importance to the survival of the patient (Morales et al., 2009).

When caregivers take responsibility for this type of care without putting much thought into it, a role change takes place in relation to the elderly family member being cared for and this proposal emerged in the following speeches:

[...] Sometimes I treat him as my son, you know. (P8).

[...] It feels like the roles change. (P14).

Sadness and commotion are factors strongly experienced by family members when faced with the impotence and deprivation that elderly members with stroke sequels go through. This factor is remarkable when the seniors' cognition, motor capacity and autonomy become so relevant that they lose their own identity and personality.

It is in this moment that a closer relationship becomes important, when care roles inevitably change and the fear of the unknown brings with it challenges and even emotional discomfort. Taking this responsibility demands self-control; this gift meets the character that has been cultivating for years, and the reward is a matter of humility and integrity.

Role change is pointed as a natural order in the life cycle. The patient's loss of motor and cognitive capacity and autonomy causes changes in the actors' roles, and children are given responsibilities that once were their mother's or fathers' (Brito & Rabinovich, 2008).

Family caregivers usually see the elderly as children and this perception at times relates to the physical dependence the latter have of the former, at times to the elderly's behavior, which revolves around stubbornness and resistance to care. Elderly patients are seen this way because of an excessive concern on the part of caregivers about meeting the survival needs of the dependent one, or because elderly individuals are no longer considered as adults (Floriano, Azevedo, Reiners, & Sudré, 2012).

Conclusion

According to the proposed objective, the results of the present study allowed concluding that: the family caregiver that cares for an elderly patient with

stroke sequels oftentimes takes responsibility for this type of care by themselves, which overburdens him or her. The elderly individuals' dependence led some participants to experience a role change, making them even more exhausted. On the other hand, many family members reported that they had no trouble as to this type of care and highlight that, face all barriers, they provide care with a lot of love and support.

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Received on March 26, 2015.

Accepted on December 15, 2015.

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