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Caring for the carer: a qualitative study based on participatory methodology

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ABSTRACT

Aim: present the results of activities conducted by nurses to improve support to family caregivers of the elderly. **Method:** This is a qualitative study based on participatory methodology. Meetings were held with twelve family caregivers and team meetings with 8 nurses from July to March 2016. The records of the speeches were submitted to content analysis. **Results:** the caregivers exposed their difficulties, their dilemmas and the contradiction between public policies and reality. In response to caregivers, the nurses constructed a plan of action. **Discussion:** the problematization of the relationship between services, health professionals and population increased the network of support to caregivers accompanied in the Unified Health System. **Conclusion:** group activities are more than a moment of catharsis; they produce interaction, the strengthening of the service, and contribute to the promotion of health.

Descriptors: Caregivers; Elderly; Nursing Care.

INTRODUCTION

By becoming an elder caregiver, there is an impact on the individual's family, social, and economic-labor life⁽¹⁾. Statistically, 50% of caregivers present an overload⁽²⁾. This study addresses the reality of these people, based on the appreciation of their knowledge and their needs.

In this context, nurses are in direct contact with the caregivers of the elderly, and therefore need to integrate the family in the planning of their care. Caregiver role is complex and incorporates different needs throughout the process⁽³⁾.

It is known that facticity is the aspect of human existence that is defined by the situations in which we find ourselves, which we are forced to confront. As nurses and health professionals, it is necessary to realize that "caring" means taking responsibility for the choices made. Nurses should take on this responsibility and also understand how difficult this issue is for the informal caregiver⁽⁴⁾.

Thus, it can be observed that the peculiarities of aging are a challenge for nursing professionals, who must be able to care for the singularities of the elderly person's health conditions⁽⁵⁾ and include in their work the health promotion of caregivers relatives of the elderly.

Based on this idea, this study is based on a doctoral thesis developed in the scenario of a public service in the midst of strikes and paralyzes. In spite of this, it was possible to develop meetings with family nurses and caregivers. This shows that the Single Health System, despite the scrapping, is still capable of producing research and promoting the health of the population. Therefore, the purpose of this article is to present the results of activities conducted by nurses to improve support to family caregivers of the elderly.

METHOD

The present study was performed in an outpatient service of the University Hospital of the State University of Rio de Janeiro. The project was submitted to the Research Ethics Committee of the institution and was approved with the protocol number CAAE 4449901520005282, on July 23, 2015, pursuant to Resolution 510 of April 7, 2016⁽⁶⁾.

It is a study based on participatory methodology. This method proposes an interaction with certain groups of social actors to identify consensus solutions and develop actions⁽⁷⁾.

The current format of the methodology obeys the following structure: three moments that unfold in phases and steps⁽⁸⁾. The term 'momentum' emphasizes the incompleteness of the set of activities, the phases are specific objectives and the steps are operational objectives.

The data collection was carried out from July to March 2016. In a previous stage of the investigative moment, the research group was formed, presenting the proposal of the study to the nurses and requesting the space to be the data collection field to the coordination of the service. After discussing the design of the study with the nursing team, it was opted for the workshop strategy titled: "Caring for who cares".

Four meetings were held in the workshop modality, with the following topics: 1) "How is your health?" 2) "Rebuilding life projects"; 3) "Look at your spine!" and 4) "Overcoming the challenges". The themes were chosen together with the group of nurses, who brought the demand for subjects that most arouse from the group discussions. Twelve elderly family caregivers and three professional nurses who were in the role of activity facilitators participated. There was no loss of data. After

the workshops, the speeches of the caregivers were analyzed and presented to the group of nurses at the team meeting. In this meeting, 8 nurses from the outpatient clinic participated. Both caregivers and nurses formed the group of co-investigators of the study, according to the action-research method.

The inclusion criterion for the group of nurses was the time of attachment in the study scenario ≥ 6 months. Inclusion criteria for caregivers were agreed with the group of nurses: to be a family caregiver of the elderly for at least six months; age ≥ 18 years; and voluntary acceptance to participate in the study.

The testimonies and collective production of the co-researchers were recorded through a digital recorder, posters, photographs, field diary, and discovery cards. The identification was by letters and numbers. The letters PC (acronym in Portuguese) correspond to the researcher-caregiver (PC1 to PC12) and PE (acronym in Portuguese), to the researcher nurse PE1 and PE2.

For the analysis of the speeches and written production of the co-researchers during the workshops, the content analysis was used⁽⁹⁾. At the end of the analysis, two categories were found, each with three subcategories.

RESULTS

The ages in the group of caregivers varied from 59 to 84 years, and 83.33% were over 70 years. The female sex predominated (66.67%) and the family income found was ≤ 3000 Reais in 50% of the sample. As for the occupation, 83.33% had regular employment. As for the bond with the elderly, 66% are children and 75% share the care with another person.

In the group of nurses, there were six

women (two divorced, two married and two single) and two men (one married and one single). The age range varied from 22 to 60 years. In relation to the time of connection to the service, it ranged from 12 years to 1 year and 6 months. As for training, there were two doctorates, one master, four were residents and one was merely graduated. One doctor had a postgraduate degree in the area of mental health and the other nurses had postgraduate degrees in gerontology.

The content analysis of the utterances originated units of registers (UR), which originated the subcategories and these originated the categories. Of the 103 units of records found, 59 originated the category "the difficulties" and 45 originated the category "future perspectives".

The category "the difficulties" was divided into three subcategories: "conflicts" (28UR); "Caring for oneself and care for the other" (23UR); and "the past comes to the surface" (8UR). Likewise, the category "future prospects" was subdivided into three subcategories: "the future" (20UR); "Adaptations" (17UR); and "overcoming" (5UR).

The analysis of the nurses' speeches, in turn, yielded 107UR; 36 gave rise to the category "contradictions" and 71 gave rise to the category "work proposals".

The "contradictions" category was divided into two subcategories: "the contradictions experienced by family caregivers" (22UR) and "the contradictions of the public health system" (14UR), while the category "work proposals" was subdivided into four subcategories: "listening" (21UR), "resolving" (20UR), "new strategies" (20UR) and "positive experiences" (10UR).

In the category "the difficulties", the subcategory "the conflicts" was highlighted. Conflicts are present both in the relationship with

the elderly and in intra-family relationships, since the dynamics of the family must adjust to meet the needs of all its members. The following statements illustrate this situation:

It is their situation to accept it. If you say it is day time, they say it is night time; it seems they're always in the opposite position. Then they say: Who do you think you are talking to? (PC8 in 2015)

My daughter said: "let go of my grandma." I thought he was aggressive. He didn't care about my grandmother; I didn't understand it. My other daughter said, "She told you not to be so worried about the future; let things follow their flow." It was kind of grotesque. (PC4- in 2015)

Still in this category, the subcategory "self-care and care for the other" is presented, and it deals with the contradiction between needing care and having to take care of. This contradiction can be observed in the following statements:

I have a lot of knee pain; sometimes the elderly walk but needs support and the person who is the support feels pain at the support spot (PC3 in 2015).

Our meeting was very good, I felt fortified and happy because I found the way and, from now on, I will live my life. I come first, and then the others. As you said, we have to be well to help others (PC8 in 2015).

Finally, there is the subcategory "the past

comes to the surface". Much of what is gone is often brought to the present, as can be seen in the following lines:

[...] is 93 years old, but she's always been a very clever person. From the moment you know how she is and see how she is now [...]. I'm 48 years old, I'm an adopted daughter. I realized a year ago that she's been forgetting things a lot; she forgets things today. Then I also realized: since I'm very stressed, I'm more forgetful, I've had hypertensive spikes, I'm hypertensive now. I'm very forgetful (PC2 in 2015).

My wife was very active, I had to learn to do everything myself, she is young, she is 60 years old; I have to be the spokesperson (PC7 in 2015).

In the second category, "future perspectives", there is the subcategory called "the future", which represents the concern with what is still to come, considering the current difficulties. This concern for the future is represented by the following statements:

My biggest problem is the eventuality of my absence, since I am not a healthy person. I am a cardiopath and have already undergone two interventions to place a stent. My wife is very dependent. Of course we have a son who helps me a lot, but she sees the son as a son. So I only think about when I'm gone, since I do everything and she doesn't worry about anything. (PC7 in 2015)

If you want your mother to be well treated... Clinic [...] I go there, it's al-

ready decided; I have a big and good house; I rent my house and I go there. (PC8 in 2015)

Still in this category, there is a subcategory called “adaptations”, which addresses the adjustments that caregivers need to make to account for the responsibility of care:

We do not want to overload them, because our children work and have children. Today, for example, to be here, she stayed at my daughter's house with the maid. (PC9 in 2015)

To go out, we have to take precautions. For example: oh, I have to leave now, but then she sits on the couch, so I watch TV with her because if she goes back to the bedroom she will change clothes again. (PC10 in 2015)

Finally, the sub-category “overcoming” is the ability to recognize that there are gains throughout the care process, developed by the caregiver, although there are difficulties and losses. This recognition can be represented by the following statements:

God sees everything and knows everything. Accept Alzheimer's disease; in this world everything passes. Thank God for the health, the willingness, and the chance to care for your loved one. It is time for reflection and asking for forgiveness for your mistakes. I love my mom. No matter how she is. We need the caregiver meetings for the elderly. (PC4 in 2015)

The team here is helping a lot to face the situation. (PC1 in 2015)

The speeches of the family caregivers were presented to the nurses at the team meeting. Next, the nurses' statements will be presented. The first category is: “the contradictions”:

I think it's related to the concept of virtue. Virtue is not to stay home taking care of someone; virtue is to have masters or doctorate. Concepts have changed. (PE1 in 2016)

Anyway, that's it. It is difficult because we are in the hospital school, but, it is bewildering; a lot of professionals in the world that collapsed, which is the disease, lack of money, dependence, and lack of family structure (PE4 in 2016, in a comment related to the caregivers' speech about the turnover of professionals)

Regarding the category of “work proposals”, it is evident the need for reception, resolution to the caregiver's demands and the importance of family-professional-service integration, as can be observed in the following registry units:

We can't be afraid to say something to each other. I notice there is a lot of need for valuation; we must then listen and stand before the other without fear of being corny. (PE7 in 2016)

I potentiated the best of each one. Every caregiver has something that can be potentiated, that can be better. (PE5 in 2016)

We should have a center day in here. The caregiver could leave the elderly here, he would be cared for by having cognitive stimulation while the caretaker left run his errands. This would leave him more refreshed and would meet the two demands: that of the elderly and the caregiver's. (PE1 in 2016)

I always liked the interconsultation and always thought that with it, he comes out more safely. You know that day he goes out and says: Today I got to hear people talking the same thing! So, I think the interconsultation is very valuable. In all the lack of structure that we are going through, such as lack of time, strike, lack of money, in short, we are so focused on that and we miss what is around. (PE4 in 2016)

DISCUSSION

The subcategories that emerged in the study refer to aspects of mental health related to self-esteem, self-improvement, affective memory, adaptability, conflict management and future projection. It is known that care delivery can negatively affect the caregiver's mental health, but the dynamic association of variables is still unclear⁽¹⁰⁾.

The results found are close to the results of another study with relatives of elderly, which showed that the family caregivers of elderly people with Alzheimer's Dementia experience physical, mental and social difficulties⁽¹¹⁾. However, other studies are needed to reveal whether caregiver overload is more

related to the social determinants or personality of the caregiver.

It is known that the illness of a family member implies an increase in expenses and a reorganization of family dynamics. Even when a caregiver is hired, care management remains the responsibility of a family member. The impact of spending on the elderly for the family varies from one social class to another. Regardless of this, there will always be a financial loss in relation to the period before the illness. This situation implies a reorganization of the budget planning of the house. Among the expenditures, it should be highlighted the direct medical costs involved in the treatment process, such as medication and transportation to the health service; and indirect costs, such as the time that caregivers dedicate themselves to the patient instead of performing a paid activity⁽¹²⁾.

Regarding the subcategory "caring for oneself and the other", it was observed that dedication to the other overlaps with the time spent for oneself, which can trigger the overload and sickness of the caregiver. At these times, the nursing accompaniment contributes to the self-care of caregivers, helping them to overcome difficulties and stimulate the development of their potentialities⁽¹³⁾.

About the subcategory "the past comes to light" it is necessary to emphasize that the family is a unit in constant transformation and change. For this reason, family conflict is associated with the development and persistence of innumerable maladaptive behaviors. That is, there are familiar environments that relate to the persistence of negative behaviors throughout the generations. In contrast, positive aspects of care may be a mechanism linking life satisfaction and caregiver overload⁽¹³⁾.

In the current scenario, family relationships have been characterized by their fragil-

ity, discontinuity and fragmentation. These conditions have produced a family dynamics in which psychic symptoms and sufferings often function as defensive mechanisms of the group and subjects. These concerns go through the reflections developed in this work. Thus, families that cannot constitute a network of mutual support present more psychological suffering among their members⁽¹⁴⁾.

These sufferings in many situations are associated with a symbolic impoverishment that occurs, above all, within the family. For this reason, questions such as the constitution of psychism, parenting, ties and psychic suffering are articulated and their knowledge contributes not only to the clinic, but also to the interventions performed by public health agents⁽¹⁾.

The second category deals with future perspectives. Caregivers reveal the following concern: and if I die before, who will replace me? Knowing that 10% of caregivers are frail elderly⁽¹⁵⁾, this questioning is pertinent. This concern generates suffering because there is an uncertainty of continuity of care if the caregiver also becomes ill. On the theme "adaptations", it is observed that the presence of members of different generations in the same family can be a support, but with limitations related to the time available and adequate preparation for care provided to the elderly⁽¹⁴⁾.

In the workshops, the co-investigators revealed that they rely on other family members for care only at certain times, because there are problems, especially regarding the availability of time and low affectivity in the relationship. When studying the familiar functionality of the elderly with dementia, it is perceived that caring becomes more difficult when there is no effective family network, making family tensions more evident and influencing family dysfunction⁽¹⁵⁾.

In this category, guilt and overcoming have also emerged. Guilt is related to what cannot be done and the overcoming is related to what can be done, feeling fulfilled. The nurses noticed in the speeches that there was a polarization of feelings, and this is one of the contradictions experienced by the family caregivers of the elderly.

In the workshops, when family caregivers talked about their conflicted history, sorrows and forgiveness with the elderly, it was noticed that care dependency rescues situations from the past and that caring for the other can trigger a new possibility of mutual relationship. For the planning and development of family care in sickness, knowledge about the family context is relevant⁽¹⁵⁾.

In the light of experiences, behaviors, personalities and different individual ways of looking at reality, there is a fine line between support and conflict, as the result of poor accommodation of certain antagonistic values, when it comes to people in different age groups whose coexistence is under the same roof⁽¹⁷⁾. Nonetheless, when nurses bring the word "I potentiate care," which a strategy of turning adversity into something positive, they become better able to meet the challenges inherent in the care process, respecting the "talents" of each member of the family. Both caregivers and nurses realized the need for nurses' support in order to mobilize resources for better care.

The nurses recognize the difficulties related to the structure of the service, but they can envisage a plan of action to face adversities and produce integral care for the family.

In summary, it was observed that participatory research implies a political engagement of the social actors involved, given that the problematization of the relationship between services, health professionals and

the population has potentiated the support network for caregivers accompanied in the Unified Health System. Thus, the social and scientific relevance of the study is to contribute to the health promotion of the elderly and caregiver, understanding health care in its entirety, since preparing the patient's family for home care is an education and health strategy that aims to maintain or improve the health status of patients and caregivers.

Therefore, this work intends to contribute to the health of the people, because when understanding the aging process as inherent to human life, the commitment for conditions favorable to family care is justified.

Finally, after the analysis of the speeches, an action plan was elaborated together with the nurses. This plan included not only the valuation of listening, the nursing consultation as a space of exchange, and the agreement of the guidelines, but also the accomplishment of activities of health promotion for the caregivers, with open themes in the form of a question, enabling the listening of their demands.

It is highlighted as a limitation of the study the fact that the scenario is a specialized service to the elderly, portraying a privileged reality in relation to family caregivers, who cannot even access a health service. The strikes and shutdowns in the service forced a reorganization of the schedule of activities. In addition, the results may vary if the social context of the elderly family is different.

It was observed that the adversities experienced by family caregivers of the elderly will not cease to exist, but there are actions nurses can take to help them overcome them. From a broader perspective for nursing, this type of research can be seen as favorable to coping with problems, by improving the conduct of work processes⁽¹⁷⁾.

In this sense, the Social Production

theory was a basis for the understanding of the context, since even knowing that the political-economic situation of the country affects all, the less well-off are the people most dependent on the services provided by public institutions⁽¹⁸⁾. Thus, social research can contribute to stimulate a sense of community and participation, countering fatalism in situations of socioeconomic crises. The sense of community would be a strategy for strengthening groups to solve common problems. In this case, family caregivers and nurses are included in a larger social group, which includes the elderly, health professionals and service managers. This participation implies a certain level of activism and commitment⁽¹⁹⁾.

This theory allowed understanding, for example, that non-adherence of caregivers to professional orientations is an issue beyond individual behavior, because there is a motive behind their attitude. Therefore, nurses need to broaden their view of the social context that these people live, their life history and how they respond to stress situations: whether they face the problem or become paralyzed.

Thus, the management of elder care brings the search for best practices related to treatment, security, guarantee of rights, and support to the family⁽²⁰⁾.

CONCLUSION

With this study, it was possible to understand that the group activities of caregivers are more than a moment of catharsis; they produce a strengthening of the group, the service and contribute to the construction of a support network. It was through the problems presented in the workshops that the nurses could draw up an action plan to respond to the needs of the caregivers of the elderly.

In this way, it is affirmed that the health promotion of family and elderly caregivers, addressing them in an integral way, provides support for home care and for coping with the inherent challenges of caring. Thus, this study is relevant for gerontological nursing, since it approximates the ideal that is disposed in public policies with the reality of health services, especially with the reality of the family caregivers of the Unified Health System.

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Authors' Participation:

Author's name	Participation
Barbara Martins Corrêa da Silva	participated in the design of the project, data collection and preparation of the final version of the manuscript
Claudia Feio da Maia Lima	participated in the data collection and preparation of the final version of the manuscript
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Célia Pereira Caldas	participated in the design of the project; data collection and preparation of the final version of the manuscript

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