GUIDANCE GROUPS FOR CAREGIVERS OF ELDERLY PEOPLE WITH DEMENTIA: RESULTS OF THE STRATEGY

GRUPOS DE ORIENTAÇÃO PARA CUIDADORES DE IDOSOS COM DEMÊNCIA: RESULTADOS DA ESTRATÉGIA

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ABSTRACT
Objective: to know about the contribution of the support workshops for elderly caregivers and the repercussions in assisting the elderly with dementia. Method: this is a descriptive-exploratory study with a qualitative approach. The Nursing Program in the Health Care of the Elderly and their Caregivers (EASIC/UFF) local were used. Twelve caregivers of elderly people with dementia responded to the semi-structured interview. Data were analyzed according to the Content Analysis Technique in the Categorical Analysis modality. Results: meetings such as PROCUIDEM and Workshops offer support as a perspective of better care and caregivers who do not participate feel more difficulties in the disease. Conclusion: guidance groups were of great importance for caregivers of elderly people with dementia, who perceived the space as a moment of exchange of experiences and to obtain greater knowledge about the disease. Descriptors: Geriatric Nursing; Caregivers; Dementia; Nursing.

RESUMO
Objetivo: conhecer a contribuição das oficinas de suporte para cuidadores de idosos e os reflexos na assistência ao idoso com demência. Método: estudo descritivo-exploratório, de abordagem qualitativa. Utilizaram-se as dependências do Programa de Extensão “A Enfermagem na Atenção à Saúde do Idoso e seus Cuidadores” (EASIC /UFF). Responderam a entrevista semiestruturada 12 cuidadores de idosos com demência. Os dados foram analisados segundo a Técnica de Análise de Conteúdo, na modalidade Análise Categorial. Resultados: os encontros como PROCUIDEM e Oficinas oferecem suporte como perspectiva de um cuidado melhor e os cuidadores que não participam sentem mais dificuldades em relação à doença. Conclusão: os grupos de orientação se mostraram de grande importância para os cuidadores de idosos com demência, pois eles percebem o espaço como um momento de troca de experiências e de obter maior conhecimento sobre a doença. Descritores: Enfermagem Geriátrica; Cuidadores; Demência; Enfermagem.

RESUMEN
Objetivo: conocer la contribución de los talleres de soporte para cuidadores de ancianos y los reflejos en la asistencia al anciano con demencia. Método: estudio descriptivo y exploratorio, de enfoque cualitativo. Se utilizaron las dependencias del Programa de Enfermería en la Atención a la Salud Del Anciano y sus Cuidadores (EASIC/UFF). Respondieron a la entrevista semi-estructurada 12 cuidadores de ancianos con demencia. Los datos fueron analizados según la Técnica de Análisis de Contenido, en la modalidad Análisis Categorial. Resultados: los encuentros como PROCUIDEM y Talleres ofrecen soporte como perspectiva de un cuidado mejor y los cuidadores que no participan sienten más dificultades en relación a la enfermedad. Conclusión: los grupos de orientación se mostraron de gran importancia para los cuidadores de ancianos con demencia, pues ellos perciben el espacio como un momento de intercambio de experiencias y de obtener mayor conocimiento sobre la enfermedad. Descriptores: Enfermería Geriátrica; Cuidadores; Demencia; Enfermería.

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INTRODUCTION

The demographic profile of Brazil has been changing over time the population over 60 years old has been increasing due to the improvement of the quality of life and the technological advances in the health area. Then, there is a rectangularization of the population pyramid. With this significant increase in the elderly population, there is also an increase in the number of chronic degenerative diseases, increasing morbidity and mortality and compromising the independence of the elderly.¹

The incidence of diseases that cause this elderly dependence predominates in situations related to osteoarticular diseases, followed by stroke and dementias.² Central and peripheral nervous system disorders that are neurodegenerative are characterized by the slow onset of signs and symptoms. Patients are treated at home as long as possible and are admitted to the acute care setting. Degenerative diseases, also known as dementia, are the most common causes of disability: Parkinson's, Alzheimer's, and Huntington's disease.

As life expectancy increases, there is also an increase in the appearance of degenerative diseases, leading to the need for home care for the elderly. They depend on their family members who, when they feel necessary, hire a caregiver to assist them in the care of this elderly person. However, this caregiver, for many times, does not have adequate knowledge for that type of illness and ends up giving poor care and lacking a scientific background. This is because they are people who already worked in the family home and end up becoming the caregiver because they are "trustworthy" people or the relatives, children, wives and husbands become responsible for the care of this elderly.

The primary caregiver is the one who has full or greater responsibility for the care provided to the elderly dependent at home. Usually, the denomination of informal caregiver is given to the relatives, friends, and volunteers of the community. They may probably have difficulties not expressed in the communication with the elderly person with cognitive disorder.³

Not only difficulties in communication but also difficulties in their care, in which the caregiver finds daily barriers to discover an ideal care for the elderly and even not knowing how to deal with cognitive disorders, not knowing how to stimulate this elderly to have a preservation of functionality. There are support groups for this caregiver who assists in this caregiving guidance on the disease and how to deal with all the difficulties and limitations that cognitive disorder can bring to the elderly, the family and the caregiver.

The education for this individual dedicated to the care of elderly people with dementia is an ever-increasing need. In this context, the importance of the performance of educational, informative and therapeutic workshops is verified. These workshops provide moments of experience exchange between caregivers and professionals, and this information can contribute to the improvement of the quality of life for the caregiver and the service provided by the caregiver will be differentiated and less deficient, minimizing suffering and anguish of caring.⁴

In this context, there is the Nursing Extension Program in the Health Care of the Elderly and their Caregivers of the UFF aiming to conduct nursing consultations for the healthy elderly and with chronic-degenerative diseases, mainly dementias, offering counseling and support groups for caregivers of elderly people with dementia, seeking to remove their doubts, inform and discuss the main demands of care, minimizing the anguishes and anxieties of the caregiver.⁵

Participating in these guidance groups, the caregiver can minimize the problems faced as well as boost positive behaviors and attitudes for an improvement in the clinical picture of the elderly person receiving the care. However, the big question was whether these workshops had any positive effect on these caregivers or not.

It is important to emphasize that guidance groups for caregivers will only be of great value if the care provided by this individual is differentiated after their insertion into these groups. Only after meetings with professionals and showing how to act in the face of the different situations that care is providing, this caregiver will be able to face them in a correct way. Thus, the importance of expanding care services for the elderly with dementia and caregiver support networks is emphasized, since the existing services provide benefits.⁶ Thus, the objective of this study is to know the contribution of the support workshops to caregivers and the reflexes in the care of the elderly with dementia.

METHOD

This article comes from the Course Completion Work << Guidance groups for...
Guidance groups for caregivers of elderly people with dementia: results of the strategy >>

This is a descriptive-exploratory study with a qualitative approach. As a field of research, the dependencies of the Extension Program Nursing in the Health Care of the Elderly and their Caregivers (EASIC/UFF) in Niterói, Brazil, were used. The survey was conducted during the first and second half of 2012.

O Programa de Extensão a Enfermagem na Atenção à Saúde do Idoso e seus Cuidadores (EASIC) da Universidade Federal Fluminense, que possui como objetivo desenvolver práticas sociais de atenção primária em saúde, priorizando a prática de educação em saúde junto aos idosos e seus familiares. Neste programa são desenvolvidas várias atividades, como consulta de enfermagem, oficinas de suporte a idosos e seus cuidadores e o PROCUIDEM (Programa de Orientação Para Cuidadores de Idosos Com Demência) com o objetivo de disponibilizar orientações informações e suporte aos cuidadores acerca da doença, tratamento e seus cuidados e a oficina de suporte aos cuidadores de idosos com demência.

The Nursing Extension Program in the Health Care of the Elderly and their Caregivers (EASIC) of the Federal Fluminense University, which aims to develop social practices of primary health care, prioritizing the practice of health education among the elderly and their families. In this program, several activities, such as nursing consultation, support workshops for the elderly and their caregivers, and the PROCUIDEM (Guidance Program for Caregivers of Elderly People with Dementia) are developed with the objective of providing information and support to caregivers about the disease, treatment And their care and support workshop for carers of elderly people with dementia.

Os critérios de inclusão consistiram em ser cuidador principal, maior de 18 anos e de exclusão cuidadores que não estejam cadastrados no EASIC e menores de 18 anos. Participaram da pesquisa três grupos de cuidadores de idosos com demência, o primeiro grupo foi daqueles que participam do programa PROCUIDEM, o segundo grupo foi dos cuidadores cadastrados na EASIC, porém que não participaram do programa PROCUIDEM e nem das oficinas de suporte.

The inclusion criteria consisted of being the primary caregiver, over 18 years of age and excluding caregivers who are not registered in the EASIC and under the age of 18 years. Three groups of elderly caregivers with dementia participated in the study, the first group was those who participated in the PROCUIDEM program, the second group was those who participated in the support workshops for the elderly caregiver with dementia and the third group was the caregivers enrolled in the program EASIC but did not participate in the PROCUIDEM program or the support workshops.

The study project was submitted to the Ethics Committee of the University Hospital Antônio Pedro (CEP/HUAP) for the collection of data, receiving a favorable opinion in October 2012, under Nº 118,420, as recommended in Resolution 196/06 of the National Health Council (CNS), on research involving human beings. The study participants were instructed to sign an Informed Consent Term (TCLE), after explaining the objectives of the study and their rights as participants in it. The participants were identified by the letter C plus a cardinal number to preserve the identity of the interviewees, promised to them at the time of the investigation.

There were twelve caregivers interviewed, three participated in the Caregiver Support Workshop, six participated in PROCUIDEM, and three participated in the nursing consultations held at EASIC. The instrument used for data collection was the semi-structured interview form. The interviews were conducted by the researcher and recorded in MP3, with the consent and authorization of the interviewees, aiming at preserving the integrity of the speech. The same questions were asked for the group of caregivers participating in PROCUIDEM and the support workshop and for the group of non-participants.

Data were analyzed according to the Content Analysis Technique in the Categorical Analysis modality. When reading the interviews, it was observed that there were common speeches between the caregivers who are part of the workshops and PROCUIDEM and among caregivers who do not participate. This led to the construction of six categories of caregivers of elderly people with dementia.

RESULTS

The common categories among caregivers of elderly people with dementia are:

1. Meetings such as PROCUIDEM and Support workshops as a perspective of better care
Ah, it influenced a lot, it helped a lot. So, it helped a lot because, as I told you when I had this with my mother, I did not have this knowledge until it became much easier for you to understand. So, about everything, you know, it has helped so much. Even to myself, it has helped me. (C5)

It influenced a lot. Before, sometimes we do not accept her problem[…] then, after we do the Procuidem, we think it is all part of the disease, you understand, you can understand. Moreover, the workshop also helps the person[…] but we know that with the advancement of the disease we will go through certain problems, so it helps because we hear from colleagues “he does it.” “he does not do that,” that helps us, because we are more or less prepared. (C6)

2. The illness limits the caregiver’s personal life

The difficulty is that as I was responsible for him, I am currently his caregiver, my life was very limited. I am a very independent person, I was married, I separated, and now as I am only as a sister, I have to outline my whole life because of this[…] The issue of caring not so much, it is more the expense that is absurd and also a little bit of my freedom that was stunned. (C3)

Moreover, my private life stopped, it was kind of complicated. I work at home, so I can be distracted. (C10)

3. It is important to have meetings to support this caregiver

I think I want to know more; you have to know how to deal with these things. (C7)

A lot, because in these meetings it is, people exchange ideas, because the patients are diverse, each has a characteristic that my mother does not have now, but that she may have, so this is important, this exchange of ideas, experiences. (C8)

4. Knowledge about the disease causing sadness

So I do not prefer to know much about the disease because otherwise, we suffer much more. (C10)

Sometimes yes, and sometimes no. Because I told you, when we look for a lot, I get a little depressed, because this disease is not a very easy thing. (C11)

5. Interest in knowing more about the disease

Yes, I have. We search the internet, search here with you in the Mequinho, in the courses that we try to do, in the books that we try to read, but it is[…] every day is a day, and every patient is a patient (C8)

I would like (to know about the disease), I think it is necessary[…] Knowledge is never too much. I need to learn to deal with it. It is necessary. (C7)

**DISCUSSION**

On the common categories among caregivers of elderly people with dementia:

1. **Meetings such as PROCUIDEM and Support workshops as a perspective of better care**

In the speeches presented, it is noted that the support workshops improved the care provided to the elderly. The role of the workshop is “fundamental” for a better understanding of the caregiver’s illness and well-being, where he finds space for socialization and coping with the disease he is caring in the workshop. The clarifications offered to become an important tool in the day-to-day caregiver’s life both about caring for the elderly with dementia and about caring for the well-being of the caregiver.

When they get information about the disease, its evolution, the different types of confrontations, the difficulties, and the challenges, this suffering is reduced. Moreover, for this, the assistance of specialized professionals at various levels of care is categorical in determining the caregiver’s well-being and the quality of care provided to the elderly with dementia.⁷

In an enriching way, the meetings through the support workshops and the course of the PROCUIDEM, the caregiver can learn more about the disease he deals daily, finding in the professionals who do this work and in the other caregivers who know in the meetings and lectures, a point of emotional and social support, facilitating their daily practice of care.

It is believed that the knowledge of care for the elderly by family/informal caregivers and the difficulties they face may contribute to the educational activities of nursing and the interdisciplinary team, so the home care actions can be developed to care for the elderly and care for the elderly’s caregiver.¹

2. **The illness limits the caregiver’s personal life**

The speeches reveal the difficulty of maintaining a social life when there is the responsibility of caring for the demented elderly. Many caregivers believe that their greatest challenge is not to take care of themselves, but to give up their social life due to this integral care of the elderly.

The most common consequences of caring for a dementia sufferer are social problems, worsening physical and mental health. The physical and psychic overload that caregivers of elderly people with dementia are often exposed leads to poor quality of life of these people.
individuals. Caregivers of the elderly with dementia show more fatigue, weariness, revolt, depression and summaries than relatives of the elderly without neurodegenerative disorders. 8

This work overload ends up hurting the caregiver, and this poor quality of life can cause harm to the health of the caregiver, and jeopardize the care provided. Caregivers need to turn their attention to these caregivers and see if there is evidence that such overload is undermining the well-being and health of the caregiver.

Regarding care, it is observed that caregivers carry out this task for long periods of the day and for many years, which causes them to be overloaded. Similarly, other studies indicate that full-time and long-term care may favor more wear and tear, worsen quality of life, and may trigger health problems such as stress and depression in the caregiver. When the caregiver remains caring for the elderly with dementia for very long periods and without having someone from the family to do this rotation, the feeling experienced will be of solitude, because he does not perceive the support of the relatives. 9

3. It is important to have meetings to support this caregiver

According to the statements, there is a need for space where caregivers can interact with other caregivers and health professionals, exchanging experiences and socialize, creating ties with people who have the same situation. The exchange of experiences and the lectures given by the team of professionals becomes the great motivation for the participation of the meetings. Caring for an elderly person with dementia is always a great surprise, there are situations that cannot be foreseen, but some caregiver may have passed through it, reporting their experience at that moment, serving as an example if another caregiver has the same situation.

In this sense, guidance groups are extremely valuable. It is necessary to encourage caregivers to participate in the workshops and to recognize the importance of formal and informal social support. 7 Caregivers who participate in caregivers’ groups have overloaded and depressed, while this situation worsens over time in a group of caregivers who do not participate. 10

The development of cognitive stimulation workshops for the elderly with Alzheimer's disease are classified as non-pharmacological interventions. They preserve the functionality of the elderly, reducing the negative impact of overload on the health of the caregiver, reducing the early institutionalization of patients, improving the quality of life of patients and their relatives. Therefore, it is necessary to create more informative spaces such as counseling support groups for those caring for these elderly people with dementia. Because of this, it is worth remembering the importance of the nurse in caring for this caregiver, as an objective to improve the quality of life of this caregiver by inserting them in a positive way in the support workshops, minimizing the impact of this disease on the caregiver’s life.

4. Knowledge about the disease causing sadness

Through the lines, it was observed that some caregivers have no interest in acquiring knowledge about the disease that they deal daily, as this causes sadness in them. Because it is a disease without a cure, many do not want to have the knowledge, knowing that there is no regression of the disease.

When we take care, we are subject to experiencing a mixture of feelings, ambiguities, contradictions, feelings of guilt, which are mostly ambivalent. These feelings are due to affective involvement from the family ties of caregivers with the elderly, with feelings such as love, gratitude for care received, fear, well-being, gratification, pity, impotence, among others. 1

The problem in the caregiver-patient relationship is precise that the caregiver cared for himself before, but now he is subject to the care of others. When this occurs in youth, it is usually fleeting. A different process occurs in old age, where there is a loss of self-care capacity with tendencies to deepening. Moreover, this is creating, a greater dependence on the one who takes care of us every day. 12

Because it is a situation in which the prognosis is not favorable and not fleeting, the sadness of the caregiver in knowing more about the disease becomes eminent, even hindering better care given, because there is denial in seeking to perfect themselves to assist the elderly better.

5. Interest in knowing more about the disease

Through the statements presented, it was observed that some caregivers are interested in gaining more knowledge of the disease because they feel more prepared to face the possible adversities that the disease can provide.
However, even with great experience presented by this person in caring for the other, it is not always enough to deal with the demented elderly, because of emotional factors, relatives end up presenting difficulties with this care.

The interest in getting to know the disease better means that the caregiver, even on his own, seeks information to help him improving the care provided.

The support workshops are important. Therefore, their contribution becomes evident, through the lines, that there was an improvement in the care dedicated to this elderly person through the participation in these workshops. Also, there was an improvement in the quality of life of the caregiver, who sees this space as a moment of exchange.

The preparation of the individuals dedicated to the care of elderly people with dementia is a growing need and, in this context, the importance of the educational workshops is verified, because in this space an environment of exchange of experiences between the caregivers and the professionals is developed, and the care provided to the elderly will be differentiated and less costly minimizing the suffering and distress of care.\(^4\) Knowledge about illness is a way of preparing for the future, so the need for learning helps to shape the disruptive behavior of elderly care and contributes to problem-solving.\(^1\)

### CONCLUSION

Guidance groups were of great importance for caregivers of elderly people with dementia, who perceived the space as a moment of exchange of experiences and obtaining greater knowledge about the disease, reflecting positively in their daily care for the elderly.

The caregivers who participated in the workshops and/or PROCUIDEM reported that there was a change in the care provided, making a positive contribution from this participation. This improvement occurs from the moment that the caregiver can know better the disease and its evolution, the specific care of each stage of the disease and how to behave before it, besides having a space where they can exchange experience and have a support through the conversations with the other caregivers and with the professional team of the workshops.

The care given to the elderly becomes different between participants in the guidance groups (Support workshops and PROCUIDEM) and those who do not participate when we observe, through the statements that the guidance group facilitated care, healing doubts and giving emotional support, when confronted with the speeches of caregivers who did not participate, we found that they feel more difficult with the disease and often feel exhausted.

This study has contributed because the caregiver in the guidance groups are fundamental, providing the caregiver with a way to understand what happens to the elderly and the stages of the illness, which may be coming and prepare him for the better Care.

Also, it shows another side of the guidance groups, space where the caregivers can have a great emotional support so that they can continue their care without seeing the elderly as an obstacle, improving the quality of life of the caregiver and consequently the care provided.

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