CARING FOR THE CAREGIVER: ASSISTANCE FOR SELF-CARE
CUIDANDO DO CUIDADOR: INTERVENÇÕES PARA O AUTOCUIDADO
CUIDANDO DEL CUIDADOR: INTERVENCIONES PARA EL AUTOCUIDADO

Cintia Lira Borges1, Jamille Pinheiro Cunha2, Alyne Andrade Silva3, Vanelly Almeida Rocha4, Maria Célia Freitas5

ABSTRACT

OBJECTIVES: To identify the profile and needs of informal caregivers of elderly and to report the implementation of interventions to promote self-care. Method: a descriptive study, experience report type with 13 caregivers. The data collection instrument contained questions about socioeconomic and health aspects based on the Orem’s Self-Care Theory and the Zarit scale. From the data analysis, workshops were held with relaxation techniques. The research project was approved by the Research Ethics Committee, Protocol no. 11517349. Results: caregivers had moderate to severe overload and applied techniques were effective in promoting self-care. Conclusion: nursing, acting through health education activities and relaxation strategies that stimulated self-care played key role in support the caregiver, reducing negative aspects of their daily lives. Descriptors: Caregivers; Self-care; Relaxation Therapy; Nursing Care.

RESUMO

Objetivos: Identificar o perfil e as necessidades de cuidadores informais de idosos e relatar a aplicação de intervenções para a promoção do autocuidado. Método: estudo descritivo, tipo relato de experiência, com 13 cuidadoras. O instrumento de coleta de dados continha perguntas sobre aspectos socioeconômicos, de saúde, questões fundamentadas na Teoria do Autocuidado de Orem e a escala de Zarit. A partir da análise dos dados, foram realizadas oficinas com técnicas de relaxamento. O projeto de pesquisa foi aprovado pelo Comitê de Ética em Pesquisa, Protocolo 11517349. Resultados: as cuidadoras apresentaram sobrecarga moderada a severa e as técnicas aplicadas foram eficazes na promoção do autocuidado. Conclusão: a enfermagem atuando por meio de atividades de educação em saúde e estratégias de relaxamento que estimularam o autocuidado exerceu papel fundamental no suporte ao cuidador, reduzindo aspectos negativos do seu cotidiano. Descritores: Cuidadores; Autocuidado; Terapia de Relaxamento; Cuidados de Enfermagem.

RESUMEN

Objetivos: identificar el perfil y las necesidades de cuidadoras informales de ancianos y relatar la aplicación de intervenciones para la promoción del autocuidado. Método: estudio descriptivo, tipo relato de experiencia con 13 cuidadoras. El instrumento de recolección de datos contenía preguntas sobre aspectos socioeconómicos, de salud, cuestiones fundamentadas en la Teoría del Autocuidado de Orem y la escala de Zarit. A partir del análisis de los datos, fueron realizadas talleres con técnicas de relajamiento. El proyecto de investigación fue aprobado por el Comité de Ética en Investigación, Protocolo 11517349. Resultados: las cuidadoras presentaron sobrecarga moderada a severa y las técnicas aplicadas fueron eficaces en la promoción del autocuidado. Conclusión: la Enfermería actuando por medio de actividades de educación en salud y estrategias de relajamiento que estimularon el autocuidado, ejerció papel fundamental en el soporte al cuidador, reduciendo aspectos negativos de lo cotidiano. Descritores: Cuidadores; Autocuidado; Terapia de Relajamiento; Cuidados de Enfermería.

1Nurse, Master in Clinical Care in Nursing and Health, Lar Melo Torres Institution. Fortaleza (CE), Brazil. E-mail: cintialiraborgues@yahoo.com.br; 2Nursing Student, State University of Ceará/UECE. Fortaleza (CE), Brazil. E-mail: jamillepinheiro@hotmail.com; 3Nurse, Specialist in Family Health, Family Health Strategy. Fortaleza (CE), Brazil. E-mail: vanellyrocha@yahoo.com.br; 4Nurse, Post-doctoral degree in Nursing, Graduate Program in Nursing/Post-Graduation Program, State University of Ceará/PCCLIS/UECE. Fortaleza (CE), Brazil. E-mail: cetfrei@hotmail.com
INTRODUCTION

During old age, the words autonomy and independence gain significance. The first refers to the ability to command decision-making and the second to the ability to perform certain action, however, at this stage of life, independence, especially, becomes compromised and often the elderly needs aid for the performance of activities of daily living.

Considering that the elderly population is increasing significantly throughout the world and, consequently, disabilities, weaknesses and dependencies, it is imperative that formal and informal caregivers in health meet the demands related to physical, cognitive, social, emotional and psychological dependencies. Formal caregivers are trained professionals and informal caregivers are generally family members and may be more than one, according to family structure, multigenerational arrangements and family and community solidarity. Most of the time, care is taken by family\(^1\), since the cost of maintaining a caregiver is very high, considering that they must perform paid work.

The elderly care is complex and sometimes arduous, demanding from caregiver reduction in leisure activities, self-care deficit by carelessness or lack of motivation to do so, mood lowering, sadness, depression, inactivity, lack of time to themselves and to maintain a social life. This process can generate double burden of stress and therefore care overload, compromising, thus, the quality of care provided to the elderly, family relationships and self-care.

The health service plays a fundamental role in providing service and care to the elderly and their caregivers, taking into account that the burden of caregivers points to the urgent need to support the task of caring held at home, in order to reduce the burden and the accessibility to expertise.\(^2\)

Thus, this study aims to:

- Identify the profile and needs of informal caregivers of elderly;
- Report the implementation of interventions to promote self-care from the lived experience.

METHOD

This is a descriptive study of experience report type, conducted with caregivers living in the area covered by the Regional Executive Office V (SER V in Portuguese), administrative area bounded by the city hall of Fortaleza, Ceará, which acts as a district city hall with infrastructure, housing, sanitation, health services, among others.

The sample consisted of 13 informal caregivers invited for the study through home visits. For sample selection, the area chosen was the nearest of the Primary Health Care Unit (UAPS in Portuguese), since interventions would be carried out with the study subjects and it would facilitate accessibility to the place where the activities would take place (UAPS itself), foreseeing losses and other difficulties in the path.

Data collection occurred in February 2013. The collection instrument included questions about socioeconomic and health aspects, family history, questions based on the Orem's Self-Care Theory. We chose this theory because it is one of the most discussed theories in nursing and because it comprises three theories that are interrelated and has as its central focus the operation and maintenance of life, health and well-being, through self-care.\(^3\)

This study addresses the third theory, the Systems Theory, which focuses nursing actions and describes the requirements for a self-care therapy and the actions or systems involved in this action in the context of interpersonal relationships that converge to a common point, the deficit of self-care. It is divided according to the need for supplementation: fully compensatory, partly compensatory and education-support.\(^3\) The study was focused on the education-support, which includes decision-making, behavior management, acquisition of knowledge and skills.\(^3\) In this case, the individuals of this study were able to perform self-care, requiring only a guidance for best performance.

In developing the collection tool based on Orem's Theory, the universal requirements for self-care were considered, according to theorist: maintenance of sufficient intake of air, water and food; the provision of care associated with disposal and processing excrement; maintenance of the balance between activity and rest and between loneliness and social interaction; the prevention of hazards to human life, human functioning and well-being; fostering the functioning and development of the human being within the social groups according to the potential; the known limitations and the desire to be normal.\(^3\)

The questions addressed use of alcohol and other illicit drugs, immunization, the practice of leisure activity, exercise or physical activity, sleep and rest, diet, habits and food restriction, the amount of liquid ingested per day, participation and attendance in social
support networks, religion, difficulty in socializing, looking for someone else in case of sadness or loneliness, the water treatment system, garbage and sewage collection in the neighborhood, the environmental and noise pollution.

Another instrument used to identify the level of caregiver’s burden was the Zarit scale. This scale was developed in 1987, translated and validated for the Brazilian culture in 2002, and consists of 22 items that assess health, psychological and socioeconomic well-being of the primary caregiver and their relationship with the patient. The score range is given depending on the caregiver’s statement in: 0 (never); 1 (rarely); 2 (sometimes); 3 (almost always) and 4 (always). The higher the score, the higher the overload⁶, so that a value ≤ 21 indicates no overload, 21-40 moderate overload, 41-60 moderate and severe overload, and ≥ 61 severe overload.⁷ This questionnaire was completed during the absence of the elder.

Then the data were tabulated using the Statistical Package for Social Sciences (SPSS) version 20.0 for both numeric and percentage distribution of the quantitative data collected, and each instrument was analyzed individually and carefully to meet the main needs, using the universal requirements of Orem’s Theory as subsidy. Therefore, if the immunization of the researched caregiver was incomplete or if the residence had no sewage system, the requirements “prevention of hazards to human life and disposal and processing excrement” would be harmed and so on. The collection of information and knowledge on the affected needs were crucial in implementing interventions to promote self-care, facilitating the organization of workshops, which will be described below.

This study obtained positive opinion from the Ethics Committee of the State University of Ceará, process no.: 11517349, and followed the ethical principles of research involving human subjects, Resolution No. 466/12 of the National Health Council.

♦ Description of the activities in the workshop Caring for the Caregiver

After identifying the needs of each caregiver and evaluate the profile of each one, intervention strategies were designed to motivate and actualize self-care and reduce caregiver’s burden. For this, a schedule was organized with different weekly activities, at intervals of a month, developed at a room of the health unit area.

The meetings were held once a week, always on the same weekday, for two hours, since participants reported difficulty in accessing health center due to distance and time limit; for lack of people who could replace them in elderly care, even for a minimal period of time; by the need to pick up their children at school; and to perform household tasks. These situations were considered limitations of the study, since the presence of the caregivers at every meeting would be decisive and crucial to the continuity of the work process, to better care and support of the demands of participants and optimization of the search results. It is emphasized that through the activities to promote self-care, caregivers could reduce negative aspects of their daily lives through understanding and support of nursing professionals.

It is noteworthy that each participant was invited verbally at the time of initial data collection and later through printed invitation, delivered the following week after of collection; and through phone calls by the researchers and visits by health workers. The contact was made repeatedly for fear of evasion and unwillingness to participate. The average of absentees, at each meeting, was five participants, except on the last workshop, in which only one attended.

The workshops will be detailed and described, then, as the equipment used and the activities carried out at all times:

♦ 1st week (02/20/2013 - 2pm to 4pm):

Material: white sheet for the badge, tape, pens, music and face drawings for final evaluation.

Moment 1: initially, the facilitators exposed the workshop’s goals, followed by a moment of presentation between participants and facilitators, with the aim of integrating the group and enabling the creation of links. The caregivers shared the expectations of meetings and expressed interest in participating in the following weeks. This moment was conducted through “Introducing Your Neighbor” dynamic. In this dynamic, participants were divided into pairs, each should manufacture a badge with the physical characteristics of the other and then present it to the group.

Moment 2: we used the relaxation technique of the eyes, mouth and hands associated with music therapy, to relieve stress and muscle tension, and to reinvigorate the physical, mental and emotional health.

Moment 3: feedback between participants-facilitators. Face drawings were used in green, yellow and red, representing the good, fair or poor concepts, respectively, for the
evaluation of the meeting under the vision of each caregiver.

3rd week (03/07/2013 - 2pm to 4pm):

Material: various objects, printed images of people taking care of themselves and songs.

Moment 1: we started with the “Hot Potato care” dynamic, which was to pass an object to each participant in the course of music. On stopping the music, the person who was with the object should answer the following questions: What is care for you? Who do you care for? Do you care for yourself? How? Have the experienced moments in this workshop helped you in self-care? This activity aimed to understand the meaning, for the caregivers, of care and self-care with the intention of subsequently explore the importance of individual care.

Moment 2: photos with people practicing self-care actions were distributed, which were chosen by the caregivers, as they considered most important to themselves, even if they did not practice it. The final result of the dynamic was the need to take care of oneself first in order to care for others.

Moment 3: At this time, for integration and relaxation of the group, in order to “break the ice”, we started a heating exercise of walking around the room and, then stretching some parts of the body: neck, shoulders, arms, hips and legs for integration and relaxation of the group.

Moment 4: after the energy discharge at the moment 3, with consequent tranquility of the group, the “objects that speak” dynamic was held, in which we exposed images of saints and angels, boxes, magazines, CDs, dolls, flowers, pens, and other objects, which should be chosen and represented according to the meaning represented by the caregiver from the workshop experience. This moment was enriching for the evaluation of the third meeting.

4th week (03/14/2013 - 2pm to 4pm):

Material: balloons, pens, self-esteem thoughts, body moisturizer, modeling clay, music.

Moment 1: we performed the “Transforming the balloon” dynamic. A balloon was distributed for each participant and we asked each of them to blow all the negative feelings, thoughts, anxieties and fears they carried. Then, we raised the question about what to do with that object. Some people decided to pop it, others agreed to make drawings in order to see differently the everyday problems.

Moment 2: it was distributed to each participant a self-esteem thought for reading, reflection and discussion. After this reflective
moment, it was stimulated a self-massage of hands.

**Moment 3:** we gave modeling clay for building something that represented that moment. Then, each participant expressed their feelings from what was created.

- **5th week (03/21/2013 - 2pm to 4pm):**

  **Material:** chocolates, personalized box, sheets of paper, music and body moisturizer.

  **Moment 1:** the proposal of the meeting was, originally, to perform the 'The gift' dynamic, which was to organize participants sitting in a circle and pass a box with chocolates as it is read a text with commands to perform a group dynamic. The text title is ‘The gift dynamic’ and contains words that express personal qualities such as beautiful, happy, cheerful, friendly and supportive. During the reading, the participant should deliver the gift to another person who considered worthy of such quality. In the end, the caregiver who was with the gift should distribute it to all others. However, due to the presence of only one caregiver, it was not possible to perform dynamic.

  **Moment 2:** at that moment, it was organized a massage therapy session by a guest professional. The room was prepared with a stretcher to comfort the caregiver, ambient light and relaxing music.

  **Moment 3:** a sheet was delivered with the following words: Good! What a pity. How about? For each expression the caregiver should write compliment, criticism and suggestions on the meetings.

### RESULTS

The sample participants were aged between 21 and 65 years old with a mean age of 46 (± 12) years old. It was found that the largest proportion of the caregivers were married/stable union (8/61.5%), had children (10/76.9%), ranged from 8 to 10 (4/30.8%) or 11/15 years of education (4/30.8%) and reported reasonable health perception (7/53.8%). The majority, 92.3% (12), did not attend social support networks, 76.9% (10) did not exercise and 73.8% (07) had difficulty to socialize.

About health history: 23.1% (03) were suffering from systemic hypertension, 15.4% (02) osteoarticular diseases, 7.7% (01) respiratory diseases, 15.4% (02) more than one and 38.5% (05) did not have any disease. About the drugs, 23.1% (03) were using antihypertensive and diuretics, 23.1% (03) took more than one type of drug and 53.8% (07) did not use any medicine. 69.2% (09) of the respondents used to go to the clinic and 76.9% (10) did not have the complete vaccination schedule. They were non-smokers 61.5% (08) and non-alcoholic 61.5% (08) of women.

From the answers of the instrument, regarding the questions developed from Orem’s theory about sleep and rest, 38.5% (05) had insomnia and 46.2% (06) did not feel rested the next day. 15.4% (04) of the caregivers mentioned noise and environmental pollution in their neighborhood. The absence of a sewage system was in 61.5% (08) of cases. It was found that 15.4% (02) of the participants had need for maintaining sufficient intake of air; 15.4% (02) had a deficit in maintenance of sufficient intake of water; 7.7% (01) in maintenance of sufficient intake of food; 61.5% (08) reported lack in the provision of care associated with disposal and processing excrements; 46.2% (06) denied maintaining the balance between activity and rest; 100% (13) had deficit as the prevention of hazards to human life; 7.7% (01) reported no development within social groups.

The total score of the scale ranged from 16 to 53 points, with an average of 43 (± 10) points, which corresponds to moderate to severe overload, in line with the Zarit scale.

### DISCUSSION

Corroborating this study, literature shows that most caregivers are women, married and have children.⁹ Despite the woman’s independence in the labor market and personal life, they are still present as the main figure responsible for home care and, therefore, the care for elderly relatives. This dynamic contributes for them not to exercise self-care activities properly.

The self-perception of health varied between good and reasonable, agreeing with another research.¹⁰ The positive self-perception of health may be strongly associated with potential resilience of these caregivers, facilitating the achievement for health interventions in relation to self-care.

It is believed that the emotional involvement of caregivers with the elderly has such a depth that justifies the intensity and diversity of responses found in the Zarit scale.¹¹ Although it was observed that, most of the time (61.5%), the elderly only asks for the help they need, the care demands high availability of time and generates overload, affecting leisure activities, privacy and self-care.

Many caregivers reported difficulty in maintaining healthy lifestyle habits, drank little water, had a diet poor in fiber and were sedentary, mentioning that this was because...
of limitation of time to worry about health and to perform physical activities or leisure activities, thus minimizing practices social interaction and therefore more difficult to socialization.

It was revealed a high level of burden and financial hardship. In agreement with the research, authors identified in their study that female caregivers had higher workload due to the degree of dependence of the elderly. It was reported also that the main factors related to overload reflect issues related to difficulties in coping with conflicting everyday situations, economic hardship and emotional stress. These women, who admitted more intensely the stress in care, were more susceptible to insomnia, or could not have a good night of rest and/or did not feel rested the following day. They agreed that it affected their physical and psychological health and the care for the elderly.

It is highlighted the importance to identify the needs of caregivers in order to act, through strategies, to meet the demands and encourage self-care, relying on the judgments of individuals about their conditions. The actions for self-care maintenance must be carried out in phases, and the nurse must be a sensitive subject and become aware of the situation, reflecting on their decisions empathetically. Therefore, attention should be paid to the main caregiver who assumes the tasks related to elderly care, which may increase the demand for labor and the stress load. The support and guidance from a multidisciplinary team can be decisive for the caregiver’s self-care and the quality of care provided to the elderly, considering that this support can contribute to improve the quality of life of both elderly and caregiver.

Reflections on the Caring for the Caregiver workshop experience

The meetings were enriching and rewarding. Researchers were able to approach the reality of caregivers, to experience the desires and needs, recognizing the importance of working with this audience so needy of attention and care. It was a unique experience that enabled developing insights to expand into other communities and long term care facilities, where the caregiver’s workload is arduous and stressful.

This can be seen through the testimonies of the caregivers who were charged with “request”, “donation”, “appeal”, “zeal”, “love and compassion”, “suffering”, “happiness”. It was a mixture of feelings that often happened, because they loved the familiar one and liked to care for them, but they recognized the negligence with themselves and, therefore, the confusion of ideas and emotions in their minds and hearts. It derived from a cycle of different and contradictory senses and meanings generated by the development of the disease, the dependency of the elderly and the exhausting function.

The statements of some caregivers were represented by:

My father has Alzheimer’s, he tells me to leave his house […] (Caregiver 1)

[…] I don’t even want to think about losing my father, about him no longer exists […]. (Caregiver 6)

My problem is not high blood pressure, it is stress […]. (Caregiver 3)

In the case of my mother, I have to cook lunch […] but thank God I have my father and my mother every day with me, I cannot imagine myself without my mom and dad […]. (Caregiver 9)

My mother is lucid, I’d been five months sleeping in her home, not sleeping, spending the night awake […] I was in neurologist treatment, I’m not doing anymore, I take prescription drugs. I had to take her Rivotril, because there were nights I did not sleep […] the pressure is 21/15 […]. (Caregiver 2)

[…] Lately, I’m so, feeling like a butterfly in the cocoon, I do not go out anymore, I do not have friends because I stay alone at home, because I have to take care of my mother. (Caregiver 13)

I live in a house next of her house and I keep going from a house to another, from a house to another. I do not have that interaction with other people, when we’re like this, people tend to isolate more […]. (Caregiver 10)

[…] the only trip that I do is to take my daughter to school […]. (Caregiver 4)

Emotions were exhibited more strongly during the dynamics, which can be perceived by the lines:

Landscape dynamic:

I chose this picture because of this darkness here, I feel that way, because I have nine siblings and only I care about […] (Caregiver 3)

If I could be here it would be too good, only I know what I’m going through […]. (Caregiver 5)

Human knot dynamic:

Sometimes, one has a knot and has to untie it the calmest way […]. (Caregiver 4)

Only with this dynamic I’m already feeling better […]. (Caregiver 2)

I’m feeling at peace, light […]. (Caregiver 7)

I could not relax, because of a problem (This caregiver takes care of the father and feels alone, without family) […]. (Caregiver 8)

Evaluation dynamic:

I am very well. (Caregiver 1)

I come here happy and I’m leaving better. (Caregiver 9)

I’m great. (Caregiver 10)

When I get home, my cat jumps on me, then she gives me affection, wanting to talk to...
me […] I felt better, you know […]. (Caregiver 3)
I made a bird, at this moment, everyone is happy, I think the bird represents it, you know, really free […]. (Caregiver 5)
I drew a sun, because this meeting cleared my problems […]. (Caregiver 2)

Through the speeches and, especially, the facial expressions of each participant, one can perceive the benefit of the dynamic performed for stress reduction. The meetings were the times when the caregivers could think a little about themselves, separating themselves, briefly, from the daily and family problems, thus allowing delivery to the moment of relaxation and enjoyment. The speech below summarizes and shows the result of activities:

I like when it is day for coming here, I have a lot to do at home, but here, I stop to think only about me, I forget a bit of the problems […]. (Caregiver 10)
The workshops enabled reflections throughout the week, progressing to an improvement, not only momentary, but daily, in an attempt to reduce stress and self-care.

This week I felt better, I was even able to speak better with my sister […] I took the piece of paper I received here and gave it to her, she treated me so much better, I think she needed it more than I […] (Caregiver 1)

These dynamics generated in the participants, physical well-being, through relaxation and massage therapy, and psychological well-being, through the moments of interaction and reflection. Added to that, in order to meet needs, nurses and caregivers must act as collaborators in the implementation of care related to self-knowledge and self-control.15 Caregivers should be encouraged to be cognizant beings about their care.

CONCLUSION
We conclude that caregiver burden permeates the direct assistance to the elderly, and goes further, with family conflicts, abdication of employment or leisure time, social constraints, lack of interest in care, non-perception of the elderly as a human being and depreciation of themselves as a person. Therefore, there is an urgent need to develop programs of assistance and support that are effective for the management of care and reduce overload. Another relevant aspect is the emotional and psychological support, since often the caregiver needs someone to listen to them and be empathic, providing comfort, security, reliability and dedication.

The techniques and technologies used for the activities of the workshops, along with the caregivers, were effective to the measure of what was desired. It is intended to expand and replicate the activities in other realities, in order to stimulate more caregivers to the practice of self-care and self-knowledge, reducing the workload and making care a pleasant moment.

Nursing plays a fundamental role in the support to the caregiver, and needs to act with health education activities in the guidance on the care actions and in the caregiver preparation to provide the best possible care. The value of self-care and caregiver needs should be prioritized in clinical nursing practice, helping caregivers to develop care plans that allow participation in decision-making on social and health aspects, quality of life and well-being.

REFERENCES
Caring for the caregiver: assistance...


Submission: 2014/05/28
Accepted: 2015/01/12
Publishing: 2015/04/01

Corresponding Address
Cíntia Lira Borges
Universidade Estadual do Ceará
Departamento de Enfermagem
Av. Dr. Silas Munguba, 1700
Campus do Itapé
CEP 60714-903 – Fortaleza (CE), Brasil