

FEELING OF GUILT AND SOCIAL SUPPORT IN THE SELF-CARE OF INFORMAL FAMILY CAREGIVERS

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Abstract: Due to the demands of the task of informal caregiver, it is essential to provide them with skills, not only for care, but to guide them towards self-care. The objective of the present study was to analyze the behavior of family caregivers in the face of feelings of guilt and the need for family support in self-care. Using a qualitative methodology and interpretative paradigm. Nine informal caregivers participated, selected for convenience. The research was carried out in two distinct phases: the first with interviews and application of a scale and the second with 10 psychoeducational intervention sessions, operationalized through group dynamics. The psychoeducational intervention proved to be effective in that it helped caregivers develop the personal/social skills necessary to maintain their self-care. The study reinforces the need for self-care as an aspect to be valued in interventions with informal family caregivers.

Keywords: informal family caregiver, competence, psychoeducation, self-care.

The sharp increase in aging worldwide has been seen by the scientific community as one of the biggest challenges of the 21st century. According to the United Nations, the senior population from a global perspective was 8% in 1950 and reached 12% in 2013 (United Nations, 2013). In the United States in 2013, the senior population already represented 14.1%. In 2040 this rate must reach 21.7% and in 2060, it must reach 98 million people (Administration on Aging, 2015).

In the European Union in 2014, the proportion of people aged 65 or over already reached the mark of 18.5% and, projections for 2080 are that it will reach 30% in the group of countries that are part of this European economic bloc, with one in eight individuals will be 80 years old or over, which will represent 12.5% of the population of countries that are

part of the European Union (Eurostat, 2015)

In Portugal between 2009 and 2014 the proportion was 141 elderly people for every 100 young people, these numbers will tend to increase and must reach the proportion of 307 elderly people for every 100 young people in 2030 (INE, 2014).

Although aging is not synonymous with illness, it is unlikely that an individual will reach this age group enjoying good health (Figueiredo, 2007). Depending on the acquired pathology, the individual may have their autonomy and self-control at risk and, as a consequence, depend on specific, long-term health care that must be carried out at home (Machado, 2012). It is in this context that the informal family caregiver emerges, who will be responsible for providing care, whether at an instrumental or emotional level (Lage, 2005; Neri & Sommerhalder, 2006; Sequeira, 2010).

The task of an informal caregiver, in addition to being complex, is demanding and has an impact on the personal, family, work and social lives of caregivers (Sequeira, 2010). With the burden of caring, they often manifest symptoms of tension, fatigue, frustration, reduced social interaction, in addition to reduced self-esteem (Martins, Ribeiro, & Garrett, 2003). All of this impact generally results from the fact that the informal caregiver, when taking on the task of caring, not receiving specific training/information to perform this task (Pereira, 2013; Sequeira, 2010).

By knowing the demands inherent to the task of being a caregiver, it is essential to provide them not only with knowledge about the illness of the family member they are caring for, but more fundamentally, to provide them with skills so that they can be properly oriented not only in caring for their family member, but above all, taking care of yourself. This article is an excerpt from the investigation called "Psychosocial Intervention Program for Informal Family Caregivers: care and

self-care". For the purposes of analyzing this article, we chose to analyze the contribution of participants related to care and self-care. Therefore, the objective was defined as: evaluating the existence of greater awareness on the part of informal family caregivers registered at the Family Health Unit of São João de Ovar, about the importance of self-care in carrying out the task of caregiver after carrying out the psychoeducational intervention.

METHOD

To achieve the proposed objective, this article is characterized by being qualitative in nature and an interpretative paradigm. The option for this methodological approach came about due to the need to describe and understand concrete situations experienced in the social context (Coutinho, 2013) and to be flexible regarding the use of various data sources (Bryman, 2012). The interpretative paradigm allows us to understand and interpret the complexity of data that a qualitative study offers through the detailed description of reality (Aires, 2011; Anthony & Jack, 2009).

PARTICIPANTS

Nine informal family caregivers, aged between 40 and 80 years old, married with parental ties of wives, daughters and granddaughter and with completed first cycle of education. They were selected for convenience by the nursing team at the São João de Ovar Portugal Health Unit. The invitation to participate in the study was made via telephone call and in person. Contact and the completion of the study stages took place at the Health Unit itself.

INSTRUMENTS

The reports were collected through Group Dynamics Exercises aimed at this purpose.

The sessions were recorded on video and audio.

PROCEDURES

The study took place in two distinct phases. In the first phase, interviews were carried out using a form and scales were applied to characterize the participants and diagnose their realities as informal caregivers. In the second phase, the objective of this article, the intervention took place, consisting of 10 psychoeducational sessions operationalized through group dynamics exercises. In the first three sessions, group integration was highlighted, information about the illnesses that the caregivers were caring for, and then what it means to be an informal family caregiver was discussed. From the fourth to the ninth session, personal/social skills were introduced, including: Self-knowledge, Empathy, Self-esteem, Assertiveness, Resilience and Social support. The tenth and final session aimed to evaluate the knowledge acquired and consisted of 16 phrases with themes related to care and self-care. Caregivers were then asked to express their perceptions and opinions about each topic presented. The research was carried out from March to October 2015. The data was analyzed with the support of the webQDA version 2.0 software and the content analysis was supported by the technique (Bardin, 2000).

RESULTS

Caring in a home context mainly means responsibility and total involvement with the task, a fact that can contribute to the caregiver most of the time neglecting their self-care.

Regarding the results of the second phase of this study, although sixteen phrases were used for reflection, analysis and opinion expression

by informal caregivers, a qualitative analysis of phrases related to the following themes will be presented: feelings of guilt, limitations of the caregiver, family involvement in care and time for self-care.

FEELING GUILTY OR NOT

Phrase: I will learn not to feel guilty about the mistakes I may unintentionally make

C.I-1: *“It’s like this, I try not to make mistakes and always do my best, but even in my innocence I make mistakes. If you make a mistake, try to correct it, we can’t blame ourselves, we’re not perfect.”*

C.I-2: *“I try not to repeat the same mistake. We’re not going to be okay with the mistake we made, are we? But let’s try not to repeat the same thing”*

C.I-3: *“To err is human. Make a mistake one day, another day is to raise your head”*

When the family member takes on the task of care, they will have to develop a series of new, unknown and unpredictable activities, which can trigger in the caregiver feelings such as fear, guilt, fear of doing something wrong, as well as uncertainty in the face of the new reality of care (Cardoso, 2011). In this sense, Sequeira (2010) argues that the caregiver must be a priority target of intervention measures that must aim not only at learning new knowledge, but also at acquiring new skills so that the caregiver feels safe enough to deal with the reality of home care as well as being able to value self-care (Cardoso, 2011).

CAREGIVER LIMITATIONS

Phrase: I will learn to say no appropriately every time the task of caring demands beyond my limits

C.I-1: *“Sometimes I let it be beyond my limits, sometimes I succeed and make my sister come and I don’t know what else, but I must say it more often, I often can’t recognize that.”*

C.I-2: *“This is difficult, we all have limitations, there are family members who don’t come, grandchildren who don’t even want to know about their grandfather. My daughter and her children are coming. The others don’t even make a phone call.”*

C. I-3: *“I can’t say no when I have no one to help me”*

C.I-4: *“I can say it at home, because if anything my children and my husband are ready to help me.”*

The context of home care is demanding as it imposes on the caregiver an increase in responsibilities that must be in accordance with the needs of the person being cared for, which causes it to trigger situations that in day-to-day life may be difficult to manage (Pereira, 2013). When the caregiver agrees to take care of their family member, they try their best to perform the task efficiently, forgetting that they have weaknesses and limitations and that, if not taken into consideration, they could have implications for the quality of the service provided (Figueiredo, 2007; Pereira, 2013).

FAMILY INVOLVEMENT IN CARE

Phrase: I will promote family meetings, so that everyone is aware of the evolution of our family member’s health condition, at the same time that I will provide information about my needs

C.I-1: *“I already did, my brother was in the Algarve and I was here and we had already called him and he came immediately. We are always in contact.”*

C.I-2: *“I let the family know when they can come or if it is very necessary.”*

C.I-3: *“My family always helped when necessary.”*

C.I-4: *“I have had help too.”*

C.I-5: *“I can do whatever it takes, my family doesn’t care. I have no support from his*

family. Everyone says you're the one who went looking for him. Now take care."

Taking on the role of informal caregiver implies the existence of a transition at several levels, however, it will generally be only one family member who will be able to develop strategies to perform the task (Schumacher & Meleis, 1994).

In this sense, it is necessary to guide and encourage the caregiver so that they do not assume this responsibility alone and that they somehow manage to negotiate with their family members the division of care responsibilities.

TIME FOR SELF-CARE

Quote: I will organize my life so that I have more time for myself and to do the things I enjoy.

C.I-1: *"How am I going to organize it if she needs me all the time."; "I will allow others to take care of it without me having to interfere."*

C.I-2: *"When I started this training I kept in mind that I needed to take time for myself. Well, I needed to take it off and I'm going to the cafe, even if it's just 10 minutes to talk, it's our time."*

C.I-3: *"I don't either."*

Interventions for caregivers, in addition to informing them about the disease being cared for, also need to guide them about the need to have time for themselves, so that they can use a few hours of their time to do what gives them pleasure, thus carrying out your self-care.

DISCUSSION

The results of this study reveal that psychoeducational interventions can be a relevant strategy to help family caregivers manage care. Studies by Figueiredo, Guerra, Marques and Sousa (2012) and Lopes and Cachioni (2012) highlight that psychoeducational actions tend to enable

family caregivers to increase their sense of competence, as they feel better prepared to deal with the illness they are caring for., in addition to having a strong impact on the informal caregiver, as this type of action not only provides guidance on how to care for the disease, but also teaches caregivers how to regulate their emotions.

CONCLUSIONS

One of the most impactful consequences resulting from increased longevity is long-term care provided at home. Performing the task of informal family caregiver is not an easy task, since the family member responsible for care most often does not receive training to perform this task. Through the results obtained in the second phase of this study, namely regarding the development of self-care skills, it was found that the objective of the present study was achieved, as it was possible to observe that the caregivers demonstrated greater awareness regarding the importance of their self-care. As a result, it can be seen that when informal caregivers are properly informed/trained about everything that involves care management, they tend to demonstrate that, in addition to awareness and sensitization regarding the task they perform, their physical and physical well-being is ensured. psychological, which will have an impact on improving the quality of the service they provide.

Therefore, guiding family caregivers through psychoeducational interventions not only to know how to deal with the disease, but also to understand the importance of self-care, must be a means by which health professionals must help informal family caregivers to provide quality care.

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