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Abstract

One of the consequences of an increase in longevity is the need for families to organise themselves, so that one of their family members undertakes the responsibility of caring for a disabled family member at home. Caregivers' physical and psychological health is often affected by this task. Therefore, in order to reduce the impact that this task has on their own health, it is important to endow them with personal and social skills that can help them to acknowledge, understand and value their self-care. The main goal of this study was to help family caregivers develop personal-social self-esteem and social support skills. A qualitative study was conducted with 10 informal caregivers from Ovar and Aveiro Health Centres (Portugal). This study was based on psychoeducation. The analysis of the data collected was completed with the webQDA software. The survey was conducted in June 2017. As a result, the informal caregivers showed a good level of self-esteem. With regards to social support they showed that they had the support of their family, friends and neighbours. Nevertheless, there was the need to develop training initiatives and raise awareness among caregivers regarding the importance of acknowledging and fulfilling their needs during the caring process.

Keywords: Self-Care; Psychoeducation; Self-Esteem; Social Support

Introduction

Increased longevity has been perceived as one of the greatest achievements of this century. Nevertheless, living longer does not necessarily mean to have good health, in fact, there is little evidence to suggest that older people today are experiencing better health than their parents did at the same age [1]. With the increase in longevity, there is a greater possibility that the individual will develop a chronic and degenerative disease, which may weaken the individual, and lead them to become care-dependent [2]. From Figueiredo's perspective (2007), a great percentage of the population aged 65 and over is prone to suffer from some type of chronic disease. When this happens, family becomes the first entity to take responsibility and provide comfort and wellbeing to the disabled family member at home.

Generally, the family unit tends to organise itself to enable family members to take on the responsibility of caregiving. This family member will be perceived as an Informal Family Caregiver. According to [3], "an informal caregiver typically include being a person who

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provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability". This individual will be responsible for all care related to the upkeep, comfort and wellbeing of the disabled family member. However, they will not be paid and in most cases they will not receive specific training for the performance of this role [4].

Pereira [5] highlights that being an informal caregiver is a complex and demanding task with implications in their personal, social and professional life. In fact, it is common among caregivers to experience symptoms of stress, fatigue, frustration, isolation, depression and low self-esteem [6]. Additionally, the person who assumes the caregiver role has a number of risk factors associated with the burden arising from this work. This, turns them into a group at risk, because they find themselves in situations of vulnerability, isolation and, in some cases, exclusion [7]. The development of all these symptoms may be associated with the fact that caregivers do not feel prepared to deal with the disease, since they only start to acquire skills and knowledge while performing this task [8]. In the same way, people may not appraise situations as stressful if they are confident and have sufficient resources to manage those situations [3]. This way, training initiatives for family caregivers have been seen as an important and urgent measure to improve the quality of live of the target audience.

However, it has been observed that a large part of the educational training sessions focus on information about the individual's illness. Educational interventions that bring to light different perspectives about the experience of being a caregiver and also about the emotional willingness to deal with long-term illnesses are scarce and are usually unrelated to the role of the family caregiver and the tasks performed. Generaly, these issues remain hidden and unimpressive [5,9].

Intervention programmes for informal caregivers started in the 1980s and their main goal was to ease the transition of family members to the role of informal caregiveres [10].

Regarding the effects of psychoeducation, several authors [11,12] emphasize that, although these effects are limited in time, structured, directive, focused on the present and on problem solving, they are based on experimental and scientific methods. Authors assume that cognitions are the driving-force of emotions and, psychoeducation can be an important asset in situations involving disease and family caregivers, specially when psychoeducation's intervention offered are designed to fit caregiver's needs.

Likewise, [13] advocate that psychoeducational groups not only provide practical information for patient care, but also focus on the psychological and emotional state of caregivers, contributing to the establishment of a social support network, being effective in improving psychological well-being and caregiver depression. Overall, psychoeducational interventions have proven to be an efficient tool, as they contribute to increase the caregiver's sense of competence to deal with the disease, and to increase self-care [13,14]. This sense of competence is recognized as self-efficacy, a person's beliefs about the capacity to sucessefully completing a given task 15]. One's sense of self-efficacy can provide the foundation for motivation, well-being, and personal accomplishment [16]. Tan., *et al.* [6] refered that selfefficacy have a protective effect on care-giver's health and that caregivers who possess a higher sense of self-efficacy are more likely to see caregiving tasks as challenges that can be overtake, are better able to recover from setbacks, and are more likely to persist in finding ways to cope.

Roe (2002) defend that competence should be defined as "a learned ability to adequately perform a task, duty or role", wich leads to the concept of evaluation [17], to the extent that it becomes necessary to evaluate the performance in relation to the task. Considering the requirement of the caregiver's task, it is necessary to provide them with certain skills to allow them to have the ability to recognise and express their emotions, both negative or positive, relating to the accomplishment of the caregiver's tasks [18]. Furthermore, "psychoeducational interventions must provide information about the disease and how to control it and, also, help caregivers to express their emotions

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and learn to deal with them" [12,13]. Trianes., et al. and Pinto and Barham we verified the relationship between the use of social skills and coping strategies and measures of perceived psychological wellbeing among eldercare providers. Method: This is a descriptive, correlational study. Participants included 20 caregivers of elderly relatives with high dependency levels. During the interviews, the caregivers completed a Social Skills Inventory, a Coping Strategies Scale, a Caregiver Burden Interview and a Quality of Dyadic Relationship Scale. The relationship between the frequency of use of social skills and coping strategies and measures of perceived burden and quality of the dyadic relationship was examined using Spearman's bivariate correlation procedure. Results: The caregivers who reported using particular social skills and coping strategies more often reported fewer conflicts with the elderly care recipient and lower perceptions of caregiver burden. Conclusion: This study on eldercare providers adds to the literature that demonstrates a positive relationship between social skills and coping strategies and indicators of better psychological wellbeing. Studies are needed to evaluate whether interventions that promote the acquisition or improvement of these social skills and coping strategies can help to improve the psychological wellbeing of eldercare providers."," container-title":"Revista Brasileira de Geriatria e Gerontologia","DOI":"10.1590/1809-9823.2014.13043","ISSN":"1809-9823","issue":"3","journalAbbreviation":"Rev. bras. geriatr. gerontol.","language":"pt","page":"525-539","source":"DOI.org (Crossref [18,19], pointed out that personal or social competences are part of the individual's psychological system and are usually associated with the ability to put oneself in someone elses shoes (empathy), the ability to live and interact in society, and the ability to self-regulate interpersonal relationships and their perception of themselves. In summary, this competences are learned over time through formal and informal processes and interactions with other people, and can always be increased through interventions in favorable conditions.

Social support is crucial for the caregivers' health and wellbeing [20]. Also, the study "Caregivers of Children with Developmental Disabilities: Exploring Perceptions of Health-Promoting Self-Care" [21] suggest that interventions should consider the inclusion of strategies for caregivers to promote positive relationships with other adults. In the same way, Pérez and Marqués [7] highlight the importance of creating associative spaces of community interaction and mutual support and psychoeducational workshops in order to understand the illness processes, promote coping strategies and empower caregivers and the people cared for.

Personal and social skills: self-esteem and social support

According to Bandura [16], self-esteem should not be seen as a value judgment on the self, but it should be perceived as an evaluation, and should be related to a particular aspect of the individual's life. Based on this assumption, the individual can feel good or bad in relation to several aspects of their life, in other words, self-esteem will be determined according to the way they experience these aspects in their day to day life.

Regarding social support, Campos [22] stresses that it is the establishment of emotional bonds at an interpersonal, group or community level, which provides a sense of protection and support to those involved, contributing to the maintenance of the individuals' physical and psychological integrity. In a broader perspective, social support networks, concern a group of people or entities which provide the needed emotional support. In this context, family, friends, neighbours and social institutions play an important role. It should be noted that in the event of a crisis situation, it is usually family and friends who are expected to help the individual overcome obstacles caused by a crisis situation [23]. To understand the informal family caregiver in their entirety, means to acknowledge them as autonomous individuals, with their own behavioural dynamics, thinking beings that reflect and have feelings who, in turn, will be called upon to deal with a health-disease situation [24]. Therefore, in order to meet their needs, it is important to develop a training/intervention proposal for informal caregivers which highlights not only their potential and caregiving skills, but also privileges the care for themselves.

Therefore, for this study, the following research question was formulated: Will family caregivers be able to ensure their self-care whilst performing their caregiving task by developing social and self-esteem support skills?

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Methods

Qualitative research, interpretive paradigm. This method was chosen given the need to understand the individuals' opinions and interpretations of their self-esteem, as well as the existence of social support networks, in light of their own perceptions. Nine family caregivers, from the Ovar and Aveiro Health Centres (Portugal), were involved in the study. The users were contacted by telephone by their respective nursing team and were later invited to take part in the study. The intervention lasted 10 sessions, held once a week, for one and a half hours. The themes worked during the sessions were self-knoledge, empathy, self esteem, assertiveness, resilience and social support. It should be noted that this study focus only the results of two transversal or generic skills adressed: self-esteem and social support. These skills were introduced, and worked on, based on the psychoeducational model. This model, in addition to an educational perspective, also includes the therapeutic perspective as a way of ensuring psychological well-being, whether in individual sessions or group sessions. Participants were tought about the caregiver's role and helped to develop personal and social skills to manage the challenging situation of being a caregiver. Strategies such as group dynamics were used to achieve several purposes within each theme: provoque reflexion, developpe self-knowledge, emphatie, self-estheme, etc. For this study, the competencies ofthemes which would be addressed during the sessions were introduced via methods to facilitate participant's active involvement, included: group dynamics, role plays, brainstorming and debates, and were oriented towards developing or activating participant's personal and social skills (self-knowledge, empathy, selfesteem, etc.). The study was conducted in June 2017 [25].

Results and Discussion

There is a lot of evidence supporting the impact of informal care on several aspects of family caregivers' lives Bom., *et al.*, [26] concluded that there is evidence of negative health effects of informal caregiving for subgroups of caregivers. which explains why interventions are needed to somehow reduce the strain caused by this activity on the family caregivers' health and wellbeing.

Considering the serious problems involved in caregiving, it can trigger feelings of satisfaction and dissatisfaction in the caregiver as they are providing assistance to those they like and who are in need [27]. Regarding self-esteem, there were statements related to the subcategory "Positive perception of their image". This subcategory emerged in 8 text units, in which caregivers describe: "I like myself, I like to be with myself, I like me as I am" (M); "I like myself because I feel good psychologically, spiritually, especially spiritually. I like to see myself and others in good health and happy because I believe in a better future and I feel a sence of accomplishment" (I); "I am a cheerful, beautiful person because I feel happy with myself, I have valued myself over the course of my life, doing what makes me feel good, at this moment I am at peace with myself" (I).

Regarding the family subcategory, some references were subdivided into the following categories: family appreciation (1 text unit) and the consequences of caregiving (1 text unit), which is related to the level of fulfilment the caregiver fells whilst performing their tasks. These references show that despite the family caregiver's difficulties, there is evidence of some degree of self-esteem. This is present in some participants' statements who said "My husband and my children always cheer me up." (M); "I feel good and fulfilled because I am with a person whom I love and who needs me" (I).

These references show that, notwithstanding the problems involved in caring, there is a sense of self-esteem mentioned by family caregivers. It is believed that the sessions raised caregivers' awareness regarding their perception of self-image, supported by the words of Caregiver A: "I am a woman who will try to be beautiful and happy".

Taking care of a family member may well be an opportunity to show love, solidarity, dignity, social inclusion and citizenship. According to Sena and Gonçalves [28], despite the fact that the caring situation may be a burden to caregivers, it may not be associated with the task

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at hand. The affective relationship between caregiver(s) and disabled relative(s) can determine the level of satisfaction and will lead to higher self-esteem levels. [29] advocate that interventions for caregivers should focus on improve relationship quality and on reducing symptom of depression, because better relationships between the caregiver and the cared person, and fewer depressive symptoms, are predictive of self-esteem, wich could lead to improve the lives of both the caregiver and the cared person. Figueiredo [30] adds that the source of satisfaction arising from caregiving, lies in the fact that the caregiver feels good about being able to provide comfort, security and wellbeing to their family member. Guaranteeing that these aspects are in place, can be decisive to foster the caregiver's sense of selfesteem.

In general terms, social support is known as the amount and combination of social relationships that the individual possesses, the strength and frequency in which ties are created and also the way in which the individual is perceived by those who receive support [31]. According to [32], social support contribute to adaptive health behaviours and provides a feeling of well-being that minimize the negative effects of the stressful situation in different aspects.

Two categories were defined based on the results. The first, whether informal caregivers receive social support, and the second to check who provides such support. Regarding the social support received, the individuals who participated in this study showed that they have such support: "whenever I need help I can rely on my nephews and the person who helps me" (C); "I have my son and my grand-daughter who helps me whenever things are more difficult" (C); "I could mention many people" (I).

Regarding who offers this support, it was found that it is offered by three different groups. Firstly, the informal caregivers mention, through 11 text units, that they rely on their household (children, husbands, fathers and grandchildren), as E. states, "in my house I rely on my daughter and grandchildren, children and granddaughters".

Through 4 text units, the caregivers mention the support of friends and neighbours, as highlighted by E., "I rely on my friend Adelaide and my nearest neighbour" and also extended family (brothers, brothers-in-law and nephews) "(...) my sister, brother-in-law and nephews to help me" (I).

Studies on this topic indicate that people who are part of a strong social support network, which supports them when they experience painful events, tend to feel less impact when faced with stressful situations [33,34-38]. Furthermore, [6] emphasized the importance of social support for informal caregiver's self-efficacy, advising that caregiver's intervention should broaden caregiver's social support network.

Thus, in the case of families whose loved ones suffer from long-term and disabling illnesses, social support networks can be an alternative when it comes to improving their informal family caregivers' health and wellbeing [25].

Conclusions

Providing home-based care is complex and challenging for the entire family unit, but it is more demanding and stressful for the family member responsible for the activities that need to be done on a daily basis. Bearing in mind everything involved in caring and being cared for, it is important for the family caregiver to understand that in order to offer comfort and wellbeing to the disabled family member, it is also important to take care of themselves.

Bearing in mind the results and considering the opinions of the caregivers who participated in the study, it is clear that in order to enable the family caregiver to reach such knowledge about themselves, it is important to carry out intervention actions which take into

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account not only information about the illness, but also that the caregivers themselves are unique individuals with feelings, needs and weaknesses, which may be disregarded during the caregiving process.

Within this framework, health professionals will be responsible for carrying out interventions which, in addition to conveying information about the illness, meet the individuals' physical or psychological needs, acknowledging the experience, wisdom and skills of each person and helping them to use these tools in managing the process of care-giving. According to the results, it is clear that the caregivers who participated in this study, became more aware of the need to ensure their self-care, and felt less guilty or negligent whenever they invested in their self-care.

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