






Stress in Informal Caregivers of Elderly People: a Non-Systematic Review

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ABSTRACT

An aging worldwide population, associated with more and more future dependence, demands scientific reflection on care for older adults. Frequently, and even admitted as desirable, such care is usually provided by an informal caregiver. Informal care refers to a type of unpaid care that requires a previous relationship between a caregiver and an older adult, at home. Its demanding's can lead to negative implications, such as stress in the informal caregiver, referred in the literature as the term *overload/overwork*. It is related to poor physical and mental health, and sometimes, cases of depression stand out. In this review, we emphasize the urgency of psychological intervention with informal caregivers of older adults, to allow them to experience greater well-being and health, minimizing stress and fostering their growth, underlining the importance of considering their individual needs. Adding to the evidence in the area is Gilbert's Compassion-Focused Therapy, which is concerned with the relief or prevention of the suffering of individuals, specifically highlighting the act of caring.

RESUME

Uma população mundial cada vez mais envelhecida, associada a uma dependência cada vez maior, exige uma reflexão científica sobre os cuidados aos idosos. Tais cuidados geralmente são prestados por um cuidador informal. Refere-se a um cuidado não remunerado que requer um relacionamento prévio entre um cuidador e um idoso, em casa. Pode levar a implicações negativas, como o stress no cuidador informal, referido na literatura como o termo sobrecarga/excesso de trabalho. Está relacionada à má saúde física e mental e, por vezes, destacam-se os casos de depressão. Nesta revisão realçamos a urgência da intervenção psicológica junto dos cuidadores informais de idosos, de forma a permitir-lhes um maior bem-estar e saúde, minimizando o stress e promovendo o seu crescimento, sublinhando a importância de considerar as suas necessidades individuais. Somando-se às evidências na área está a Terapia Focada na Compaixão de Gilbert, que se preocupa com o alívio ou prevenção do sofrimento dos indivíduos, destacando especificamente o ato de cuidar.

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Introduction

The recognition of a population delimited by aging entails understanding a panoply of changes inherent to the process, namely biological, psychological, and social. Despite the unique nature of the process, it is expected to be closely related to difficulties and fragilities, which transform the pre-existing dynamics, reflecting the loss of autonomy of elderly people. Within this framework, it is imperative to highlight the care of the elderly provided by an informal caregiver. However, informal caregiving is recognized as a complex and challenging role, with repercussions on the informal caregiver's health, mainly due to the stress associated with it (Cachada, 2015; Carneiro et. al., 2012; Martins & Santos, 2020; Medeiros, 2012; Santos, 2020). In this context, we emphasize the reconnaissance of this issue to better understand it and serve as a groundwork for developing future interventions founded in scientific research.

Methods

September and October 2022 were dedicated to the research on the topic, which was carried out in databases such as Google Scholar, Pub Med, SciELO, and Rcaap. We used the following keywords in Portuguese and English: “stress, “informal caregivers of the elderly”, “stress intervention”, “intervention with informal caregivers”, and “Compassion-Focused Therapy”. The inclusion criteria were carefully considered: i) contributions published between 2002 and 2022; ii) published in English or Portuguese; iii) containing the keywords in the abstract.

Discussion

Stress

It is agreed that organisms seek a harmonious balance that is constantly tested (Granjo, 2008). Thus, and although subject to divergent contributions and views, the term stress, which began in psychology after World War II, is based, considering the psychological model of Lazarus and Folkman (1984), on a response (encompassing physiological and psychological aspects) to the interaction between the individual and the environment. There is an understanding that the demands of the environment are more significant than the resources gathered by the individual, thus constituting a threatening situation (Granjo, 2008; Tavares, 2019). Taking over an international perspective, basic properties related to the individual and his/her interaction with the environment are considered, as well as a transactional perspective, focusing on the psychological mechanisms (in particular, the cognitive processes present in the assessment of the situation and the strategies applied, Granjo, 2008). Thus, stress is a psychological state that encompasses cognition and emotion and is understood as "the internal representation of a particular and problematic transaction between individuals and their environment" (Granjo, 2008, p.9).

As a result of an interaction between the individual and the environment, a disparity occurs between resources (biological, psychological, social). The individual has an active role in this interaction, with the ability to influence the repercussions of a stress-causing event through some strategies known as coping strategies (Granjo, 2008). They seek to promote balance in hostile situations, like cognitive, behavioural, and emotional situations, encompassing attitudes, thoughts, and feelings (Granjo, 2008). They depend on aspects of the individual and his environment and are guided by the goal of mastering stress through exchanges with the environment. Sometimes, there is a certain rigidity in the master and use of the strategies (Granjo, 2008). Lazarus and Folkman explained two ramifications of coping, namely (1) coping whose *focus is on the problem*, and thus seeks to modify it (minimizing the demands or expanding the means to solve it), can be directed to external sources of stress (which may include strategies such as asking someone for help) or to internal sources (including cognitive restructuring of the issue); and (2) *emotion-directed coping*, which seeks to harmonize emotional responses, demonstrating a different attitude towards the situation (such as looking at the unwanted effects in a restored and better way) (Granjo, 2008). The first tends to occur when one believes in a transformation of the circumstances, while the second occurs when one believes in the opposite, that the transformation depends on internal changes. However, once inherent and essential to human nature, there is a significant distinction between two stress responses that may occur: (1) a response that allows experiencing stress as something constructive and favourable to the individual; and (2) a response considered harmful to the individual, which does not solve the problem and brings unwanted repercussions in several dimensions of life (distress) (Granjo, 2008). The review of the literature of the second response is the focus of this paper, among the implications of different related diseases, such as cardiovascular and psychological (with emphasis on depression and anxiety, Figueiredo, 2013; Granjo, 2008).

Informal Caregivers of Elderly People

Considering the current worldwide panorama, the issue of informal caregivers is becoming increasingly present. Due to the multiple adaptations and efforts that it implies, the demands associated with this role means an experience that might bring stress and, consequently, repercussions on the caregiver's health and quality of life (Cachada, 2014; Santos, 2020). Informal caregivers refer to mostly unpaid work care in which an interpersonal relationship between the caregiver and the care receiver is assumed (Santos, 2020). The deep-rooted tradition of the family being in charge of caring for the elderly is understood, and although the degree of kinship, availability and willingness of the individual to provide care are taken into account, it tends to be a female relative (usually a spouse or daughter). Moreover, since this is a form of care that precedes a connection between those involved, it is perceived

as being supported by them. It may be something that becomes necessary, gradually or abruptly (Cachada, 2015; Granjo, 2008; Santos, 2020).

Taking into account that the act of caring symbolizes much more than a simple task, encompassing "(...) relational, emotional, psychological, ethical, social and demographic dimensions (...)", as well as "(...) clinical, technical and community aspects (...)" (Cachada, 2015, p.34), brings immanent a great responsibility, relating to "finding the other in his/her fragility and accompanying him/her to protect his/her life with respect and dignity" (Cachada, 2015, p.34). According to Cerqueira and colleagues (2004), three stages are implicit in this role, namely: (1) a first stage in which the individual prepares and assumes the care; (2) then the assumption of the associated burdens; and, finally, (3) the end of care provision, usually due to the death of the older adult. Each stage is characterized by different sources of stress and consequent demands while emphasizing the connection between them (Granjo, 2008). In addition, several reasons may be inherent to this assumption of the role, including shared affections, rejection of institutionalisation, perception of the normative, monetary reasons and geographical aspects. However, the sense of duty, whether moral or social, is most frequently pointed out by informal caregivers. Among them, there may be different levels of responsibility and commitment, depending on whether they are primary, secondary, or tertiary caregivers. In the present study, the primary informal caregivers will be considered since they are the ones who have a greater commitment and responsibility. In contrast, the others contribute mainly as part of their support network, as well as, primarily, the secondary stage. The complexity of this role is reflected in the tasks associated with it, which encompass support for basic and instrumental activities and emotional support and guidance for the elderly. Unlike a so-called "common" job, there is no specific prediction of its duration, as it is a long task that can occupy many hours of the caregiver's day (on average seventeen and a half hours) (Cachada, 2014; Santos, 2020). The importance of caring is well recognized, which is intrinsic to all cultures, although, in different ways, its complexity cannot be disregarded. This role can benefit the caregiver in terms of his/her personal growth (feelings of gratitude and competence). However, mainly due to its demanding nature, it can also lead to negative implications, such as an overload (Cachada, 2014; Pereira, 2018; Santos, 2020).

Stress in Informal Caregivers of Elderly People

Several aspects of caregiving stimulates overburdening, since it requires a readjustment of caregivers' lives (Rocha & Pacheco, 2013). Thus, the following aspects are underlined: (1) the elderly dependence resulting from his/her condition and the care/tasks that it implies; (2) the lack of knowledge, information or training to deal with the situation; (3) the lack of support (social, economic, family), including the government; (4) the demand for tasks, schedule, responsibilities; and, (5) the, usually, long duration of care. Moreover, the caregiver's characteristics are also pointed out, such as education, profession, age and coping strategies,

as well as the characteristics of the elderly (Brito, 2002; Cruz et al., 2010; Soares, 2017). So, overload represents a negative implication caused by too many stressful events for the informal caregiver. It comprises an objective and subjective factor, which are clearly related. The objective encompasses the circumstances of the elderly's dependence and the implications of caring in several areas of the caregiver's life. On the other hand, the subjective factor, incorporates the caregiver's meaning and emotional responses to caring for an older adult and all this requires. In general, it can be observed "at a social, emotional, psychological, physical, economic, relational, and professional level" (Cachada, 2014, p. 43), with the emphasis being placed on the caregiver's mental and emotional health (Cachada, 2014; Rocha & Pacheco, 2013; Soares, 2017). The informal caregiver perceives a discrepancy between their resources and what caring for an older adult requires and, mostly ends up neglecting their lives because of caring, putting the elderly at the forefront and overlooking their needs and interests (Cachada, 2015; Lage, 2005; Santos, 2020).

Despite the representation of burden in several areas, the literature points out the emotional burden of informal care. In addition to their physical exhaustion, the emotional overload may lead to several effects, such as depressive situations (the most common ones), isolation and loneliness, anxiety, depersonalization, feelings of guilt, and interference in self-concept and self-esteem. In addition, they see their health deteriorating in general and behave accordingly (greater vulnerability of the immune system, infectious, cardiovascular, respiratory, sleep and musculus diseases) and consequently consume more medication (André et al., 2013; Brito, 2002; Cachada, 2015; Cardoso et al., 2012; Fernandes, 2009; Fialho, 2010; Loureiro, 2009; Pereira, 2012; Santos, 2020; Soares, 2017). In a study conducted by Seima and Lenardt (2011), 62% of the informal caregivers had at least one disease (full report of 6), highlighting diseases related to high blood pressure, depression, inflammatory, digestive and musculus aspects. In the study developed by Cachada (2014), most participants perceived an overload in caring. Seima and Lenardt (2011) refer to female individuals who live with the older adult and provide care for more than three years. However, although it is not their only job function, as those who have the highest burden (which also corresponds to those who most appreciate the role of caregiver).

In addition, it is pertinent to highlight the stage of life in which informal caregivers are usually. Most of them are going through middle age and experiencing a period which, is characterized by stability and change. It occurs in a transition that reflects a crucial psychological moment. Several important events take place at this stage of life, namely: (1) their own aging, in which identity is highlighted, they analyse their self-perceptions based on their experience and what they know from other people, but also their health and work issues (such as retirement); (2) coping with the aging and frailness of their parents, and often with the added and addressed task of caregiving; (3) relating to, guiding, or raising their own children, who in some cases may also be leaving home and building their lives independently;

(4) becoming grandparents and adding and discovering a new role in their life's. Moreover, it is important to mention the fact that most of the elderly are informally cared for by women at the age of major hormonal changes due to menopause. Among others, these events require a significant reorganization (Papalia & Feldman, 2013; Sousa et al., 2006). According to Papalia and Feldman (2013), socioemotional support is very important. Filial maturity (opposed to filial anxiety) is of major importance as it represents an acceptance by the children in dealing with and accepting their parents' aging (Papalia & Feldman, 2013).

Also, the burden becomes more prominent when the informal caregiver lacks knowledge, skills, efficiency and adequate resources to cope with the demands he/she faces. Not ignoring several other influential aspects of the caregiver, the role of the caregiver's coping strategies and social support was discussed in literature since it is considered crucial for moderating the burden stages (Lage, 2005; Soares, 2017).

Coping strategies focus mainly on regulating emotions, solving problems, defining priorities, and searching for positive viewpoints. These coping strategies help caregivers manage stress in a more adaptive and balanced way (Rocha & Pacheco, 2013; Santos, 2020; Soares, 2017). Soares (2017) points out that some have proven to be effective: (i) the focus on thinking about the good moments shared with the person cared for; (ii) the awareness that it was not the elderly who wanted to be in that position (but managed to deal with it); (iii) not neglecting their needs (in terms of time and interests); (iv) also focusing on preventing harmful stress levels; and, finally, (v) the search for help from formal services and information about the situation that can empower. Rocha and Pacheco (2013) added: (vi) acceptance of the situation; (vii) occupation with other activities; (viii) seeking the positive sides of the situations, living one day at a time. They first mention the benefit of adopting strategies focused on the environment and the problem so that there is an organized and favourable environment for care (formal and informal support, material resources, and training). This is followed by strategies for the caregiver (responsible for reducing the stress felt) and at the different perceptions of the situation, focusing on the caregiver's role and adaptation (adjusting expectations and setting of realistic goals) (Rocha & Pacheco, 2013). In addition, they also consider the benefit of sometimes adopting a protective attitude towards oneself; it can be most effective in difficult circumstances.

There still needs to be more recognition by the formal services, of the informal caregivers, which represent less expense for the government. At the European level, informal caregivers provide an average of 80% of care, with Portugal being the country with the highest rate (Cachada, 2014; Granjo, 2008; Pereira, 2018; Santos, 2020; Soares, 2017). Concerning formal caregivers of the elderly (who, unlike informal caregivers, are professionals in the area, paid and have an instituted work schedule), they present lower levels of stress and less vulnerability to diseases (Martins et al, 2019). Such professionals, according to Marques and collaborators (2012), represent a support to the informal caregiver, helping him/her to manage

stressful situations. Though, this formal cooperation, like the help from the remaining informal network, is essential for the success of informal care, but it is also very precarious (Imaginário, 2004). Tavares (2019) also refers to social and emotional support as a stress reliever in informal caregivers, specifically using formal supportive services. According to a study by Cachada (2014), in which informal caregivers benefited from formal support, it was not seen as important in the caregivers' network. This leads to the consideration of explanations such as: the noncongruence between the support provided and the caregivers' needs (primarily directed to the elderly); and the pattern of relationship between formal and informal caregivers, based on power inequality in which the formal aspect is the master and the informal one is uninformed (Cachada, 2015).

Psychological Intervention with Informal Caregivers of Elderly People

According to the World Health Organization (WHO, 2002), mental health is defined as "the state of well-being in which an individual realizes his or her capabilities, can cope with the normal stress of life, work productively and fruitfully, and contribute to the community in which he or she lives", in addition to "feeling good about oneself and interacting with others" (Soares, 2017, p.22). Accordingly, the denomination of informal caregivers of the elderly as "hidden patients" (Granjo, 2008 p.5) is understandable when we account for the lack of help at different levels (such as physical, psychological and emotional) (Granjo, 2008). Despite the interest and dedication to research on the issue of informal caregivers of the elderly, particularly regarding the impact of caring for them, there is no evidence of effective solutions capable of contributing to their health, quality of life and well-being. According to Santos (2020), to bridge this gap, it is essential to know their needs and take their particularities into account when planning an intervention. The therapeutic psychological intervention regarding the stress of informal caregivers of the elderly will focus on several spheres of the individual's life, but primarily on their (mental and emotional) meanings about the role they play, as well as on the caregivers' neglect of themselves, since it is an important aspect in demand for care and its consequent adverse effects (Figueira, 2013; Santos, 2020).

Adding to the growing evidence (and the fact that it is linked to Beck's Cognitive Behavioral Therapy), the close connection with the act of caring and altruism, Gilbert's Compassion Focused Therapy (CBT) has assumed itself as the choice of explanation for the therapeutic intervention on the stress of the elderly informal caregivers (Murfield et al., 2020; Reis et al., 2018). It is based on sensitivity to suffering, in oneself and others, and its relief or prevention through understanding. It aspires for individuals to look at themselves and others in a compassionate, appropriate, and kind way so that their behaviours can follow the same continuum with an adaptive nature. It aims at balancing the three systems of affect regulation: (1) defense-threat; (2) resource-seeking and reward; and (3) affiliation. It focuses on and proposes the beneficial activation of the affiliation system, seeking that the individual, instead

of a posture marked by guilt and criticism, assumes an attitude of compassion. Compassion focuses on three attitudes to be trained: (1) kindness (instead of a judgmental posture) based on not being critical in times of suffering; (2) shared humanity (instead of isolation), referring to the awareness that we all experience difficulties; (3) and full attention (instead of excessive identification), referring to a balanced recognition of experiences. In the first phase, he emphasizes the importance of the process being co-constructed, and of psychoeducation. This is followed by the formulation of the case, in which an attempt is made to understand the behaviours that stand out most in the individual's behavioural repertoire (paying attention to early experiences, fears related to others and oneself, safety strategies, and unintended consequences). This form of therapy is characterized by Compassionate Mental Training (CMT), which involves the desire to balance sensitivity, overactivity, and conflict between defence-threat and resource-seeking systems and rewards by stimulating the affiliation system, allowing the individual to generate alternative thoughts and adopt caring and helping behaviors towards others and themselves, using strategies such as Socratic questioning, exposure, functional analysis, reframing, and mindfulness. There are several compassionate skills to be trained, such as: compassionate attention; compassionate reasoning; (3) compassionate behavior; (4) compassionate imagination; (5) compassionate feelings; (6) compassionate sensations (Fialho et al., 2012; Gilbert, 2009; Murfield et al., 2020).

Considering the existence of a system that is more evident than another, in the theme under analysis, we can understand an (easy) overactivation of the defence-threat system, in which the informal caregiver perceives himself/herself as facing constant threats (stress), not being able to reason about the information, and relating it to negative emotions and possible psychopathology. To decrease their activity, CMT proposes the activation of the affiliation and care system (not only to the other, but to oneself), which seeks to manage stress and promote connection (making it possible to reason about information, make decisions, resolve problematic issues, and an adequate understanding of situations). In this way, the caregiver will experience feelings of well-being, act in a kind and caring manner with themselves and others, something so important to the caregiver, and perceive the world more adaptively and appropriately way, not only decreasing stress levels but also building ways to cope with the various events in their life. The resource and reward system can be dangerous if overused in the short term, particularly in stressful situations, because of its connection to addictive disorders. The intervention then focuses on the activation of the affiliation system to reduce the inadequate activation of the other two systems, being characterized primarily, in this case, by the search to develop compassionate strategies in informal caregivers that allow them to experience greater well-being (resulting from a more adaptive interpretation of reality), and regulating stress (Fialho et. al., 2012; Gilbert, 2009; Murfield et al., 2020).

The literature also emphasizes the benefits of psychological intervention with informal caregivers who present stress, assured by Wiegelmann and colleagues (2021). Psychosocial

interventions are highlighted as crucial sharing experiences (in addition to the social network, such as psychoeducation groups) to mitigate the difficult consequences of caring. This increases the caregivers' well-being, including countering the isolation in which they often find themselves, as well as serving as a source of information on, for example, aspects of the situation, available resources and emotional management strategies (Cachada, 2014; Chiquelho et. al., 2011; Figueiredo, 2009; Guerra et. al., 2011). Pereira (2012) also emphasizes a multidisciplinary intervention (physicians, psychologists, nurses, and social workers) to empower the individual. Although individual interventions are the most common in this condition, the intervention with the caregiver's network is also beneficial (since the cooperation and mutual help between them is an added value) (Rocha, 2009). Fialho (2010) suggests that interventions based on social support have a minimizing effect on depression. In addition, he confirms that a healthy lifestyle positively affects the informal caregiver's health. In turn, Motivational Interviewing, which aims at facilitating the change of health-threatening behaviours, can also be used in stressful situations (Hall et al., 2012).

Conclusions

Taking into consideration the accentuated aging overtime, it is important to reflect on the burden of stress in informal caregivers of elderly. A role that goes beyond a simple instrumental task and that, despite having positive effects, encompasses several negative repercussions in various areas and aspects of the caregivers' lives. The unavailability of "care" should be taken into consideration at different levels (family support network, and the formal care systems) since it mirrors the indifference of an entire society for the well-being of those who spend their days caring for others. It's vital that we genuinely look at the unique reality of each informal caregiver and pay attention to their needs so that useful interventions for their health and quality of life are made possible, which will inherently bring multiple benefits. The path must be through valuing informal caregivers (e.g. establishment social policies), so that healthy gains are maximized and not stressed.

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