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Resilience in caregivers of persons with Alzheimer's disease: A human condition to overcome caregiver vulnerability

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Abstract

In general, the experience of providing assistance to and dealing with the complications experienced by a person with Alzheimer's disease puts caregivers in a situation of high risk, vulnerability, and stress, causing serious physical and emotional problems. However, some caregivers adopt a *resilient mindset*, which helps them to experience and express positive feelings as well as lower their burden in relation to the care. This positive experience occurs because caregivers perceive the process of caring as less adverse. They face the situation of care with a more positive mindset and are able to resist and maintain adaptive functioning. The objective of the present narrative literature review was to emphasize the need to develop intervention programs for caregivers based on salutogenic models of resilience, resistance, and personal growth to promote positive individual, family, and community resources.

Keywords: alzheimer's disease; resilience; vulnerability; psychological intervention; caregivers.

Resumo

A Resiliência em cuidadores de pessoas com doença de Alzheimer: Uma condição humana para superar a vulnerabilidade do cuidador. Em geral, a experiência de proporcionar assistência e lidar com as complicações da pessoa com doença de Alzheimer coloca os cuidadores em uma situação de alto risco, vulnerabilidade e estresse, causando sérios problemas físicos e emocionais. Entretanto, existem cuidadores com uma *mentalidade resiliente* que os leva a experimentar e expressar sentimentos positivos e uma menor sobrecarga associada ao cuidado. Esta experiência positiva acontece porque percebem o processo de cuidar como menos prejudicial. Enfrentam a situação de cuidado com uma atitude mais positiva e são capazes de resistir e manter um funcionamento adaptativo. O objetivo desta revisão narrativa da literatura foi indicar a necessidade de se desenvolver programas de intervenção para o cuidador, com base em modelos salutogênicos, de resiliência, resistência e crescimento pessoal, para promover os recursos positivos da pessoa, da família e da comunidade.

Palavras-chave: doença de alzheimer; resiliência; vulnerabilidade; intervenção psicológica; cuidadores.

Resumen

La resiliencia en cuidadores de personas con enfermedad de Alzheimer: Una condición humana para superar la vulnerabilidad del cuidador. En general, la experiencia de proporcionar asistencia y lidiar con las complicaciones del enfermo de Alzheimer sitúa a los cuidadores en una situación de alto riesgo, vulnerabilidad y estrés, ocasionando importantes problemas físicos y emocionales en muchos familiares. En cambio, existen cuidadores que disponen de una *mentalidad resiliente* que les protege y lleva a experimentar sentimientos positivos y experimentar menor sobrecarga. Esta experiencia positiva sucede porque interpretan el proceso de cuidado como menos negativo, afrontan la situación con una actitud positiva y son capaces de resistir y mantener un funcionamiento adaptativo. El objetivo de esta revisión narrativa da literatura fue señalar la necesidad de desarrollar programas de intervenciones centradas en el cuidador que promuevan los modelos salutogênicos, de resistencia, resistencia y crecimiento personal, para potenciar los recursos positivos del cuidador, de la familia y de la comunidad.

Palabras clave: enfermedad de alzheimer; resiliencia, vulnerabilidad; intervención psicológica; cuidador.

Dementia consists of a clinical syndrome, which is characterized by cognitive deterioration of the higher mental functions that interferes significantly in the individual's daily life activities (DSM-IV-TR; American Psychological Association, 2000). Alzheimer's disease (AD), which is considered the most common form of dementia (Hsiung, 2007), is classified as a neurodegenerative syndrome with an insidious onset and a progressive course that is implicated in a gradual loss of the patient's autonomy and quality of life (Whitehouse, 2006).

Therefore, the person responsible for caring for a person with Alzheimer's disease (PwAD), who is referred to as the "main caregiver", adopts the special position of protagonist, particularly when taking on the implicit commitment and/or the responsibility to assist with the patient's emergent needs (Fernández-Calvo, 2010). The situation of caring for a PwAD is perceived as potentially stressful and negative for the caregiver (Zarit, Todd, & Zarit, 1986), especially when this person lacks the necessary psychosocial resources to face the demands of caring for a PwAD (Vitaliano, Young, & Zhang, 2004). As the disease progresses, caring for a PwAD becomes an increasingly demanding task, which may affect the well-being (physical, psychological, social, and/or economic) and the quality of life of the caregiver as well as of the family (Brodsky & Berman, 2008; Scharlach, Li, & Tapashi, 2006).

Based on a person-centered perspective, adapting to the act of caring for a PwAD may be more successful for some caregivers than for others (Maslow, 1985). Thus, some caregivers find themselves flooded by feelings of abandonment and helplessness, whereas others in similar situations might adapt successfully not only to the act of caring for a very dependent patient but also to the uncertainties associated with AD (Fernández-Calvo, Menezes de Lucena, Contador, Ramos, & Fernandes de Araújo, 2009).

Resilience is a powerful human quality related to resistance (Manciaux, Vanistendael, Lecomte, & Cyrulnik, 2001) toward life's adversities as well as to the capacities to recover (Garmezy, 1991) or to maintain adaptive conduct (Bonanno, 2004) after a stressful and/or traumatic event. Therefore, in a risky situation such as caring for a PwAD, this human behavior or quality decreases the caregivers' vulnerability (Quintero et al., 2007) and is explained by the interaction between personal attributes, family support, and community resources (Quintero & Hernández-Martin, 2009).

Thus, individuals with resilient mindsets cope better with painful emotions (e.g., anger, distress, disappointment). Bowlby (1992) describes "resilient" individuals as those who bend when faced with life adversities but do not break or feel discouraged or defeated. In addition, these individuals are able to experience positive emotions even when facing adversities (Fredrickson, 2001). Based on this context, "resilient" individuals activate a series of internal (e.g., optimism) and external (e.g., search for structural support-supportive community services) resources, which generate more positive attitudes in the presence of stress (Quintero et al., 2007). As a consequence, these individuals emerge from stressful situations with more strength (Siebert, 2007).

The objective of this literature review was to provide an overview of studies that have shown the positive effects of resilience and positive emotions on caregiver stress. These psychological constructs comprise two promising pillars of new psychological interventions focused on promoting a resilient mindset in caregivers, which might be useful to attenuate such caregivers' discomfort and psychological burdens. The scarcity of studies published on resilience in caregivers of PwAD makes it unfeasible to conduct a systematic review. Therefore, we opted to conduct a narrative review of this theme, considering previous studies of the group and the most relevant evidence we know of in the area.

Hence, the first part of this review briefly describes the family caregiver's profile and factors that characterize the burden, especially, resilience. The second part describes the most effective interventions to minimize the negative outcomes associated with care, emphasizing the need to develop interventions that are focused on positive emotions and resilience.

The informal caregiver

In most families, the responsibility of care falls on almost exclusively one person (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). The profile of the "main caregiver" is defined as a person who comes from the informal support system, whether it is a family member or a friend, who dedicates a large part of his or her time to accomplishing tasks related to the care of the PwAD over the span of at least six weeks and without paid compensation (Dwyer, Lee, & Jankowski, 1994; Wilson 1989).

Based on the work of Brodsky and Donkin (2009), the typical caregiver profile is that of a woman, such as

the patient's daughter (60%) or spouse (30%), in middle age [mean (M) = 52.9 years old]. Approximately 97.6% of caregivers assist the patient every day and dedicate a mean of 73.5 h/week (Boada et al., 1999). The economic value associated with the hours of attention provided by the caregiver to the activities of the patient's daily life (basic and instrumental) increases with the degree of cognitive and functional deterioration, which may reach €1,092.70 monthly during the most advanced phases of the disease (López-Pousa et al., 2004). In general, caregivers do not enjoy any days off for rest (Crespo & López, 2007) and require leave from work (M = 1.46 h/week) in cases of caregivers who have paid jobs (Boada et al., 1999). The mean time the caregiver performs this role is 48.3 months (Boada et al., 1999; López-Pousa et al., 2004).

The tasks involved in the care of a PwAD may be more or less intense; however, in any case, they demand constant effort with ongoing re-adaptations of the daily routine, which typically evolves into a situation that triggers chronic stress (Montorio & Losada, 2005). Facing stressful situations on a daily basis increases the caregiver's vulnerability, which intensifies the risk of suffering from various physical, psychological, and social problems (Crespo & López, 2007). Based on the work of Marriott, Donaldson, Tarrier, and Burns (2000), this situation is passed on to the PwAD, considering that the caregiver responds more strongly to his or her own mood than to the actual demands of the surrounding context.

Maslow (1985) states that stress splits individuals in two groups: those who, from the beginning, cope poorly with the stress and those who are strong enough to cope with stress in a way that if stress is experienced, the individuals will become stronger, more seasoned, and tougher. Therefore, the ways in which an individual can react to a situation of potential stress, such as caring for a family member with AD, are heterogeneous (Lazarus & Folkman, 1986; Schulz, Gallagher-Thomson, Haley, & Czaja, 2000; Yates, Tennstedt, & Bei-Hung, 1999). In large part, this reaction depends on the subjective evaluation of the care task, on the caregiver's capacity of facing the demand, and on the perception of the support received from the environment (Montorio, Yanguas, & Díaz-Veiga, 1999; Vitaliano et al., 2004).

In addition, when care tasks are perceived as negative or threatening and the caregiver evaluates that he or she has neither the external nor internal resources to handle them, a set of physiological, emotional, and/or behavioral reactions are triggered, which are called

"burden" (Zarit et al., 1986). For example, caregivers who possess coping strategies centered on emotions (e.g., flight and/or avoidance) and who receive little perceived social support experience more burden (Powers, Gallagher, Thompson, & Kraemer, 2002) and exhibit poor mental health (e.g., anxiety and depression; Cooper, Katona, Orrell, & Livingston, 2006; Crespo, López, & Zarit, 2004).

However, the caregiver might see the situation of care as less threatening or evaluate it as manageable. In both cases, it is possible to generate positive emotional responses in caring for a PwAD. Therefore, caregivers who express positive emotions associated with the care experience improvements in family cohesion and self-esteem, as well as opportunities for personal growth (Cohen, Colantonio, & Vernich, 2002; Ott, Sanders, & Kelber, 2007). These elements contribute to the adaptation of individuals to adversities and reduce their vulnerability in situations of stress that are associated with the care of a PwAD (Quintero et al., 2007).

Based on this perspective, there are different elements that might help reduce negative outcomes related to the care. For example, positive emotions are associated with better health, as caregivers who express positive attributions in relation to the care express lower levels of depression and burden, compared with those who do not report these states (Farran, Miller, Kaufman, & Davis, 1997). Other factors, such as the level of perceived social support, the use of proper coping strategies (Sörensen, Duberstein, Gill, & Pinquart, 2006), the degree of perceived personal control demonstrated (Contador, Fernández-Calvo, Palenzuela, Miguéis, & Ramos, 2012) and a *resilient mindset* (Quintero et al., 2007) seem to be protective elements against caregiver burden.

Caregivers with good perceived personal control (PPC) believe they have more control over the situation, which encourages the use of active coping strategies, such as seeking information, tackling the problem, maintaining the care of the PwAD within the family environment (Contador, Fernández-Calvo, Palenzuela, Ramos, Rivera-Navarro, & de Lucena, 2015), or making better use of social support. In turn, caregivers who feel helpless or unlucky are inclined toward abandonment and employ passive coping, which generates a greater perception of burden (Contador et al., 2012). Similarly, the *resilient mindset* is associated with better adaptation to changes during the care, better perceived physical health of the caregivers, and less burden (Quintero et al.,

2007), which decreases institutionalization of PwADs (Gaugler, Kane, & Newcomer, 2007).

Grotberg (1995) attributes the formation of a *resilient mindset* to the sum of individual, family, and social factors. Thus, dispositional attributes such as optimism, persistence, internal locus of control, self-efficacy, affective family bonds, and external support are some of the essential elements for the formation of a *resilient mindset*. Having a *resilient mindset* in a situation of care is likely a protective factor against burden and improves commitment to the care. Family caregivers who are more resilient are capable of using their energy and involvement in the care to overcome difficulties and enjoy more positive emotions. In contrast, caregivers who are less resilient exhibit a predisposition toward negative emotions (e.g., tiredness and indifference) and overvaluing stressors associated with the care, increasing the risk of manifesting overburden prematurely (Quintero et al., 2007).

Therefore, some caregivers adapt to the situation of care with positive attitudes, which are specific characteristics of a *resilient mindset*, and more precisely, this mindset should activate proper behaviors (e.g., resource utilization) to decrease the risk of suffering from physical and emotional problems associated with the care of a PwAD (Quintero & Hernandez-Martin, 2010). In these instances, the situation of care might be evaluated as a rewarding experience. The caregiver may perceive the work of caring as a fight for a loved one, the expression of affection and interest (Román et al., 2005), and/or a way to pay back attention that was received in the past (Delmann-Jenkins, Blankemeyer, & Pinkard., 2001; Murray, Schneider, Bernerjee, & Mann, 1999).

As mentioned previously, promoting resilience seems to mitigate the negative effects related to changes or destabilizing events associated with the care and to maintain projections of the future (Manciaux et al., 2001). However, making good use of a *resilient mindset* does not mean that caregivers do not feel pain, distress, or compassion in the process of care. In contrast, they are able to manage their feelings in adaptive and healthy ways, experience some positive emotions, and react based on a desire to assume personal control over the situation. It is possible that caregivers who are more resilient can also suffer from burden; however, it is far more likely that they gain abilities and competencies from the care (Fernandez-Calvo et al., 2010; Quintero et al., 2007). Therefore, a resilient person makes better use of the available resources because, as caregivers,

their function is to offer affection, encouragement, and support (Quintero et al., 2007).

Nevertheless, structural support is also characterized as a protective factor against stress that promotes resilience in caregivers (Quintero & Hernández-Martín, 2010). Thus, it is possible that caregivers with more formal resources (e.g., economic and professional-supportive community services) may maintain the family member in his or her household for a longer period of time and cope better with the burden associated with the care (Gaugler et al., 2007).

Interventions in caregivers

In theory, the common objective of supportive programs for caregivers is to prevent burden in such a way that caregivers may perform their functions under the best possible conditions, given the impossibility of abandoning the person they care for (Crespo & López, 2007). Basically, the intention is *to care for the caregiver* by increasing his or her subjective well-being. These interventions generate significant outcomes regarding mental health improvement (e.g., reduction of depression) as well as a prolonged delay in institutionalizing the PwAD (Gaugler, Yu, Krichbaum, & Wyman, 2009).

Current intervention programs are rather heterogeneous regarding their objectives, contents, and format. In general, they are classified as respite services (formal support), educational interventions (psychoeducation), support group (SG), psychotherapeutic interventions, case management multicomponent intervention, and other non-classified interventions (Olazarán et al., 2010; Sörensen et al., 2006).

Respite services (RS) replaces the planned care, temporarily or on an emergency basis, to provide relief to caregivers. This type of care is offered in short-stay institutions for the elderly with dementia, in adult day care centers, or via home care; temporary stay also provides respite care in long-stay institutions for the elderly. The PwAD, in turn, benefits from the specialized assistance that is proffered by professionals.

Psychoeducation provides structured information on AD to caregivers. Examples of some of the content that is taught includes disease characteristics and progression, secondary issues (mobility and falls), legal issues, stress management, and techniques to address the behavior of a PwAD. This intervention may also include role playing and other active learning techniques.

SGs offer caregivers the opportunity to share personal feelings and concerns, promote reciprocity, and overcome feelings of social isolation. Different specialists on the theme are invited to provide information about socio-health and legal aspects related to dementia. The SG approach is less structured than interventions used in psychoeducational and therapeutic groups.

Psychotherapeutic interventions are conducted using different models—for example, cognitive-behavioral therapy and systemic family therapy. In this context, the cognitive-behavioral approach is the most frequently used (Pinquart & Sörensen, 2006). The scope of these therapeutic approaches consists of identifying and restructuring caregivers' dysfunctional thoughts, offering strategies and resources for them to adapt as best as possible with adverse situations, and showing empathy for the uneasiness experienced.

Case management includes information and practical counseling, family consultation, and referral to supportive community services and non-profit organizations (e.g., Alzheimer's Associations). This approach has a directive focus and does not intend to change either caregivers' beliefs or their coping skills.

Multicomponent intervention is based on the combination of different intervention strategies (e.g., psychoeducation, SG, and RS or psychotherapeutic intervention). The degree of structure adopted by these programs may vary; however, it is highly recommended that caregivers experience all elements that are part of the program.

Lastly, there are other suitable forms of intervention, such as life review (autobiography model), yoga, helpline services, and strength-based positive interventions. These types of interventions are rarely used, and currently, little scientific evidence exists regarding the effectiveness of their outcome in caregivers.

Pinquart and Sörensen (2006) conducted a meta-analysis in which they showed that the interventions mentioned above were effective. Nevertheless, the results are relatively limited and specific to the intervention that was developed. Psychotherapeutic interventions seem to provide better results in the reduction of caregivers' depression, anxiety, and distress. However, the effects of psychoeducation and counseling led to better understanding of disease of the PwAD and the caregiver burden, respectively. Respite service, in turn, seems to achieve better results in combination with other therapeutic approaches (López & Crespo,

2007). Multicomponent intervention is more effective in delaying the PwAD's institutionalization but does not improve the benefits of specific therapies (Pinquart & Sörensen, 2006). In contrast, a more recent meta-analysis showed that multicomponent intervention is the most effective among all programs applied to caregivers to improve their quality of life (Olazarán et al., 2010).

The questions raised are how to improve the effectiveness of the intervention used with the caregiver and how to validate a specific and generalized therapy for them. In particular, when situations are experienced differently (e.g., because spouses and children are in different life-cycle stages), the impact of the care varies among caregivers. Therefore, considering the resources available in the community, interventions should go beyond the simplistic "situation of care" conceptualization and instead, cater to the needs of the PwAD-caregiver pair, with consideration paid to the most affected areas and the factors involved in each specific situation (Sörensen et al., 2006). In the initial phases of dementia, the risk of institutionalization might increase due to the sudden intensification of stressors experienced by the caregiver (Gaugler, Kane, Kane, Clay, & Newcomer, 2007). Thus, the manner in which interventions are implemented and synchronized is important for the prevention of early institutionalization of the PwAD (Sörensen et al., 2006).

Moving forward in this discussion, interventions that focus on positive emotions promote a *resilient mindset* and help prevent the negative consequences of care (Fredrickson, Mancuso, Branigan, & Tugade, 2000). Pinquart and Sörensen (2006) emphasize that interventions that encourage active coping techniques have the best effects on caregivers in reducing the impact of adversities generated during care. Therefore, positive interventions, in addition to skills training aimed at the provision of better assistance, must create an environment where the caregiver generates self-confidence to move forward, experience positive emotions, and promote self-efficacy and competence in providing care. Additionally, these types of interventions must minimize negative or dysfunctional thoughts (Losada et al., 2010) resulting from the care and provide training with hands-on exercises that aim to increase activities that are rewarding to caregivers.

A shift in the individuals' mindset may occur. Thus, a better understanding of the foundation of the beliefs that guide our behaviors will help to stimulate the process towards a *resilient mindset*. An individual may

be resilient or learn how to be or may have the strength and the necessary social skills for becoming resilient; however, if he or she lacks the sufficient opportunity to receive support (from family or the community), his or her resources will be limited. Therefore, the family and community, as flexible spaces and facilitators of adaption and well-being of the caregiver, can and should promote the caregiver's resilience (Kotliarenco, Cáceres, & Álvarez, 1996).

In any case, this process is not easy. As Siebert (2007) suggests, human beings are able to gain skills at any age, but developing strength or a *resilient mindset* requires something beyond time and energy; it requires the ability to overcome and release oneself from various barriers, dysfunctional thoughts, and irrational beliefs.

Conclusions

The care of a PwAD is a challenge to the family and, in particular, to the caregiver. However, despite the constant adversities experienced by caregivers over extended periods of time, caregivers can experience positive situations and personal growth. These aspects might strengthen a caregiver's self-esteem and self-concept as well as facilitate the care of the family member.

Caregivers who maintain a *resilient mindset* experience the care situation as less negative; moreover, they cope better and maintain adaptive functioning. It is true that when an individual is forced to adapt to very stressful changes that profoundly alter his or her life, he or she will never be the same. However, a *resilient mindset* provides a reservoir of emotional strength that can be accessed to face life's challenges. It may be that this mindset does not eliminate stress, pressure, conflict, or adverse conditions. Nevertheless, it helps individuals to effectively cope with these adversities and, possibly, experience personal growth.

For this reason, future research in this area should focus on the factors related to a *resilient mindset*, which operate as real "bumpers" against negative factors and promote healthy caregiver development (Menezes de Lucena Carvalho, Fernández-Calvo, Hernandez Martín, Ramos Campo, & Contador Castillo, 2006; Quintero et al., 2007), thus helping to prevent the negative consequences of care and foster the individual's positive capabilities. These features will positively influence the quality of the care provided and the attention paid to the PwAD. Interventions based on a more positive, salutogenic, resilient, and strengths-based model-that

focus on the well-being of the caregiver-should be developed. However, we are not aware of other studies published on this theme; thus, further research in this area is warranted.

Strength-based positive interventions could be useful in attenuating the discomfort and burden caregiver, especially in a therapeutic context, as they aid caregivers in understanding how beliefs and emotions guide an individual's behaviors. Interventions involving mindfulness (Whitebird et al., 2013) or Acceptance and Commitment Therapy (Losada et al., 2015) would be included in this list.

Therefore, more therapeutic resources should be available to assist the caregiver because personalized, intensive, and multicomponent interventions that offer opportunities for decision making and active participation have been shown to be more effective (Olazarán et al., 2010; Pinquart & Sorensen, 2006; Spijker et al., 2008).

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