

EXPLANATION OF CAREGIVERS DISTRESS FROM THE COGNITIVE MODEL: THE ROLE OF DYSFUNCTIONAL THOUGHTS

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Resumen

Aunque el estudio del constructo de pensamientos o actitudes disfuncionales tiene una amplia tradición en las teorías cognitivo-conductuales del malestar emocional, el número de estudios que han analizado la influencia de los pensamientos disfuncionales de los cuidadores sobre el proceso de estrés del cuidador es bastante escaso. La literatura sobre la teoría y terapia cognitivo-conductual sugiere que los pensamientos negativos automáticos que los cuidadores mantienen acerca del cuidado estarán asociados con su nivel de depresión y de otras emociones negativas. En este trabajo se realiza una breve revisión de los estudios que han analizado los pensamientos o actitudes disfuncionales de los cuidadores. Además, se propone una adaptación del modelo cognitivo a la situación del cuidado. De acuerdo con este modelo, se proponen dos vías a través de las cuáles los pensamientos de los cuidadores acerca de la situación de cuidado pueden afectar a las consecuencias del cuidado: una saludable, en la que estarían implicados pensamientos adaptativos o realistas, y otra patológica, en la que los pensamientos disfuncionales ocuparían un lugar central. Se discuten las implicaciones de estas cuestiones de cara a la intervención.

PALABRAS CLAVE: *cuidado, cuidadores, demencia, ideas irracionales, modelo cognitivo, pensamientos disfuncionales.*

Abstract

The study of the construct of dysfunctional thoughts has a long tradition in cognitive behavioural theories of emotional distress. However, the number of studies that have analyzed the influence of the caregivers' dysfunctional thoughts on the caregiving stress process is rather sparse. The general literature on cognitive behavior theory and therapy suggest that the negative automatic thoughts maintained by the caregivers about caregiving would be associated with depres-

sion and other negative emotional outcomes. This work presents a review of the studies that have analyzed the caregivers' dysfunctional thoughts or attitudes. Furthermore, an adaptation of the cognitive model to the caregiving situation is suggested. In accordance with this model, there are two possible pathways through which caregivers thoughts on caregiving may affect caregiving consequences: a healthy one, involving adaptive or realistic thoughts; and a pathological one, in which dysfunctional thoughts play a central role. The implications of these considerations for interventions are discussed.

KEY WORDS: *caregivers, caregiving, cognitive model, dementia, irrational beliefs, dysfunctional thoughts.*

Introduction

Although the study of the construct of dysfunctional thoughts has a long tradition in psychology, its relationship with the caregiving stress process has been scarcely studied. The concept of dysfunctional thoughts plays a central role in influential theories such as the cognitive theory of depression (e.g., Beck *et al.*, 1979; Clark, Beck & Alford, 1999) or the ABC theory of emotion (e.g., Ellis, 2003), and represents the key target of the therapies developed in the context of the mentioned theories.

Although some differences exist between the theories (see, for example, Ellis, 2003; Padesky & Beck, 2003), they share two main assumptions: a) people's life experiences shape their cognitive system, determining their basic beliefs or *schemata*, which constitute the basis of their way of perceiving and interpreting the world; and b) people's cognitive system guide their emotional and behavioural responses (McGinn & Young, 1996).

The basic or central beliefs are expressed in terms of automatic thoughts that, depending on their adaptativeness, will have different influences on the affective and behavioral responses of the individual. Hence, a realistic and adaptive perception of the reality is critical for an appropriate functioning and adjustment to the everyday situations (J.S. Beck, 1995; Lazarus & Folkman, 1984). On the contrary, irrational beliefs or thoughts are a key factor when trying to explain the cases of people who do not have an adaptive and realistic perception of the reality. Dysfunctional thoughts, a variable whose relationship with psychological disorders has been well established in the psychological literature (e.g., Weich, Churchill, & Lewis, 2003), may be defined as stable and unrealistic rules, beliefs, or attitudes about the world and oneself, which hamper an adaptive coping with the environmental demands (Beck *et al.*, 1979).

These thoughts establish rigid and inappropriate contingencies that guide behavior (Beck, Rush, Shaw, & Emery, 1979; Halamandaris & Power, 1997). For example, some of them are related to perfectionism, which has been pointed out as an important factor in the etiology, maintenance and course of different psychological disorders (Shafran, Cooper, & Fairburn, 2002). In this way, people with dysfunctional thoughts are considered to be cognitively vulnerable to depression. Specifically, these thoughts increase the likelihood of depressive symptomatology

when stressful events make it difficult for the person to respond to his rigid or unrealistic beliefs (Kuiper, Olinger, & Air, 1989). These dysfunctional thoughts are not specific to depression, and they have been linked to other disorders such as anxiety disorders, type A behavior and bulimia (Martín, Kuiper & Westra, 1989; Poulakis & Wertheim, 1993).

Dysfunctional thoughts and caregiving

Some recent studies in the caregiving field emphasize the significant relationship between dysfunctional thoughts and caregivers' psychological distress (McNaughton *et al.*, 1995; Stebbins *et al.*, 2000), and dysfunctional thoughts have been considered as a therapeutic target that, when treated, can lead to positive outcomes for caregivers (e.g., Dick & Gallagher-Thompson, 1995; Losada-Baltar *et al.*, 2004). McNaughton, Patterson, Smith, and Grant (1995) studied the relationship between stress, depression, physical health and irrational beliefs in Alzheimer's caregivers. They found that irrational beliefs were positively associated with depression, external locus of control and poorer health. The results of a 6-month follow-up revealed that a lesser adherence to irrational beliefs was linked with an improvement in perceived health. These authors hypothesized that the beliefs affected caregiver's health through a negative influence on the way a person faced a stressful situation, increasing the probability that the caregivers would experience negative affect and physiological changes that predispose them to worse physical health. The results found by McNaughton *et al.*, (1995) coincide with those reported by Lichtenberg, Jonson and Arachtingi (1992), who found, in a non-caregiving study, that dysfunctional thoughts (related to perfectionism, avoidance of problems and need for approval) mediated the relationship between stress and illness.

Stebbins & Pakenham (2001) studied the relationship between dysfunctional thoughts and psychological distress in caregivers of people with traumatic brain injury. They found that dysfunctional thoughts are related with caregiver's distress, in the sense that a higher adherence to irrational schematic beliefs was linked with higher levels of psychological stress.

Although these works found that maintaining dysfunctional thoughts was damaging for physical and psychological health, to our knowledge there is no study that analyzes the mechanisms of action through which the dysfunctional thoughts impact caregiving. In this paper, a cognitive-behavioral model is proposed that suggests different paths through which dysfunctional thoughts may impact caregiving.

Mechanisms of action of the dysfunctional thoughts about caregiving on caregiver's distress

Some examples of unrealistic beliefs or thoughts that caregivers may maintain can be found in the literature, and they can affect in different ways how caregivers interpret and cope with diverse caregiving situations.

Interpretation of the relative's behaviors

The way in which caregivers interpret their relatives' behaviors affect their response and skills or disposition to make adjustments to the caregiving situation and responding to the needs of their relative. Many caregivers misinterpret their relatives' symptoms due to lack of knowledge concerning the dementias (Mittelman *et al.*, 2003, p. 184). This may be especially the case in early stages of the disorder, in which it is particularly difficult for the caregiver to know if the relative's behavior is attributable to the disorder or to another circumstance. It's not unusual that the caregiver interprets intentionality in a behavior that, in reality, is due to the disorder and is not controlled by the sick person. In these cases, the caregivers think and say «he behaves like that to bother me» or «he does that because he knows that disturbs me» or «I know that he/she can do it better, but doesn't make an effort to behave correctly». The caregiver may also misinterpret the meaning of the behaviour. For example, as Mittelman *et al.* (2003, p. 184) state, caregivers may interpret an effort of their relatives to express an emotion (e.g., distress or discomfort) as aggression. This construal of emotional behavior as aggressive will likely lead to an emotional or even aggressive response from the caregiver and so create a negative cycle of reciprocal behaviors that may lead to a crisis situation.

These misperceptions can be taken as reflecting the «education needs» of the caregivers in early stages of the dementia (Moniz-Cook & Woods, 1997; Sullivan & O'Connor, 2001). Caregivers have, in general terms, low levels of knowledge about dementia causes and symptoms (Edelstein, Spira, & Koven, 2003; Werner, 2001). Although no significant relationship between knowledge of these issues and burden has been found (Werner, 2001), greater knowledge has been linked with significantly lower levels of depression (Graham *et al.*, 1997). However, clinical experience suggests that these misperceptions of dementia are not easily changed in most cases by information alone, but need to be addressed repeatedly within the context of a supportive relationship in a psychological intervention

Perception of the need of social support

It is frequently observed that the primary caregiver is the only person involved in the caregiving and that he or she is refusing the participation of others in the caregiving or is unable to ask for help (Gruetzner, 1992, p. 125). Although asking for help from others may be beneficial for the caregivers, the reality is that, as Mittelman *et al.* (2003, p. 262) state, some caregivers, specially the spouses, think that they must give all the care to their relative without help. The reasons they give for this not help-seeking behaviour are multiple: they do not want to disturb their relatives, they do not want to introduce changes in the way they provide the care, or they fear the reactions of other relatives to this help-seeking behaviour. This behaviour is influenced by the fact that the 90% of the caregivers consider that caring is a moral responsibility for them as. For example, in the case of children caring for a parent with dementia, the parent for whom they are caring now took care of them when they were children (INSERSO; 1995, p. 243).

A fact that is striking for many researchers is to find that although the utilization of resources such as home care or day care centers have a positive influence on caregivers' distress, only a few caregivers request these resources (Arai *et al.*, 2000; Gaugler *et al.*, 2003; Kosloski, Montgomery & Karner, 1999; Llacer, Zunzunegui & Béland, 1999). In accordance with different researchers (Brody, 1985; Cantor, 1991; Collins, Stommel, King, & Given, 1991; Pedlar & Biegel, 1999), caregivers' low use of these formal resources is related to the caregiver's attitudes with respect to the family responsibility in the caregiving. Many caregivers, although they report significant levels of distress (e.g., depression or burden), indicate that they do not need help, and some authors have reported that this may be because they consider that «help must be provided in the family» and because they are worried about what others will say if they ask for formal help (Arai, Sugiura, Miura, Washio, & Kudo, 2000).

Other reasons that may hamper the search for help are that caregivers may consider that nobody can take care of their relative as they do (Lustbader & Hooyman, 1994, p. 23; Mittelman *et al.*, 2003, p. 262) or that they think that other relatives or friends are very busy with their own lives and, so, they should not be bothered (Janevic & Connell, 2004). The maintenance of these thoughts and beliefs about caregiving not only may contribute to the appearance of feelings of anger, guilt or sadness (e.g., Gruetzner, 1992, p. 140), but also may be on the basis of why many caregivers are reticent to ask for both formal and informal help (Mittelman y otros, 2003, p. 72).

Beliefs regarding receiving help are significantly associated with mental and physical burden and isolation of the caregivers (Smyth, & Milidonis, 1999). The lack of social support and the isolation of the caregivers are positively related with depression (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Laserna *et al.*, 1997) and negatively with life satisfaction (Haley *et al.*, 1996). People with difficulties for asking for or obtaining help have more burden (Chang, Brecht, & Carter, 2001), and receiving help from others has been found to be significantly associated with a better caregiver's physical and psychological health (Kelly *et al.*, 1999). For example, a recent study by Rapp *et al.* (1998) points out that those caregivers that actively establish and maintain sources of support have better well being (less depression, better quality of life, more perceived benefits from caregiving and better perceived health).

Cultural Values: Familism

The socio-cultural value of familism can influence these preferences of the caregivers. Familism is thought to be present in the general population, without regard to caregiving status (Bazo, 1998). The influence of the society is a basic factor in the shaping of values such as familism, and this influence will guide the thoughts, feelings and behaviours of the person. In principle, familism is linked with positive consequences for caregiving coping, since it could lead to a positive evaluation of caregiving tasks. In this way, it has been suggested as a possible protective factor against negative caregiving outcomes (Coon *et al.*, 2004).

However, familism attitudes and beliefs may act as barriers for the development of appropriate coping strategies, thus adding complications to the already difficult task of caring for a sick relative, becoming a source of stress and negative feelings for the caregiver. For example, strong familistic attitudes may impede the search for help outside the family, even when help from relatives is not available. Also, familism may make caregivers more reluctant to express their caregiving-related negative feelings or experiences to non-relatives, as it would be a sort of «betrayal» to their family. In fact, Cox & Monk (1993) found a positive and significant association between depression and the adherence to the cultural norm of filial support, that forced the children to take care of their fathers and to not use professional help due to the shame this will bring to the family. Similar results have been reported by Losada *et al.* (2006), who found a significant and positive association between familism and depression in a sample of Spanish caregivers.

There are other reasons that can explain the association of familism with negative outcomes for the caregivers. In recent years, social transformations (reduction of family size, increase in the number of childless couples, and the incorporation of the women in the working world) limit the availability of personal and family resources for informal caregiving (Pérez, 2002; Stanford, Peddecord & Lockery, 1990).

Self-neglect: the «forgetting of themselves»

Cultural and family norms may also contribute to another situation frequently observed in the caregivers: they dedicate themselves completely to the care of their relatives, setting aside their interests and well-being, in a sort of «self-neglect», perhaps as a way to avoid the facing of feelings of guilt or pain (e.g., Lindoerfer, 1991, p. 121). In this sense, caregivers tend to avoid doing leisure activities, despite the fact that leisure activities reduce negative feelings linked with caregiving (Haley *et al.*, 1996; Thompson *et al.*, 2002). In these cases, the caregiver may become overinvolved in the care of his/her relative, preventing the person with dementia from doing what he/she can still do (Lindoerfer, 1991), and thus, maximizing the probability that the relative becomes more dependent than expected (excess disability). In turn, this overinvolvement leads to the caregiver feeling overwhelmed by the excessive burdens stemming from the recipient's excess disability (Gruetzner, 1992, p. 141).

In association with the caregivers «self-neglect» just described, an important problem that is usually observed in caregiving contexts is related to the belief that «conflicts should never be expressed» or «negative feelings should never be expressed» (Gallagher-Thompson, Solano, Coon & Arian, 2003). Even in the best circumstances, caregivers experience negative feelings or emotions related with the task of caring for a relative with dementia. In this way, it is relatively frequent that a caregiver thinks that «it would be better for everyone that my relative dies» or that they get angry or ashamed about some behaviours of their relative, while knowing that the relative can do nothing to control the illness. Although experienced, these feelings and thoughts are not easily expressed by the caregivers.

A potential reason for this avoidance of the expression of negative feelings is that many caregivers consider that a good caregiver must be happy most of the time, performing his/her role with joy and enthusiasm, and that he/she should never get angry or have negative feelings towards their relative. Holding these beliefs, they feel guilty and ashamed when they have thoughts or feelings that are contrary to what they consider right, and so inhibit expression of negative emotions. Caregivers sometimes think that discussing mental health problems of the relative with others is equivalent to tarnishing the image of the care recipient and his/her family in the community (Gallagher-Thompson, Solano, Coon & Areán, 2003). Not expressing feelings, attitudes, wishes, thoughts or rights has been linked to higher burden (Muela, Torres, & Peláez, 2001). Some authors point out that recognizing and sharing these type of feelings makes caregivers feel better (Lustbader & Hooyman, 1994, p. 50), especially expressing them to someone that accepts them (Lindoefer, 1991). The importance of this issue is revealed by the fact that this expression of feelings is one of the most valued consequences of the participation of caregivers in group interventions (e.g., Morano & Bravo, 2002).

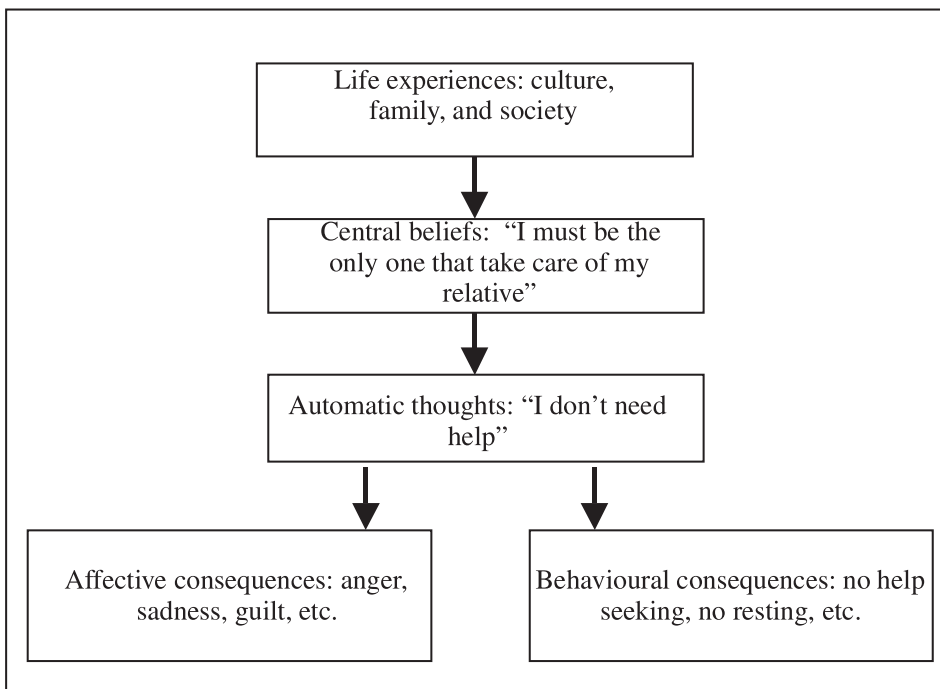
Adapting the Cognitive Model to the explanation of the consequences of caregiving

Dementia and other types of disability pose multiple difficulties for many families that have to cope with them. They are diseases that result in a progressive impairment of the sick person and require constant adjustments in the way care must be provided. In fact, dementia caregiving has been described as a career (Aneschensel *et al.*, 1995) given that, in the same way as a career, it has a beginning, multiple phases, transitions, and changes, and has an end point. In the same way as a professional career, caregiving is influenced by past events and learning experiences (individual, family, social or cultural history of the person) and it becomes a central theme in the life of the person responsible of the principal care (see, for example, Mittelman *et al.*, 2003, p. 24).

Conceptualizing caregiving as a career points to the pertinence of the Cognitive Behavioural Theory (CBT) as a frame for the analysis of this experience. A basic principle of CBT is that the life experience of the persons (e.g., familial, cultural or social experiences, personal or vicarious) significantly contributes to the development of the cognitive system, which guides people's behaviour and emotional responses. When applied to the field of caregiving, this model appears as a powerful tool for explaining and predicting diverse empirical findings. Hence, although the caregiving situation is stressful for most caregivers, the particular response and coping of each caregiver is different, because each caregiver has a unique system of schemas and beliefs to interpret and analyze the world and its diverse situations, which has been shaped by his/her personal history and learning experiences. These differences in the way of coping with caregiving will obviously lead to important differences in the consequences associated with caregiving (e.g., level of depression, anger or isolation).

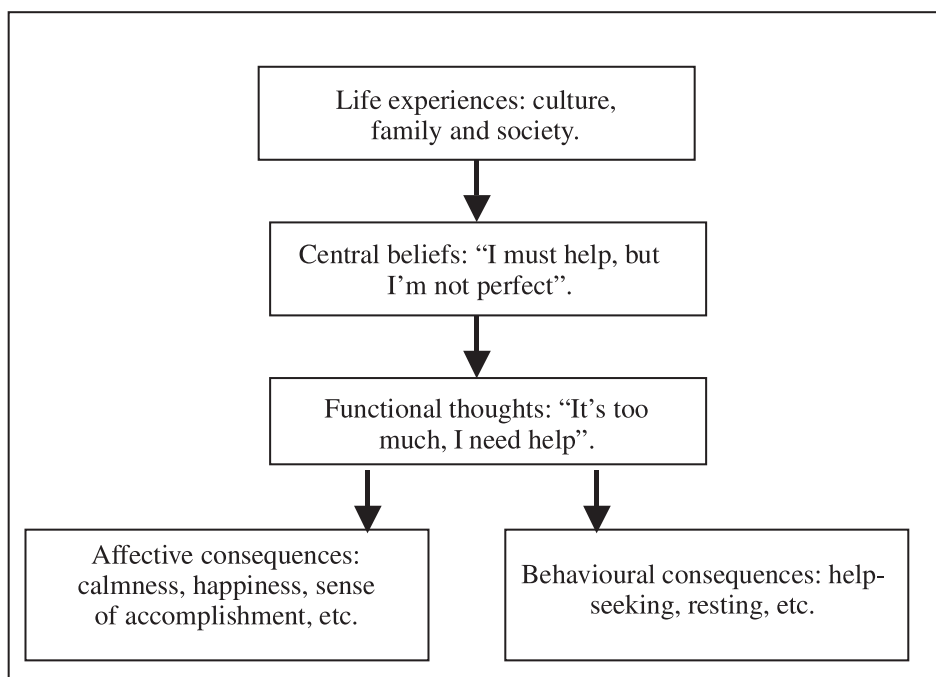
It is obvious that each caregiver has his/her particular history of life experiences and has developed his/her life in specific cultural, familiar, and social contexts which differ more or less from the experiences and contexts of other caregivers. Specific circumstances and contexts might have contributed to the development of more traditional values such as «I, as a relative, must be the one that provides care» or «I should set aside my needs and interests because I have a relative that needs me», in some caregivers. These type of beliefs may contribute to create in the caregivers a general attitude of «self-sacrifice» and «self-neglect», which could be stated as «I must dedicate my whole life to the care of my relative». Bringing the CBT model to the analysis of caregiving, given that dementia caregiving is highly demanding and it lasts a long period of time, the maintainance of these «self-sacrifice» and «self-neglect» attitudes is likely to lead to a «pathological pathway» of coping with caregiving (Figure 1), consisting of behaviours that will result, sooner or later, in negative physical and psychological consequences for the caregiver. Examples of the behaviours generated by this type of attitude include the formerly analyzed behaviour of not asking for or not seeking formal or informal help, but also other behaviours such as not resting, not having leisure time, not expressing the negative feelings, etc., behaviours which are linked with physical and psychological distress.

Figure 1
Cognitive model of caregiving: pathological pathway



On the contrary, a «rational» approach to the demanding and «chronic» caregiving task is represented by more realistic beliefs regarding caregiving, such as «Caregiving is a complex and highly demanding set of tasks which requires more than one person to be carried out effectively» or «I am a human being and, hence, I can feel shame, anger or even disgust regarding some of my relative's behaviours». These beliefs, held by caregivers who have either adapted to caregiving in a positive way since the beginning, or learned from their experience that in order to care well a caregiver must take care of himself, are related with more skilled responses to caregiving demands. As Castleman, Gallagher-Thompson & Naythons (1999, p. 194) point out, behaviours such as asking other people for help, obtaining free time for resting and/or for leisure activities, and acknowledging and expressing the negative feelings will be associated with less distress related to caregiving and, in general, with less negative affective and behavioural consequences of caregiving (Figure 2).

Figure 2
Cognitive model of caregiving: healthy path-way



Recent CBT intervention studies with caregivers suggest that changing specific dysfunctional thoughts about caregiving, similar to those pointed out in this study, is possible and has a positive impact on caregivers' distress (e.g., Losada *et al.*, 2004). This line of interventions was pioneered by Gallagher-Thompson and colleagues

(e.g., Dick & Gallagher-Thompson, 1995; Kaplan & Gallagher-Thompson, 1995; Gallagher-Thompson, Coon, Solano, Ambler, Rabinowitz & Thompson, 2003), which confer a central role to the detection, analysis and modification of beliefs and thoughts that, although not specific to caregiving (e.g., «I am no good unless I am all things to everyone»; Dick & Gallagher-Thompson, 1995, p. 219), affect the way caregivers cope with caregiving and can be treated through specific cognitive techniques.

Conclusions

The number of articles aimed at studying the negative consequences of dementia family caregiving has increased in a significant way. However, there are still only a few studies aimed at analyzing the concrete mechanisms or paths through which the distress is produced. The few studies which have dealt with this issue have relied primarily on stress and coping theory.

In this paper we have presented arguments that support the utility of the CBT as a theoretical framework to analyze the caregiving stress process and to understand the specific pathways that lead to negative outcomes in some caregivers. Specifically, we have offered a theoretical analysis of the role of dysfunctional thoughts in the caregiving process, process that has been considered a prototypical example of chronic distress (Vitaliano *et al.*, 2004). From this analysis, we can conclude that some caregivers beliefs and thoughts, developed as a consequence of personal life experience, family history, or socio-cultural influences, may act as barriers or obstacles when trying to cope in an adaptative way with caregiving, making the appearance of negative physical and psychological consequences more probable. Other beliefs and thoughts, arising from differing experiences, history and sociocultural influences would tend to lead to more positive views of caregiving.

Based on this review and theoretical analysis, it is recommended that an evaluation of these maladaptative thoughts be included in the assessment of caregivers. Preliminary analysis of the relationship between dysfunctional thoughts about caregiving such as those pointed out in this work (e.g., «Caregivers should avoid talking about their problems with others because others have their own lives and don't need to be bothered with more problems» or «A caregiver should only seek help from others or find other alternatives when the caregiving situation is at its worst or when he/she can no longer handle it») and variables such as dysfunctional attitudes, depressive symptomatology, and social support provide preliminary empirical support to the negative influence of these thoughts in the caregiving process (Losada, 2005). Professionals should be aware that attention should be paid to these thoughts and that the efforts to change them through cognitive behavioural interventions is appropriate, as suggested by increasing empirical evidence.

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