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Pilot study of a psychotherapeutic intervention for reducing guilt feelings in highly distressed dementia family caregivers (Innovative practice)

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Abstract

Many caregivers of people with dementia experience guilt but few interventions have been deigned to help them with these feelings. This study aimed to describe a psychological intervention specifically developed for decreasing caregivers´ guilt. The sample was composed of four caregivers, individually interviewed before and after the intervention. The intervention consisted of eight group-based sessions and was based on cognitive-behavioral, acceptance and self-compassion techniques. Three participants reported clinically reliable change in guilt. Clinically significant changes were also observed in their levels of anxiety and depression. The results suggest that carers might benefit from interventions designed to reduce their feelings of guilt.

Keywords: acceptance and commitment therapy, caregiver, dementia, guilt, self-compassion.

Introduction

Caring for a relative with dementia may have a negative impact on caregivers´ levels of anxiety and depression (Sallim, Sayampanathan, Cuttilan, & Ho, 2015). However, other negative emotions frequently experienced by caregivers in the daily routine of taking care of their relatives, such as guilt, have scarcely been studied (Gonyea, Paris, & de Saxe Zerden, 2008; Losada, Márquez-González, Peñacoba, & Romero-Moreno, 2010), even though they may cause caregivers considerable distress (Losada et al., 2010; 2018).

Guilt has been described as "the dysphoric feeling associated with the recognition that one has violated a personally relevant moral or social standard" (Kugler & Jones, 1992, p. 318). The importance of guilt in in caregiving is highlighted by findings showing that guilt is linked with higher distress among caregivers of people with dementia (Feast, Orrell, Charlesworth, & Moniz-Cook, 2017; Losada et al., 2010; Martin, Gilbert, McEwan, & Irons, 2006; Romero-Moreno et al., 2014).

Despite the growing literature on guilt, studies about its causes are scarce (Baumeister et al., 1994). Beliefs and thoughts about the caregiving task are likely to play an important role in the emergence of guilt feelings. This idea is congruent with cognitive-behavioral models. According to these models, caregivers´ beliefs and norms, strongly influenced by cultural expectations, are the main source of guilt and other emotions, which are likely to arise when caregivers perceive they have failed to meet these norms or behave according to their beliefs (Losada, Márquez-González, Knight, Yanguas, Sayegh, & Romero-Moreno, 2010).

Another relevant source of guilt is the experience of negative emotions towards the relative cared for. It is very common for caregivers to feel guilty for having emotions -such as sadness or anger- and thoughts (e.g. "I feel guilty about being sad and feel hopeless") that can arise in caregiving situations. This type of guilt may be related to experiential avoidance (Hayes, Strosahl, & Wilson, 1999). which is the attempt to avoid or escape from negative thoughts or emotions (Hayes et al., 1999). Among caregivers, higher levels of experiential avoidance have been associated with higher psychological distress, dysfunctional thoughts and higher blood pressure (Márquez-González, Cabrera, Losada, & Knight, 2018). Acceptance and Commitment Therapy (ACT; Hayes et al., 1999) focus on acceptance may be especially appropriate to help caregivers deal with

these emotions and thoughts. Other correlates of guilt are the consequences or effects that these feelings may have in the caregiving process. Given the aversion to guilt, caregivers may avoid performing adaptive behaviors (e.g., self-care and leisure activities) in order to try and escape these feelings. Hence, caregivers' feelings of guilt may predict the use of maladaptive coping strategies in stress contexts. For example, they may be associated with a decreased realization of relevant activities, such as those related to self-care, due to irrational beliefs about the caregiving task.

Despite the growing literature on the development and outcomes of psychotherapeutic interventions for improving dementia family caregivers wellbeing (e.g., Gallagher-Thompson et al., 2012) most of the available interventions have been mainly focused on reducing depressive symptomatology or 'burden' (Gallagher-Thompson et al., 2012). Considering the above-mentioned relationships between guilt and distress, the dearth of interventions aimed at targeting caregivers' guilt feelings is surprising. Targeting dementia caregivers´ levels of guilt may be of strong clinical interest due to the distress associated with this feeling and its relevant role in the explanation of caregivers' depression (Losada et al., 2017).

Only one published study appears to have analyzed the efficacy of a psychological intervention (CBT) for reducing caregivers' guilt feelings (Mahmoudi, Mohammadkhani, Bonan, & Bagheri, 2017). The results showed a reduction in guilt feelings at post-treatment and follow-up.

Considering the gap in the availability of interventions specifically developed for treating dementia family caregivers' guilt, the objectives of the present study are twofold: 1) To design and describe a group intervention specifically developed for decreasing guilt feelings experienced by caregivers (that merges CBT with ACT and self-compassion techniques); and 2) to provide preliminary data of a pilot study analyzing the effects of this intervention in dementia family caregivers with high levels of guilt and distress (depressive or anxious symptomatology).

Method

Participants

Participants were twenty caregivers of relatives affected by dementia from Madrid (Spain). Inclusion criteria for participation were: a) being at least 18 years old; b) self-

identifying as the primary caregiver of the relative with dementia; c) caring for at least an average of one hour per day during at least three consecutive months; d) obtaining clinically significant scores on depressive and/or anxious symptomatology; e), and having significant levels of guilt.

Measures

Guilt. The Caregiver Guilt Questionnaire was used (CGQ; Losada et al., 2010). It measures the caregivers' guilt feelings during the previous week through 22 items with Likert-type responses from 0 = "never" to 4 = "almost always". The cut-off for determining significant levels of guilt was 16, the average score obtained in the original study conducted by Losada et al. (2010).

Depression. The Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) was used. The scale has 20 items and answers vary from 0 = "rarely or never" to 3 = "most or all of the time". The cut-off for clinical depression are scores equal to or higher than 16 (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993).

Anxiety. The Tension-Anxiety subscale from the Profile of Mood States (POMS; McNair, Lorr, & Droppleman, 1971) was used. This instrument consists of 9 items with Likert-type response options ranging from 0 = "not at all" to 4 = "extremely". A score equal to or higher than 13 has been considered an indicator of the presence of clinically significant anxiety (Losada et al., 2015).

Procedure

Participants were recruited through different adult day care centers. A telephone interview was carried out to check whether participants met the study inclusion criteria. This was followed by face-to-face interviews. Before enrolling in the study, all participants signed an informed consent form. Figure 1 represents the flowchart for recruitment. After completing the intervention, participants were assessed for the same variables again at post-treatment. The study was approved by the Spanish Ministry of Science and Innovation and the Ethics Committee of the Universidad Rey Juan Carlos.

Guilt focused intervention

A specific group intervention for reducing guilt feelings in caregivers was designed for the study. The program was based on the previous literature about psychological interventions for caregivers (e.g., Losada et al., 2015), data regarding relevant factors associated with guilt feelings (Gonyea et al., 2006; Losada et al., 2010; Romero-Moreno et al., 2014; Spillers et al., 2008), and the authors´ previous clinical experience. The intervention is developed around three dysfunctional beliefs based on the factors associated with the origin or maintenance of guilt feelings in family caregivers. The main dysfunctional statements are: a) “I have to be a competent and perfect caregiver. I must have the diverse caregiving situations “under control”; b) “Self-care is a selfish behavior. The wellness and happiness of my relatives are my main and unique responsibility”; and c) “I have to experience positive feelings and thoughts about my relative and my role as a caregiver. It is not correct to experience caregiving-related negative emotions and thoughts”. In this intervention, caregivers are guided to explore and acknowledge their guilt and other negative feelings in the frame of these irrational beliefs; however, instead of using cognitive restructuring techniques to change these beliefs, caregivers´ ability to tolerate and accept guilt and distressing emotions and thoughts is fostered through exercises based on ACT (Hayes, et al., 1999) and Compassion Focused Therapy (Gilbert, 2009).

The principal aim of the intervention was to increase the acceptance of negative private events (mainly guilt feelings) related to caregiving, and the commitment to personal values through the increase in the frequency of actions oriented toward these values, and, in this way to reduce the distress experienced by them. The specific objectives are to increase (a) awareness and acceptance of the three dysfunctional beliefs, their relation with guilt, and the negative impact of acting fused with these dysfunctional beliefs on the caregiver's health and daily routine, (b) the acceptance of negative emotions, primarily guilt, and negative thoughts, (c) the frequency of actions oriented to personal values, despite experiencing guilt feelings during their performance, and (d) compassionate self-judgment.

The intervention consisted of eight weekly group sessions, each lasting approximately two hours, and in each session it was promoted active participation of the caregivers in exercises related to the main topics of the session, including experiential exercises, metaphors, and other techniques. The sessions and principal contents of each one are shown in Table 1.

Table 1.

Contents of the psychological intervention for reducing caregivers' guilt feelings.

Session	**Main objective**	**Content of the session**
1	Identifying and understanding guilt feelings.	-Presentation of participants and therapists. -Experiential exercise: Visualizing and activating my guilt feelings. -Debate: Definition of guilt. Unhealthy guilt versus healthy guilt. Consequences of unhealthy guilt. -Work with personal values: Identifying my values.
2	Working with the belief "I have to be a perfect and competent caregiver".	-Experiential exercise: Experiencing guilt about doing wrong with my relative with dementia. -Focus on the belief about perfectionism and the consequences of acting fused with this belief. -Working with personal values: Garden metaphor (Hayes et al., 1999) -Mindfulness exercise: Breathing exercise.
3	Working with the belief, "Self-care is a selfish behaviour. The entire wellness and happiness of my relatives are my main and unique responsibility".	-Case exercise: Herminia´s case (I). Analyzing Herminia´s garden, non-self-caring behavior and its consequences. -Focus on the belief "Self-care is a selfish behavior" and its consequences of acting fused with this belief. -Garden metaphor: Checking my plant and guilt feelings derived from caring for one-self. Negative consequences of the absence of self-care. -Mindfulness exercise: Working with uncomfortable sensations and emotions.

		- Working with personal values: Schedule for committed actions with self-care and a relevant personal value.
4	Increasing the new strategy of acceptance of dysfunctional beliefs.	-Working on the barriers for committed action and scheduling new actions. - Exercise: Guilt as a sign of change in my life. Working with guilt as a barrier for committed actions. - Exercise: My watering can. Working on the incompatibilities between life areas: Identifying guilt when I am not able to meet all my life aspects. -Exercises for reorganizing tasks and time. -The influence of the cultural and social environmental factors in guilt feelings and beliefs. -Bus metaphor (Hayes et al., 1999). Promoting the acceptance of guilt and other negative private events. -Working with personal values: Scheduling new committed actions and working with barriers.
5	Working with the belief "I have to experience positive feelings and thoughts about my relative and my caregiver role. It is not correct to experience caregiving related negative emotion and thoughts".	-Case exercise: Herminia´s case (II). Focus on the belief about how I should and should not feel in caregiving, and on the consequences of acing fused with this belief: Experiential avoidance. -Exercises for accepting guilt and negative thoughts. -Mindfulness exercises for negative and uncomfortable thoughts -Working with personal values: Scheduling new committed actions and working with barriers.

6	Reviewing the three dysfunctional beliefs: What is a good caregiver?	-Exercise: Analyzing my caregiver role and my dysfunctional beliefs about caregiving. -Review of the three dysfunctional beliefs discussed in the previous sessions. -Accepting guilt feelings with the help of mindfulness exercises. -Mindfulness exercise: Working with uncomfortable sensations and emotions. -Working with personal values: Scheduling new committed actions and working with barriers.
7	Reviewing my guilt sources and my owns´ limitations Promoting a Self-compassionate judgement	-Assertive rights: The right of making mistakes without feeling guilty. -Self-compassion experiential exercise: Self-compassion as a strategy to accept my limitations and my mistakes. -Working with personal values: Scheduling new committed actions and working with barriers.
8	Final	-Closing, summarizing and reinforcement of the advances obtained through the intervention.

Data analysis

The Jacobson and Truax criteria (, 1991) for reliable change was used. Using these criteria (1991), a participant obtained a clinically significant change if his/her change score (the result of the difference between post- and pre-intevention values) was greater than the RCI value, which was calculated using reliability data of the reference groups.

Results

Description of participants

As shown in the flowchart (Figure 1), five of the 20 participants met the inclusion criteria to participate in the study. Finally, four were evaluated at post-treatment.

[Please, insert Figure 1]

Participants included in this study were four family caregivers (two women and two men) of a relative affected by dementia.. Details of the participants can be found below:

Caregiver 1: A 57-year-old woman taking care of her 83-year-old mother diagnosed with Alzheimer´s type dementia. She was caring for her mother an average of one hour per day and had been caring for the last two years.

Caregiver 2: A 70-year-old woman taking care of her 78-year-old husband who had Alzheimer´s type dementia. She was caring for her husband an average of nine hours daily and had been caring for the last seven years.

Caregiver 3: A 64-year-old man taking care of his 60-year-old sister who had a Korsakov´s dementia. He reported caring for his relative for an average of 17 hours daily and had been caring for the last three years.

Caregiver 4: The fourth caregiver was a 77-year-old man taking care of his 72-year-old who had Alzheimer´s type dementia. He was caring for his wife for an average of 14 hours daily and had been caring for the last six years.

Changes in assessed variables

Table 2 shows the descriptive data for each participant in the measured variables at baseline and at post-intervention.

After the intervention, three caregivers reported scores under the cut-off point for guilt feelings. Three caregivers reported scores under the cut-off score for depressive symptoms, while one reported an important increase in depressive symptoms. One scored under the cut-off point for anxiety symptoms.

Table 2

Caregivers' scores in outcome variables from pre to post-intervention and change.

Variable		Caregiver 1	Caregiver 2	Caregiver 3	Caregiver 4
Guilt	Pre	26	32	23	26
	Post	4	29	9	12
	Change	22*	3	14*	14*
Depression	Pre	21	8	16	27
	Post	14	17	11	17
	Change	7	-9	5	10*
Anxiety	Pre	12	22	23	17
	Post	12	21	2	13
	Change	0	1	21*	4*

*Reliable change.

The obtained RCI value for guilt was 3.62 ($p < .05$). Therefore, caregivers 1, 3 and 4 showed a clinically relevant change in guilt feelings. Regarding depressive symptomatology, the RCI value was 7.72 ($p < .05$). Caregiver 4 showed a clinically relevant change in this variable. However, caregiver 2 obtained a clinically relevant deterioration. Finally, in terms of anxiety, caregivers 3 and 4 showed a clinically relevant change for that variable (RCI = 3.97; $p < .05$).

Discussion

The aim of the present work was to describe a psychological intervention aimed at targeting dementia family caregivers' guilt symptoms that merges CBT focus on irrational beliefs with ACT and self-compassion techniques and, to present the preliminary findings of its efficacy through a pilot study of four caregivers with high levels of guilt feelings and distress.

Three of the four participants reported clinically significant changes (reliable change) in guilt feelings (Caregivers 1, 3 and 4). At post-intervention, these three caregivers all showed a guilt score below the cut-off points, which was considered suggestive of clinical relevance. Clinically significant reductions were also observed in these three caregivers in depressive and anxious symptoms (as measured through the RCI

or by obtaining a post-intervention score in the depression or anxiety scales lower than the cut-off point), except for Caregiver 1, who reported no change in anxious symptoms. No clinically significant changes were obtained for one participant in guilt feelings (Caregiver 2), even though a change in the expected direction was observed which was very close to meeting the RCI value considered to be a reliable change for guilt feelings. One possible explanation for this result is that Caregiver 2 presented higher levels of guilt at the beginning of the intervention as compared with the other participants. The intervention's limited number of sessions may not be enough for reaching clinically significant effects in all participants. Thus, a limited number of sessions or lack of follow-up or booster sessions may be one of the principal causes for not finding positive outcomes after the treatment (Pinquart & Sörensen, 2006). Future studies should consider adding booster sessions after the end of the intervention.

Despite the positive trends found in the results regarding guilt feelings, Caregiver 2 showed a clinically significant deterioration in depressive symptomatology. In her particular case, external influences unrelated to the intervention may have influenced the results. Caregiver 2 reported at post-intervention that a family relative had an accident a week earlier and was hospitalized. Another possible explanation for the deterioration reported by Caregiver 2 is the social comparison phenomenon facilitated by the group format. During the final sessions, Caregiver 2 mentioned her worries about her husband´s future decline, upon which other caregivers commented on the possible appearance of functional, legal and other problems related to higher disability in the care recipient. Hence, it would be interesting to assess the efficacy of the application of this intervention in an individual format, which has been shown to possess higher levels of efficacy (Pinquart & Sörensen, 2006).

The present study has several limitations. The findings should be considered with caution due to the limited sample size and the lack of a control group. More studies with larger samples and a randomized controlled design are needed. Also, the lack of follow-up data limits the power of our results, and future studies are needed that include a follow-up assessment in order to clarify the long-term effects of the intervention.

In spite of the mentioned limitations, the present study represents a first approach to developing a psychotherapeutic intervention specifically designed for targeting significant guilt feelings in caregivers. The obtained results, although preliminary,

suggest that the intervention has the potential to clinically reduce guilt levels as well as related distress constructs such as depression or anxiety in caregivers showing baseline clinical scores on these measures.

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Figure 1. Flowchart of the study.