Universidad Rey Juan Carlos

TESIS DOCTORAL

Cognitive fusion and mental health in caregivers of people with dementia.

Cross-sectional, longitudinal and intervention data

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Programa de Doctorado en Ciencias de la Salud

Escuela Internacional de Doctorado

2022

Agradecimientos

"Yo no cuido a mi mujer: yo la amo; y lo haré siempre, aunque ella ya no sepa el significado de la palabra amor" Anónimo.

Una vez aprendí que las cosas importantes hay que decirlas muchas veces. Por tanto, espero que esta Tesis Doctoral, junto con todos los trabajos que se desarrollan en este ámbito, sirva para visibilizar lo que implica cuidar de un familiar, mayoritariamente querido, con demencia. Me siento tremendamente agradecida de haber conocido personalmente a tantas personas cuidadoras y de haber aprendido tanto de sus tan valiosas experiencias. De todos ellos he aprendido lo que significa e implica cuidar; y ahora me toca a mí reflexionar y dar las gracias a todas las personas que han formado parte de este proyecto y me han atendido y cuidado a lo largo de todo este proceso.

En primer lugar, quiero mostrar mi más sincero agradecimiento a mis directores de tesis: Andrés Losada y Rosa Romero. Ellos fueron quienes visualizaron en mí esta trayectoria y me acompañaron desde el principio y hasta el final de este camino. Muchas gracias, Andrés, por haberme dado tan buena formación, por inculcarme la importancia del trabajo en equipo, por haber creído en mí desde el principio y seguir haciéndolo a día de hoy. Gracias también por saber escucharme y estar disponible casi en cualquier momento. Rosa, gracias por mostrarme el camino del Mindfulness y por transmitirme la motivación que tienes hacia la investigación. Gracias también por escucharme con los ojos bien abiertos cuando debatimos, por apoyarme en cada decisión, por entender en ocasiones mis vaivenes y en definitiva, por cuidarme de la mejor forma. Gracias a los dos por las innumerables horas que hemos pasado en frente del ordenador, por vuestra paciencia, por haberme enseñado lo que implica investigar y todos sus caminos posibles. Espero que algún día mis alumnos me aprecien de la misma forma que yo a vosotros.

Quisiera dar las gracias también al resto de personas del equipo cuidemos: personas fundamentales que han formado parte de este camino, sin las que nada de esto hubiera sido posible. Si existiese la figura de "mentor" sería, sin duda alguna, para Carlos Vara, la persona con la paciencia más infinita que he conocido jamás. Gracias por no perder nunca los nervios ante mis miles de preguntas y responder siempre de forma amable después de un: "Claro, Sam, dime". Gracias también por saber escuchar mi lenguaje, no solo verbal, y apoyarme de la mejor manera en esos momentos. Quisiera dar las gracias también a María Pedroso, con quien empecé todo esto, por su cariño y su acompañamiento durante todos estos años. También quisiera agradecer a mis compañeras Lucía Jiménez y Cristina Huertas, por su trabajo y esfuerzo constante. Gracias también a Laura Gallego-Alberto, a María Márquez, Isabel Cabrera y José Pires, ya que sin su ayuda y trabajo grupal, nada de esto hubiera sido posible. Agradecer también al Doctor Javier Olazarán, por su constante colaboración en el proyecto, y por interés y disposición en cada trabajo que le enviaba. Por otro lado, me siento tremendamente agradecida hacia el profesor Ricardo Olmos, por su infinita paciencia y por trabajar mano a mano conmigo, siempre con un tono cálido y amable durante las eternas revisiones del segundo artículo de esta tesis.

Y aunque no son del equipo cuidemos, quisiera agradecer también a mis compañeros del Departamento de Psicología, puesto que muchos de ellos han sido mis profesores del Grado y Máster y hacia quienes solo siento una tremenda admiración. Agradecer también a los más jóvenes: Lorena, David, Borja, Roberto y Alberto, ya que son la alegría de este Departamento; y a Celia Nogales, por cobrar tanta importancia al final de este camino, entenderme tan bien y ser ejemplo a seguir en esta trayectoria.

I am also thankful to Gill Livingston for letting me stay with her and with her amazing research team for three months in London. Thank you for your incredible help in the last study of this thesis and for teaching me other ways to research.

Por otro lado, mi eterno agradecimiento al Ministerio de Universidades por la Ayuda para la Formación de Profesorado Universitario (FPU) concedida para poder iniciarme y proseguir en este camino de la investigación y la docencia en la Universidad Rey Juan Carlos, así como al Ministerio de Economía, Industria y Competitividad por la financiación de los proyectos (PSI2012-31239 y PSI2015-65152-C2-1-R) en los que se enmarca la presente tesis. Agradecer también al Hospital Gregorio Marañón, y a los centros de salud colaboradores por prestar sus espacios para el desarrollo de la labor investigadora.

Ahora quisiera dar las gracias a las personas que han formado parte de este proyecto y me han cuidado en el sentido más emocional de la palabra: a mi familia y amigos

. En primer lugar, quisiera dar las gracias a mis padres. El lenguaje y las palabras de agradecimiento no alcanzan a expresar todo lo que tengo dentro. Gracias por demostrarme cada día lo que significa querer y cuidar. Gracias por ser ejemplo en valores tan relevantes en mi vida, como la humildad, la bondad la perseverancia y el esfuerzo. Gracias por enseñarme e inculcarme tan a fondo que lo más importante de la vida, es vivirla. Gracias por respetar, entender y apoyar cada una de mis decisiones. No puedo estar más orgullosa de vosotros. Tampoco puedo estar más orgullosa de mis abuelos. Lo que soy se lo debo también a ellos. Gracias Yaya por ser la bondad hecha persona, cuidadora con mayúsculas de cada uno de nosotros y por ser ejemplo de coraje y valentía. Gracias Yayo por tus miradas llenas de orgullo y amor. Nunca nadie sabrá mirarme de la misma forma que tú. Os llevaré a los dos siempre en mi piel. Parte de lo que soy también se lo debo a mis tíos y primos. Sois la mejor familia que una puede tener. Gracias por mostrarme apoyo siempre y por ser reflejo de humildad y de vida valiosa.

También quiero dedicar unas líneas de agradecimiento a Manu, mi pareja, por haberme acompañado en los mejores y peores momentos a lo largo de estos dos años. Gracias por tener el valor del cuidado tan presente y por hacerlo con tanto cariño y amor. Muchas gracias por saber "defusionarme" en los momentos más críticos y por saber hacer que mire las cosas con la perspectiva que a veces no alcanzo a distinguir. Gracias por bajarme a la tierra cuando mi cabeza está en otras partes. Gracias por ser balsa en los peores oleajes y por llevar la Sierra de Gredos contigo. Muchas gracias por demostrarme tanto aprecio y cariño, por valorar tantas cosas de mí y por ofrecerme tantos momentos para el recuerdo.

También quiero darle las gracias a Sandra, mi compañera de vida. Gracias por conocerme tan bien, por ser brisa, inspiración y por tus innumerables muestras de cariño. Es precioso saber que siempre nos tendremos la una a la otra. Otra persona importantísima es Laura, de quien he aprendido y sigo aprendiendo cada día tanto. Gracias por tu eterna confianza en mí misma y por tus infinitos cuidados. Gracias también a Irene, una amiga de verdad que siempre está presente y dispuesta a escucharme de la mejor forma. Gracias también a mis amigas de la universidad, con quien empecé este camino, y a Laura Vela, por ser la alegría de la Calle Pericles y por saber dedicarme siempre las mejores palabras. Por último, quisiera dar las gracias a mis amigos de Fuenlabrada, a quienes debo también gran parte de lo que soy. Con vosotros he aprendido a disfrutar de la vida más simple y rica a la vez, ya que solo nos hace falta un banco y a veces, ni eso, para juntarnos y reír. Eso me lo llevo para siempre. Gracias por ser amigos de verdad, y por todas las noches de verano.

Por último, quisiera mostrar de nuevo mi más cálido agradecimiento a todas las personas cuidadoras que han participado en este proyecto de forma voluntaria. Espero que esta Tesis Doctoral, junto con todo el trabajo previo, sirva para visibilizar vuestras vidas. Gracias.

ÍNDICE

ÍNDICE DE TABLAS Y FIGURAS

2. Introducción General

4. Metodología General

5. Estudio Uno: Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feelings

6. Estudio Dos: Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers

7. Estudio Tres: Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values

8.Estudio Cuatro: Longitudinal effects of cognitive fusion in depressive, anxiety, and ambivalent symptoms of family caregivers of people with dementia

9. Estudio Cinco: Cognitive fusion and treatment response to depression in caregivers of relatives with dementia

1. Resumen General

El cuidado familiar de una persona con demencia se asocia a consecuencias psicológicas negativas (p.ej., Collins y Kishita 2020). La investigación sobre el cuidado se centra, principalmente, en el estudio de la depresión en cuidadores, siendo menos frecuente el estudio acerca de la ansiedad (p. ej., Cooper et al., 2012), los sentimientos de ambivalencia y la sintomatología comórbida ansioso-depresiva, a pesar de que parecen ser síntomas frecuentes entre los cuidadores familiares de personas con demencia.

La fusión cognitiva, que se define como la tendencia a creer el contenido literal de los pensamientos, es una variable transdiagnóstica, puesto que se relaciona con diferentes consecuencias psicológicas negativas en población clínica y subclínica (Hayes et al., 2011). Las personas con niveles elevados de fusión cognitiva actúan como si sus pensamientos fueran literalmente ciertos, siendo difícil distanciarse de ellos, viéndose su conducta regulada por el contenido de estos. Los escasos estudios llevados a cabo para analizar la relación entre esta variable y el malestar psicológico en cuidadores de personas con demencia han mostrado su relación positiva (Romero-Moreno et al., 2014). Sin embargo, ningún estudio hasta la fecha ha analizado la relación entre fusión cognitiva y los sentimientos de ambivalencia y la sintomatología comórbida ansioso-depresiva de los cuidadores de forma transversal ni longitudinal, y tampoco se ha estudiado el rol moderador de esta variable en la repuesta a distintas terapias psicológicas dirigidas a cuidadores. Asimismo, la investigación en el cuidado es escasa en analizar potenciales mecanismos explicativos o posibles vías sobre por qué la fusión cognitiva se asocia con mayor malestar emocional, sin existir ningún estudio que haya analizado el papel de la satisfacción con los valores personales en dicha relación.

Tomando como referencia el modelo de estrés sociocultural y afrontamiento adaptado al cuidado (Knight & Sayegh, 2010), la presente Tesis Doctoral tuvo como objetivo ampliar el conocimiento acerca de la fusión cognitiva y su relación con el malestar psicológico de los cuidadores a través de estudios con distintos diseños y metodologías. Para este fin, se han realizado cinco estudios. Aunque cada estudio se presenta de forma independiente se ha realizado una introducción general para describir el marco teórico y empírico sobre la cual se asienta la presente tesis. Tras esta introducción se describe el objetivo principal de esta tesis así como los objetivos específicos e hipótesis de cada estudio. También se presenta un apartado describiendo la metodología general y, a continuación, se presenta cada estudio con sus propios apartados: Introducción, Método, Resultados, Discusión y Referencias. Tras esto, se presenta la discusión final donde se consideran de forma global los principales resultados e implicaciones derivadas de esta investigación. Para concluir, se describen las conclusiones generales de la presente Tesis Doctoral.

El objetivo principal del primer estudio fue analizar la relación entre estresores (frecuencia y reacción a comportamientos problemáticos), fusión cognitiva y ambivalencia en cuidadores, y analizar si actuaba como variable mediadora en la relación entre estrés y ambivalencia. La muestra de este estudio estuvo compuesta por 364 cuidadores familiares de personas con demencia. Los resultados sugieren que existe una relación significativa y positiva entre la reacción a los comportamientos problemáticos del familiar y los sentimientos de ambivalencia de los cuidadores aunque parece estar mediada por la fusión cognitiva. El modelo final explica el 37% de la varianza de la ambivalencia y muestra un ajuste excelente a los datos, lo que parece demostrar que la fusión cognitiva y la reacción a comportamientos disruptivos pueden ser variables relevantes en la explicación de los sentimientos de ambivalencia de los cuidadores.

El segundo estudio tuvo como objetivo principal analizar las diferencias existentes entre cuidadores con diferentes perfiles de sintomatología (comórbido, ansioso, depresivo o subclínico) en variables sociodemográficas, estresoras y en fusión cognitiva. La muestra de este estudio estuvo compuesta por un total de 553 cuidadores familiares de personas con demencia. Los cuidadores se agruparon en cuatro grupos o perfiles en función de la sintomatología que presentaban: 1) comórbido (altos niveles de sintomatología depresiva y altos niveles de sintomatología ansiosa) (n = 303, 54.8%); 2) depresivo (altos niveles de sintomatología depresiva y bajos niveles de sintomatología ansiosa) (n = 40, 7.2%); 3) ansiosos (bajos niveles de sintomatología depresiva y altos niveles de sintomatología ansiosa) (n = 86, 15.6%); 4) subclínico (bajos niveles de sintomatología depresiva y bajos niveles de sintomatología ansiosa) (n = 124, 22.4%). Los resultados sugieren que la probabilidad de presentar un perfil comórbido en relación con el subclínico fue mayor en las mujeres cuidadoras. Además, los resultados mostraron que mayor frecuencia de conductas disruptivas del enfermo era un factor de riesgo para presentar un perfil comórbido en relación con los otros tres perfiles (ansiedad, depresión, y subclínica). Asimismo se encontró que mayores puntuaciones en fusión cognitiva fueron un factor de riesgo de comorbilidad en relación con los otros perfiles. Los hallazgos sugieren que la probabilidad de presentar sintomatología comórbida es mayor para las mujeres cuidadoras y para aquellos que informan de niveles más altos de fusión cognitiva y una mayor frecuencia de problemas disruptivos por parte del familiar cuidado. De este estudio, por ende, se derivan unas características que pueden describir un perfil vulnerable de los cuidadores familiares de demencia.

En el tercer estudio de la presente tesis se analiza un posible mecanismo mediante el cual la fusión cognitiva se relaciona con la sintomatología depresiva y ansiosa en los cuidadores. Específicamente se analiza el papel de la satisfacción con el valor del cuidado y otros valores personales (por ejemplo, el crecimiento personal) en la relación entre la fusión cognitiva y el malestar psicológico de los cuidadores. La muestra de este estudio estuvo formada por 287 cuidadores familiares de personas con demencia. Se analizó el efecto indirecto de la fusión cognitiva sobre el malestar psicológico de los cuidadores a través de la satisfacción de los cuidadores con el valor del cuidado y con otros valores personales a través de cuatro modelos de regresión jerárquica. Los resultados mostraron un efecto indirecto de la fusión cognitiva sobre los síntomas depresivos y de ansiedad solo a través de la satisfacción con otros valores personales. Aquellos que informaron de mayor fusión cognitiva informaron a su vez, menor satisfacción con otros valores personales, y esta asociación se relacionó con mayores niveles de síntomas depresivos y de ansiedad. De este estudio se deriva que la fusión cognitiva podría ser una variable que interfiere en la obtención de satisfacción a partir de los valores personales, lo que aumenta el malestar de los cuidadores.

Tras los datos obtenidos en los estudios anteriores, el objetivo principal del cuarto estudio fue analizar el efecto longitudinal de la fusión cognitiva en la sintomatología depresiva, ansiosa y en los sentimientos de ambivalencia de los cuidadores, tras controlar el efecto de variables sociodemográficas, estresoras y cese del cuidado. Se trata de un diseño longitudinal, donde se realizaron tres evaluaciones en dos años (línea base, 12 meses y 24 meses después de la línea base). La muestra de este estudio estuvo formada por 176 cuidadores familiares de demencia. Se utilizaron análisis de modelos mixtos lineales para analizar las relaciones entre las variables. Los resultados sugieren que los aumentos en la fusión cognitiva a lo largo del tiempo predijeron incrementos en los sentimientos depresivos, ansiosos y ambivalentes de los cuidadores. La reacción por parte de los cuidadores ante los problemas disruptivos del enfermo predijo significativamente aumentos en la ansiedad y los síntomas ambivalentes a lo largo del tiempo. Los resultados sugieren que la fusión cognitiva podría constituir un mecanismo disfuncional central involucrado en los síntomas depresivos, de ansiedad y de ambivalencia. De este estudio se deriva que las estrategias psicológicas dirigidas a reducir la fusión cognitiva y los niveles de estrés podrían ser especialmente útiles para reducir el malestar emocional de los cuidadores.

Por otro lado, el objetivo del quinto y último estudio de la presente tesis fue analizar si los niveles basales de fusión cognitiva predecían diferentes respuestas al tratamiento de los síntomas depresivos, comparando la Terapia de Aceptación y Compromiso (ACT), la Terapia Cognitiva y Conductual (TCC) y un grupo control. Participaron en el estudio un total de 130 cuidadores familiares: intervención ACT (N= 49), intervención TCC (N= 41) y grupo control (N= 40). Se realizaron análisis de moderación. Los resultados mostraron un efecto significativo de la interacción entre los niveles basales de fusión cognitiva y la condición de tratamiento ($p < 0,05$) sobre los síntomas depresivos. Específicamente, los cuidadores en la condición de TCC presentaron un mayor cambio en los síntomas depresivos que los del grupo control cuando sus niveles basales de fusión cognitiva eran bajos, medios y altos. Los participantes en la condición ACT mostraron un mayor cambio en los síntomas depresivos que los participantes en el grupo de control cuando sus niveles iniciales de fusión cognitiva eran medios y altos. Finalmente, los hallazgos sugieren que los cuidadores en la condición ACT mostraron un mayor cambio en los síntomas depresivos que aquellos en la condición CBT cuando sus niveles iniciales de fusión cognitiva eran altos. Estos resultados parecen respaldar el uso de la fusión cognitiva como herramienta de cribado para la asignación de intervenciones en la práctica clínica con cuidadores de personas con demencia.

1. General Abstract

Caring for a relative with dementia is associated with negative psychological consequences (e.g., Collins and Kishita 2020). The available research has focused mainly in the study of depression in caregivers, with less available studies focused on anxiety (e.g., Cooper et al., 2012), feelings of ambivalence, and comorbid depressive and anxious symptomatology, despite the fact that they seem to be frequent symptoms among family caregivers of people with dementia.

Cognitive fusion, which is defined as the tendency to believe the literal content of thoughts, is a transdiagnostic variable, since it is related to different negative psychological consequences in the clinical and subclinical population (Hayes et al., 2011). People with high levels of cognitive fusion behave as if their thoughts were literally true, making it difficult to distance themselves from them, seeing their behavior regulated by their content. The few studies carried out to analyze the relationship between this variable and psychological distress in caregivers have suggested that cognitive fusion is an important variable for understanding caregivers' distress (Romero-Moreno et al., 2014). However, to date, no study has analyzed the relationship between cognitive fusion and feelings of ambivalence and comorbid symptomatology in family caregivers in cross-sectional or longitudinal studies, and no study has analyzed the moderating role of this variable in the effects of different psychological therapies developed for targeting caregivers' distress. Likewise, research in care is scarce in analyzing potential explanatory mechanisms or possible pathways as to why cognitive fusion is associated with greater emotional distress, without any study analyzing the role of satisfaction with personal values in the relationship between cognitive fusion and caregivers' psychological distress.

Drawing upon the stress and coping adapted to care (Knight & Sayegh, 2010), this Doctoral Thesis aimed to expand knowledge about cognitive fusion as a transdiagnostic variable, and its relationship with family caregivers' psychological distress through different designs and methodologies. Specifically, five studies have been conducted. Although each study is presented independently with its own introduction, a general introduction has been made to describe the theoretical and empirical framework on which this thesis is based. After this introduction, the main objective of the thesis is described. A general methodology is also presented and then each study is described with its own sections: Introduction, Method, Results, Discussion and References. Finally, a general discussion is presented, and the main results and implications are considered globally. To conclude, the general conclusions of this Doctoral Thesis are described.

The main objective of the first study was to analyze the relationship between stressors (frequency and reaction to problem behaviors associated with the dementias), cognitive fusion and ambivalence in caregivers, and to analyze whether cognitive fusion acted as a mediating variable in the relationship between stress and ambivalence. The sample of this study was composed of 364 family caregivers of people with dementia. The results suggested that there is a significant and positive relationship between reaction to the problematic behaviors of the relative and caregivers' feelings of ambivalence, although it seems to be mediated by cognitive fusion. The final model explains 37% of the variance of ambivalence and shows an excellent fit to the data, which suggest that cognitive fusion and reaction to disruptive behaviors may be relevant in explaining caregivers' feelings of ambivalence.

The main objective of the second study was to analyze the differences between caregivers with different symptom profiles (depressive and/or anxious and subclinical symptoms) in sociodemographic, stressor and cognitive fusion variables. The sample of this study was composed of a total of 553 family caregivers of people with dementia. They were grouped into four groups or profiles according to the symptoms they presented: 1) comorbid (high levels of depressive symptomatology and high levels of anxious symptomatology) (n = 303, 54.8%); 2) depressive (high levels of depressive symptoms and low levels of anxious symptoms) (n = 40, 7.2%); 3) anxious (low levels of depressive symptomatology and high levels of anxious symptomatology) (n = 86, 15.6%); 4) subclinical (low levels of depressive symptomatology and low levels of anxious symptomatology) (n = 124, 22.4%). The results suggested that the probability of presenting a comorbid profile in relation to the subclinical profile was higher for female caregivers. In addition, a higher frequency of disruptive behaviors and higher cognitive fusion scores were risk factors for comorbidity in relation to the other profiles (anxiety, depression, and subclinical). The findings suggested that the probability of presenting comorbid symptomatology is higher for female caregivers and those who report higher levels of cognitive fusion and a higher frequency of disruptive problems on the part of the family member. Therefore, from this study, some characteristics are derived that can describe a vulnerable profile of family caregivers with dementia.

In the third study, a possible mechanism by which cognitive fusion is related to depressive and anxious symptoms in caregivers was analyzed. Specifically, the role of satisfaction with the caregiving value and with other personal values (for example, personal growth) in the relationship between cognitive fusion and caregivers' psychological distress was analyzed. The sample of this study consisted of 287 family caregivers of people with dementia. The indirect effect of cognitive fusion on caregivers' psychological distress was analyzed through caregivers' satisfaction with the caregiving value and with other personal values through four hierarchical regression models. The results showed an indirect effect of cognitive fusion on depressive and anxiety symptoms only through satisfaction with other personal values. Those family caregivers who reported higher cognitive fusion reported lower satisfaction with other personal values, and this association was related to higher levels of depressive and anxiety symptoms. It is concluded that cognitive fusion seems to be a variable that interferes in obtaining satisfaction from personal values, which increases caregivers' depressive and anxious symptoms.

Following the main results data obtained in previous studies, the main aim of the fourth study was to analyze the longitudinal effect of cognitive fusion in depressive, anxious and ambivalent caregivers’ symptoms, after controlling for the effect of sociodemographic and stressor variables. It has a longitudinal design, where three evaluations were carried out in two years. The sample of this study consisted of 176 family caregivers with dementia. Linear mixed model analyzes were used to analyze relationships between variables. The results suggested that increases in cognitive fusion over time predicted caregivers' depressive, anxious, and ambivalent symptoms. Caregivers' reaction to the care-recipients’ disruptive behaviors significantly predicted increases in anxiety and ambivalent symptoms over time. The results suggested that cognitive fusion may constitute a central maladaptive mechanism involved in depressive, anxious and ambivalence symptoms.

Finally, the objective of the fifth and last study of this doctoral thesis was to analyze whether baseline levels of cognitive fusion predicted different responses to treatment of depressive symptoms, comparing and Acceptance and Commitment Therapy (ACT) with a Cognitive and Behavioral Therapy (CBT) and a control group. A total of 130 family caregivers participated in the study: ACT intervention (N= 49), CBT intervention (N= 41) and control group (N= 40). Moderation analyzes were performed. The results showed a significant effect of the interaction between baseline levels of cognitive fusion and the treatment condition ($p < 0.05$) on depressive symptoms. Specifically, caregivers in the CBT condition had a greater change in depressive symptoms than those in the control group when their baseline levels of cognitive fusion were low, medium, and high. Participants in the ACT condition showed greater change in depressive symptoms than participants in the control group when their initial levels of cognitive fusion were medium and high. Finally, the findings suggested that caregivers in the ACT condition showed greater change in depressive symptoms than those in the CBT condition when their baseline levels of cognitive fusion were high. These results seem to support the use of cognitive fusion as a screening tool for the allocation of dementia family caregivers to different interventions.

2. Introducción General

2.1 El gran reto del siglo XXI: Envejecimiento poblacional y aumento de las demencias

El abordaje de las demencias es uno de los principales desafíos mundiales para la atención sociosanitaria del siglo XXI. Se trata de una gran pandemia silenciosa que, dada su dimensión y alcance socioeconómico, se ha convertido en una prioridad de salud pública y supone un gran reto en la sostenibilidad de cualquier sistema sociosanitario (Livingston et al., 2020).

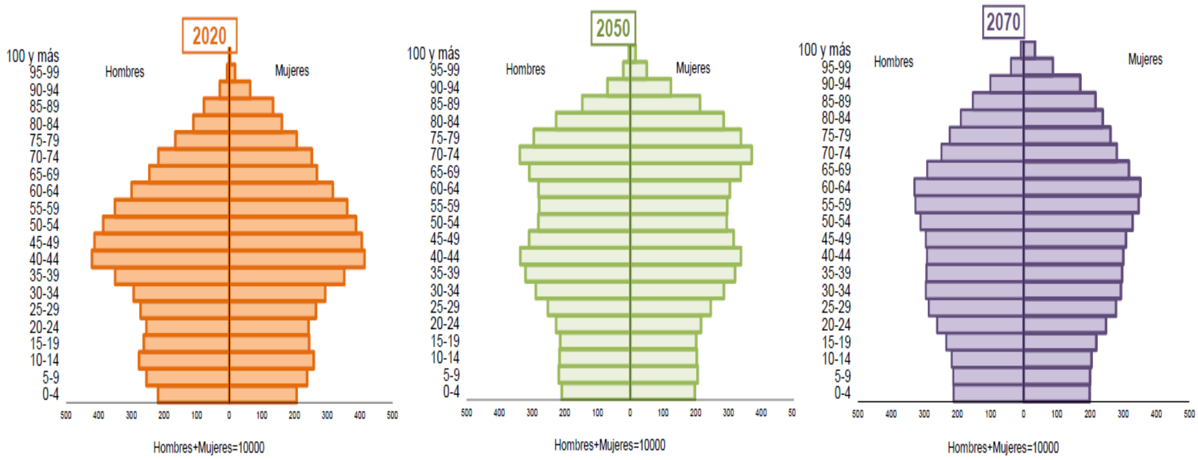
El término “demencias”, según la Organización Mundial de la Salud (OMS, 2015), engloba aquellas enfermedades progresivas y neurodegenerativas que afectan a la memoria o a otras capacidades cognitivas y al comportamiento, y que interfieren de manera notable en la capacidad de la persona para llevar a cabo actividades de la vida diaria. Este término abarca diferentes tipos de afecciones, como la enfermedad de Parkinson, la demencia por cuerpos de Lewy, la demencia vascular, la demencia frontotemporal, así como la enfermedad de Alzheimer (EA), que se trata de la forma más frecuente de demencia, ya que representa entre un 60 y 70 % de los casos (Alzheimer's Association, 2019). Cabe destacar que los límites entre los distintos tipos de demencia son difusos y puede ocurrir que se desarrollen afecciones mixtas, es decir, que coexistan distintos tipos de demencia.

Las demencias y, en concreto, la enfermedad de Alzheimer, son una de las principales causas de discapacidad y dependencia, y se asocian a graves y progresivos déficits tanto cognitivos, como comportamentales, que afectan a la autonomía para desempeñar actividades básicas e instrumentales de la vida diaria de la persona. Conllevan la pérdida de la independencia que la persona tenía en el funcionamiento normal en los contextos personal, laboral, social y familiar (Livingston et al., 2020). Este tipo de afecciones tienen lugar en términos generales en personas mayores, por lo que el incremento en la prevalencia mundial de las demencias es impulsado por el aumento, también mundial, en la esperanza de vida, resultante de distintos factores, entre los que se encuentran la reducción de las personas que fallecen de forma prematura (Livingston et al., 2020).

Según la OMS (2017), en el año 2015 había alrededor de 47 millones de personas afectadas de la enfermedad de Alzheimer u otras demencias en el todo el mundo, lo que suponía el 5% de la población mundial de edad avanzada. Según dicho informe, esta cifra tenderá prácticamente a duplicarse cada 20 años, puesto que se prevé que para el año 2030 aumente a 66 millones de personas y a 115 millones para el año 2050. Gran parte de este aumento tendrá lugar en países de ingresos bajos y medios. En el año 2015, el 58% de la población con la enfermedad de Alzheimer vivía en estos países, previéndose que alcance el 63% en 2030 y el 68% en el año 2050.

Según el Instituto Nacional de Estadística (INE; 2020) las proyecciones de población española subrayan también el proceso de envejecimiento poblacional. Para el año 2050 la población entre 20 y 64 años, que actualmente supone el 60,8% del total, pasaría a representar el 51,9% del total en 2050. El grupo de edad más numeroso, aquellas personas de entre 40 y 49 años, nacidos entre 1970 y 1979, en la actualidad, lo seguiría siendo en 2050, con edades entre 70 y 79 años. Se espera que, para el año 2050, el porcentaje de población de 65 años y más, que actualmente se sitúa en el 19,6% del total de la población, alcance un máximo del 31,4% y, a partir de ahí, comience a disminuir. Estos datos se reflejan en un cambio en la proyección de población actual comparada con la esperada para los años 2050 y 2070, tal y como se muestra la Figura 2.1.

Figura 2.1. Proyecciones de población de España (años 2020, 2050 y 2070). Extraído del INE, 2020.



La demencia no sólo afecta al individuo que la padece, que de forma progresiva pierde habilidades y cada vez le cuesta más desenvolverse en su día a día, sino también a los familiares y personas allegadas a la persona enferma, ya que, por un lado, tienen que afrontar ver a su persona querida enfermar y, por otro lado, tienen que atender y responder a sus necesidades, ligadas en gran medida, a cambios comportamentales en la persona enferma. La sociedad en general también sufre las consecuencias de este tipo de enfermedades, ya que las personas requieren atención sociosanitaria y su atención tiene un gran impacto en la economía general de la sociedad. Según la OMS (2017) el coste global de la demencia en 2015 fue de 818 mil millones de dólares, cifra que se prevé que aumente conforme aumente también el número de personas con demencia. Esta situación tendrá un fuerte impacto en el desarrollo social y económico mundial al desbordar los servicios de atención social y sanitaria (INE, 2020).

Las demencias llevan asociadas grandes consecuencias, no sólo para los pacientes, sino también para sus familiares, que en muchas ocasiones adquieren el rol de personas cuidadoras. Según el Ministerio de Sanidad, Consumo y Bienestar Social

(2019), la familia ejerce un papel primordial en la provisión de cuidados a la persona con la enfermedad. Tan sólo un 15% de los costes relacionados con la enfermedad de Alzheimer son cubiertos por los sistemas sanitarios y sociales, y es la familia quien asume el 85% restante (OMS, 2017). Además de las consecuencias en la salud física y psicológica de los cuidadores, que se analizarán en mayor medida más adelante, la familia y, en concreto, la persona que ejerce las tareas de cuidadora principal sufre muy a menudo sobrecarga y distintas esferas de su vida (personal, social y laboral) se ven gravemente desestructuradas. Además, el hecho de que la conciliación laboral y el cuidado al familiar sea complicada, hace que muchas personas se vean en la obligación de realizar ajustes, como la reducción en los horarios de trabajo o incluso el cese de este. Esto, a su vez, conlleva graves consecuencias: por un lado, la reducción en la capacidad económica familiar, y por otro, la dificultad de la reincorporación al mercado laboral tras el cese del cuidado (Ministerio de Sanidad, Consumo y Bienestar Social, 2019).

2.2 El cuidado familiar de una persona con demencia

La Real Academia de la lengua Española (RAE) define el cuidado como la “acción de cuidar, asistir, guardar, conservar”. El proceso del cuidado hace referencia a la atención ofrecida ante las necesidades del otro, proveyendo de los servicios que el otro necesite para la conservación de sus condiciones físicas, psíquicas y sociales (García, 2010). Aspectos asociados al concepto de cuidado son los componentes de eficacia y eficiencia, puesto que para su ejecución requiere un mínimo de diligencia, así como el de responsabilidad social ante la persona cuidada, uno mismo, la familia y la comunidad. El cuidado que ofrecen los familiares o amigos a personas con dificultades para realizar alguna actividad de autocuidado es una práctica social extendida, resaltando así la importancia del componente social en la salud (García, 2010).

En España, a pesar de la existencia de iniciativas para la atención a personas con dependencia, (p. ej., la Ley 39/2006 de Promoción de la Autonomía Personal), los recursos formales disponibles para atender este problema social continúan siendo insuficientes. El cuidado no formal, ofrecido en su mayoría por los familiares, es el mecanismo principal de atención a la dependencia, muy por encima del cuidado formal, ofrecido por el Estado (Abellán et al., 2017). Según García (2010), una definición que reúne todos los componentes del cuidado informal sería la siguiente: "el cuidado informal está formado por aquellas actividades de ayuda que van dirigidas a personas con algún grado de dependencia, que son provistas por personas de su red social y en las que no existe entidad intermediaria o relación contractual" (p.39). Esta forma de cuidado también es la predominante en otros países. Según el informe mundial sobre la enfermedad de Alzheimer (2015), llevado a cabo por la Alzheimer's Disease International (ADI) (2015), el cuidado informal familiar, no remunerado, que proporciona toda la atención requerida por sus familiares a nivel físico, psicológico y social, es la forma de atención más frecuente en los países europeos de ingresos bajos y medios, frente al cuidado formal, es decir, remunerado (por ej., asistencia en el hogar).

Dado el aumento de las demandas, por un lado, y el cambio en las estrategias de las familias en la atención de sus miembros con dependencia, por otro, existe en la actualidad una creciente preocupación en lo que respecta al sistema de provisión de cuidados (por ej., Livingston et al., 2020). Este cambio o transformación en el núcleo familiar es debido, entre otros motivos, a la evolución demográfica, el descenso en la tasa de natalidad y fecundidad, la incorporación de la mujer al mercado laboral y la participación, todavía muy poco generalizada, de los hombres en la tarea del cuidado (por ej., ADI, 2015). Ante la necesidad de atender y promover el bienestar de población afectada de demencia y sus cuidadores (Confederación Española de Alzheimer, 2017), el

Ministerio de Sanidad, Consumo y Bienestar Social (2019) ha lanzado el Plan Integral de Alzheimer y otras Demencias 2019–2023. El objetivo principal de este plan es mejorar la consideración de la sociedad hacia el papel de los familiares cuidadores de las personas con demencia, así como prevenir situaciones de sobrecarga y estrés en el cuidador mediante servicios, apoyos y prestaciones que eviten su claudicación y permitan mantener al paciente durante el mayor tiempo posible en du medio natural.

Los cuidadores familiares presentan distintos perfiles, pudiendo ser cuidador o cuidadora principal (primario) o secundario (que ofrece ayuda complementaria). Por otro lado, en función del parentesco, pueden ser cónyuges o hijos, principalmente, así como nueras o nueros u otros familiares o allegados. Los cuidadores pueden prestar ayuda de manera directa o indirecta, por ejemplo, en la organización de la atención suministrada por otros y, por otro lado, pueden vivir en el mismo domicilio que la persona enferma o dedicarse a la tarea del cuidado de manera ocasional o rutinaria (OMS, 2013). Según Abellán et al. (2017), el perfil prototípico de cuidador familiar en España es el de una mujer (76%). A pesar de que existen hombres que asumen el rol de cuidador principal (24%), es evidente que el cuidado se describe en género femenino. En cuanto al parentesco, el grupo más presente es el de las hijas, seguidas de las esposas, y, en un menor número, las nueras. Se deduce que en muchos casos estas personas combinan su rol de cuidadoras con su rol laboral, así como con la atención a la familia. Por otro lado, según Abellán et al. (2017), un tercio de los cuidadores atienden a sus familiares de forma continua durante todo el día (el 32% señalaba una dedicación de 24 horas al día), siendo las personas con demencia y grandes dependientes (grado III en la terminología de la Ley de Dependencia) quienes requieren mayor número de horas de cuidado.

De forma general, los cuidadores familiares de personas con demencia están sometidos a altas demandas, supervisión y realización de tareas asociadas al cuidado, durante un tiempo prolongado, normalmente de años y durante un elevado número de horas diarias (Alzheimer's Association, 2019). Los cuidadores familiares de personas con demencia pueden verse sometidos a un fuerte impacto emocional derivado de presenciar el deterioro de su familiar, así como de las altas demandas también derivadas de la sintomatología comportamental y afectiva de la persona con demencia. Es por ello que, debido a la naturaleza tan demandante que supone cuidar a un familiar con demencia, así como debido a la presencia de otros estresores en la situación (p. ej. falta de conciliación familiar y laboral), existe un amplio consenso en la literatura científica a la hora considerar el cuidado familiar de personas con demencia como una situación de estrés crónico (Knight y Sayegh, 2010), que se asocia con consecuencias negativas sobre la salud psicológica y física de los cuidadores (Mausbach et al, 2013; Vitaliano et al., 2004) que incluso pueden alargarse tras el cese del cuidado (Robinson-Whelen et al., 2001).

2.3. Modelo de estrés y afrontamiento adaptado al cuidado

El marco teórico que mayor respaldo empírico ha recibido es el modelo de estrés y afrontamiento propuesto por Lazarus y Folkman (1984) adaptado al cuidado (Knight y Sayegh, 2010). Este modelo, basado en la revisión del modelo sociocultural de estrés y afrontamiento adaptado al cuidado de Aranda y Knight (1997), intenta dar respuesta al hecho de que exista tanta heterogeneidad en el impacto que tienen las similares demandas y estresores a los que se enfrentan los cuidadores en sus consecuencias emocionales y físicas.

Dentro de este enfoque, el estrés no es simplemente una fuerza externa que de forma automática genera efectos negativos en todas las personas que lo experimentan, sino que surge de una relación o transacción entre el individuo y su entorno o contexto. En este modelo se postula que el impacto que tienen las situaciones difíciles y demandas (estresores) a las que se enfrentan los cuidadores en su salud física y emocional depende de otras variables moduladoras que pueden amortiguar o, por el contrario, acentuar este impacto. Por tanto, este modelo cuenta con distintas dimensiones. Además de las variables sociodemográficas y/o contextuales (p. ej., género, edad), se encuentran las variables estresoras derivadas del proceso del cuidado, (p. ej., frecuencia de comportamientos problemáticos de la persona cuidada); por otro lado, las consecuencias o malestar a nivel psicológico o físico y las variables denominadas moduladoras, incluidas las evaluaciones cognitivas, las respuestas de afrontamiento y el apoyo social, que se tratan de factores importantes para predecir el impacto del estrés en las consecuencias.

Por todo ello, de acuerdo con el modelo de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), es importante, por claridad conceptual, evaluar de forma independiente todas las dimensiones de este, los estresores, las variables moduladoras y las diversas consecuencias derivadas de cuidar, ya que son las relaciones que se establecen entre estas variables las que permiten explicar las diferencias que existen entorno a la experiencia del cuidado. A continuación, se procede a explicar con mayor detalle cada dimensión del modelo en el que se enmarca la presente tesis doctoral.

2.3.1 Variables sociodemográficas y contextuales

En primer lugar, las variables sociodemográficas son aquellas características de cuidadores y personas cuidadas que pueden influir de manera relevante en la experiencia del cuidado. Existe cierto consenso en la literatura al considerar la edad, el sexo y la relación de parentesco como características sociodemográficas relevantes a tener en cuenta en la investigación sobre la experiencia del cuidado, así como el nivel educativo y socioeconómico y variables relacionadas con el contexto social, como la existencia o no de ayudas formales.

Si bien es cierto que existe cierta ambigüedad en los resultados científicos en cuanto a la influencia de la edad de los cuidadores puesto que, mientras que distintos estudios no encuentran relaciones significativas entre edad y malestar psicológico (p. ej., Smith et al., 2011), otros estudios señalan que son los cuidadores más jóvenes quienes se encuentran en una situación de mayor vulnerabilidad dado que existe mayor prevalencia de depresión y ansiedad en personas más jóvenes (Pinquart y Sörensen, 2007; Schulz et al.,2008). Esto pudiera deberse a las diversas tareas que, además del cuidado, llevan a cabo personas más jóvenes, llegando en algunos casos a atender demandas de atención o cuidado de la misma generación (cónyuges), de la generación anterior (padres) y de generaciones posteriores (hijos o nietos) (García, 2010). Sin embargo, cabe destacar que, en cuanto a consecuencias relacionadas con la salud física, la edad se asociaba de forma positiva con el riesgo cardiovascular (Mausbach et al. 2007).

Esta ambigüedad de resultados no la encontramos respecto a la variable sexo de los cuidadores. La investigación en este sentido parece consistente al afirmar que son las mujeres quienes, además de asumir con mayor frecuencia el rol de cuidadoras, son quienes más informan de consecuencias negativas derivadas de esta situación. Son numerosos los estudios que muestran que las mujeres informan de mayores niveles de malestar psicológico (ansiedad, depresión y estrés) que los hombres cuidadores (Collins & Kishita, 2019; Joling et al., 2015; Kaddour & Kishita, 2020). Recientemente, Losada et al. (2021) han señalado que las mujeres cuidadoras con altos niveles de obligaciones familiares presentaban menores niveles de autoeficacia. A su vez, las puntuaciones más altas en la dimensión obligaciones familiares se asociaron con menor autoeficacia para el autocuidado, obtención de descanso y frecuencia de ocio y con mayor sintomatología depresiva y ansiosa.

En cuanto a la relación de parentesco entre cuidador y persona cuidada, Pinquart y Sorensen, (2011), en un metaánalisis en el que se comparan las diferencias entre cuidar de la pareja, del padre o madre y del suegro o suegra, señalaron que los esposos y esposas difieren significativamente de los hijos e hijas y yernos y nueras en cuanto a las variables sociodemográficas. Suelen ser personas jubiladas, que conviven con la persona cuidada y que, por ende, suelen dedicar más tiempo al cuidado del familiar. Por otro lado, Losada et al. (2018) encontraron resultados que sugieren que cuidar de un padre o una madre se asociaba con mayores niveles de malestar psicológico, en concreto a mayores niveles de culpa. Romero-Moreno et al. (2014) encontraron que, sólo en hijas cuidadoras, los sentimientos de culpa moderaban el efecto de la relación entre la frecuencia de actividades de ocio y los sentimientos depresivos de los cuidadores. En línea con lo anterior, Huertas-Domingo et al. (2021) señalan que, en hijas cuidadoras, una mayor percepción de obligaciones familiares se asocia a mayor sensación de soledad dada la relación entre dichas obligaciones y pensamientos disfuncionales que se asocian a su vez con menor apoyo social y ocio.

Las variables nivel educativo y nivel socioeconómico son también relevantes puesto que bajos niveles en ambas variables se asocian con mayor malestar en los cuidadores (Brodaty y Donkin, 2009). En concreto, Butterworth et al. (2010) subrayan que un bajo nivel educativo predice mayores niveles de síntomas ansiosos y depresivos en cuidadores e incluso von Känel et al. (2008) afirman que el bajo nivel educativo en los cuidadores se asocia con un mayor riesgo cardiovascular. Además, no sólo el bajo nivel socioeconómico se asocia a mayor malestar, sino también la percepción de que los recursos no son adecuados para afrontar el cuidado del familiar (Sun et al., 2009).

Por último, en la revisión del modelo sociocultural de estrés y afrontamiento adaptado al cuidado de Aranda y Knight (1997), Knight y Sayegh (2010) ponen de relieve la importancia del estudio de variables culturales y contextuales como el familismo. El familismo se refiere a la presencia de sentimientos de lealtad, reciprocidad y solidaridad entre las personas de una misma familia (Losada et al., 2006). En población cuidadora esta variable se ha asociado en numerosos estudios y en distintas culturas, con un estilo de afrontamiento basado en la evitación y con peor salud física y mental en los cuidadores (Kim et al., 2007; Parveen et al., 2013, Rozario y DeRienzis, 2008; Sayegh & Knight, 2011). Recientemente, Losada et al. (2020), en un estudio en el que revisan la escala de familismo validada con población española, confirman la multidimensionalidad del constructo de familismo, sugiriendo una estructura de tres factores: “Interconexión familiar”, “Obligaciones familiares” y “Apoyo familiar extenso”. En un estudio anterior, los mismos autores apuntan a las diferencias entre las dimensiones del familismo, ya que parece que las obligaciones familiares se relacionan de forma positiva con los pensamientos disfuncionales y sintomatología depresiva en cuidadores, mientras que el hecho de percibir apoyo social por parte de la familia se asociaba a efectos positivos en el proceso del cuidado (Losada et al., 2010).

2.3.2. Variables estresoras

En esta dimensión se incluyen las distintas variables que, en el contexto de la situación de cuidado, pueden activar o suscitar una respuesta de estrés, como la frecuencia de los distintos síntomas neuropsiquiátricos y conductuales y psicológicos de las demencias (por ej., fallos de memoria, ánimo irascible, agitación). Dentro de esta dimensión también se incluirían el tiempo y horas diarias dedicadas al cuidado del familiar, así como el grado de deterioro funcional o nivel de dependencia de la persona cuidada.

Entre las variables estresoras más estudiadas en la literatura respecto al cuidado familiar se encuentran los síntomas conductuales y psicológicos asociados a la demencia (BPSD). La literatura es consistente al señalar la relación entre la frecuencia de este tipo de comportamientos y problemas emocionales en los cuidadores, como estrés o sobrecarga (Ornstein y Gaugler, 2012), depresión (Fauth y Gibbons, 2014; Nogales-González et al., 2015; Romero-Moreno et al., 2012) y ansiedad (García-Alberca et al., 2011; Romero-Moreno et al., 2011). Entre los BPSD, son los comportamientos disruptivos de la persona cuidada (por ej., agitación, agresión, desinhibición) los que se relacionan con mayor carga y depresión en los cuidadores (Cheng 2017; Fauth y Gibbons, 2014). Además de los comportamientos disruptivos, otros problemas de conducta asociados con la demencia, como los problemas de memoria y los problemas depresivos, suponen también una fuente de estrés en los cuidadores (Ornstein et al., 2013; von Känel et al., 2010).

Por otro lado, parece que invertir mayor tiempo al cuidado (tanto en horas como en tiempo cuidando) se asocia con mayor malestar psicológico y carga (Kim et al., 2019). Por último, Lara-Ruiz et al. (2019) señalaron la importancia de tener en cuenta además del tipo de diagnóstico, la fase o etapa de la enfermedad y/o de la dependencia funcional de la persona, que se refiere al grado de dependencia que la persona con demencia experimenta en actividades instrumentales (p.ej, comprar, hacer gestiones bancarias) y en actividades básicas de la vida diaria, como comer o vestirse. Los estudios a este respecto muestran que mayor deterioro de la persona con demencia en las actividades básicas, así como una menor capacidad cognitiva y funcional se asocia con mayores niveles de malestar psicológico mayor carga y depresión en los cuidadores (Lara-Ruiz et al., 2019; Molyneux et al., 2008).

2.3.3. Consecuencias psicológicas del cuidado de un familiar con demencia

Una de las principales razones por las que el cuidado familiar de personas con demencia ha suscitado un gran interés científico tiene que ver con las importantes consecuencias que esta situación tiene para la salud tanto física (p. ej., Vara-García et al., 2021; p. ej., Von-Känel et al.,2012), como emocional o psicológica de los cuidadores (p. ej., Collins y Kishita, 2019; p. ej., Kaddour y Kishita, 2020). Si bien las personas que cuidan pueden mencionar aspectos positivos asociados a esta tarea, (p. ej., Quinn y Toms, 2019) existe consenso en la literatura en cuanto a las consecuencias negativas asociadas al cuidado. Una de las variables más estudiada relacionada con el malestar emocional derivada del proceso del cuidado es la depresión o la sintomatología depresiva, debido, entre otros motivos, a su alta prevalencia y a las consecuencias negativas asociadas que presenta (p. ej., Collins y Kishita, 2019). En la investigación con cuidadores de personas con demencia se hace mayor hincapié en el estudio sobre la sintomatología depresiva, en lugar de sobre el trastorno de depresión mayor, y una de las medidas de autoinforme más utilizada en la investigación sobre cuidadores es la Escala de Depresión de Estudios Epidemiológicos (CES-D; Radloff, 1977) (Collins y Kishita, 2019). La literatura científica muestra que la prevalencia de sintomatología depresiva es mayor entre población cuidadora que no cuidadora (p. ej., Pinquart y Sörensen, 2003), y son los cuidadores de personas con demencia quienes presentan mayor probabilidad de padecer depresión en comparación con otros tipos de cuidadores (p.ej., cuidadores de personas con discapacidad; Kim y Schulz, 2008). Un reciente metaanálisis llevado a cabo por Collins y Kishita (2019) muestra que la prevalencia estimada ajustada de depresión entre cuidadores de personas con demencia fue de un 31.24%, lo que se traduce en que alrededor de un cuidador entre tres, sufre de depresión.

En cuanto a las consecuencias asociadas a la sintomatología depresiva cabe destacar que puede relacionarse con problemas en el funcionamiento diario y una peor salud física en los cuidadores (p.ej., Cucciare et al., 2010). En un estudio longitudinal llevado a cabo por Mausbach et al. (2007), se concluyó que este tipo de sintomatología predice de forma significativa un declive en la salud cardiovascular del cuidador. Por otro lado, Gallagher et al. (2011) demuestran que mayores niveles de sintomatología depresiva se relacionan con una mayor probabilidad de institucionalización de la persona cuidada. Además, un estudio llevado a cabo con más de 500 cuidadores reveló que aproximadamente el 16% de los mismos había contemplado el suicidio en más de una ocasión el año anterior (O'Dwyer et al., 2016). En un estudio longitudinal llevado a cabo por Joling et al. (2018), se demuestra también que la depresión es un factor de riesgo importante para la ideación suicida. Todo ello explica y justifica la necesidad de seguir investigando sobre este tipo de sintomatología, tan presente y devastadora en este tipo de población.

Por otro lado, también es frecuente que los cuidadores experimenten sintomatología ansiosa. Sin embargo, se trata de una variable que ha recibido menos atención en la literatura (Kaddour y Kishita, 2020). La investigación muestra que la prevalencia de sintomatología ansiosa es mayor en población cuidadora que en población no cuidadora. Un estudio de revisión mostró que la ansiedad clínicamente significativa afecta aproximadamente a una cuarta parte de los cuidadores de personas con demencia (Cooper et al., 2007). Más recientemente Kaddour y Kishita (2020) respaldan este dato e incluso lo incrementan a través de un meta-análisis en el que encuentran que la sintomatología ansiosa clínicamente relevante está presente en un 42.6% de los cuidadores, cifra realmente relevante teniendo en cuenta las consecuencias asociadas a este tipo de sintomatología. La literatura sugiere que la ansiedad en los adultos mayores se asocia con un mayor uso de los servicios de atención médica (p. ej., ingresos hospitalarios) y una mayor tasa de mortalidad (Schuurmans y van Balkom, 2011). Respecto a cuidadores, la ansiedad también tiene un impacto negativo sobre los mismos, afectando a su calidad de vida (Farina et al., 2017).

La sintomatología depresiva y ansiosa son, por tanto, consecuencias frecuentes e importantes derivadas del proceso del cuidado familiar de personas con demencia. Han sido variables ampliamente estudiadas, pero la mayor parte de la investigación se ha centrado en el estudio de la sintomatología depresiva o ansiosa en los cuidadores de forma independiente, por separado. Sin embargo, resulta muy escasa la literatura existente respecto al el estudio de la presencia simultánea de ambos tipos de sintomatología o comorbilidad, pese a la importancia de este fenómeno. Mahoney et al. (2005) ponen de manifiesto que es frecuente que aquellos cuidadores que presenten sintomatología depresiva experimenten también ansiedad comórbida. En un estudio longitudinal llevado a cabo por Joling et al. (2015) a lo largo de dos años, encontraron en una muestra de esposas y esposos cuidadoras, que el 32% de los participantes presentaba un cuadro de comorbilidad de depresión y ansiedad. Esta incidencia tan alta subraya la extrema vulnerabilidad de esta población.

Estudios llevados a cabo con otras poblaciones de cuidadores (por ejemplo, cuidadores de niños con enfermedades como cáncer o fibrosis) también informan de tasas similares y una alta prevalencia de comorbilidad de sintomatología depresiva y ansiosa (Driscoll et al., 2009; Quittner et al., 2014). Debido a que los estudios llevados a cabo con cuidadores de personas con demencia son escasos, desconocemos las repercusiones que la forma comórbida de depresión y ansiedad pueden acarrear pero, en población general, los estudios alertan de las graves consecuencias de este cuadro, como un mayor malestar y aumento de la discapacidad e incluso ideación suicida (p. e.j., Brown et al., 1996; Cairne et al., 2008; Norton et al., 2008). Además, tal y como se refleja en un estudio recientemente publicado (Romero-Moreno et al., 2021), la comorbilidad impide un beneficio máximo de la terapia psicológica, puesto que aquellos cuidadores que presentaban sintomatología depresiva y ansiosa comórbida en la línea base se beneficiaban en menor medida de dos programas de intervención psicológica, que aquellos cuidadores que presentaban únicamente sintomatología depresiva. Por todo ello, resulta muy importante avanzar en el estudio sobre este tipo de sintomatología comórbida en cuidadores.

Por último, una variable apenas estudiada en cuidadores pero que está cobrando cada vez mayor atención en la literatura es la ambivalencia (Losada et al., 2017), siendo frecuente que los cuidadores experimenten de forma simultánea emociones tanto negativas como positivas entorno a la experiencia del cuidado (Shim et al., 2012). La ambivalencia resulta un concepto útil en el estudio del cuidado de personas con demencia. Se trata de una experiencia compleja que tiene que ver con la sensación de estar “dividido entre dos direcciones” tanto a nivel emocional como cognitivo, en torno al familiar o a la experiencia del cuidado (Pillemer et al., 2007). Entre los factores que pueden explicar este tipo de emoción compleja se encuentran los cambios en la calidad de la relación entre el cuidador y la persona cuidada, los cambios en patrones de interdependencia cuando las demandas son altas (Willson et al., 2003) o la incompatibilidad del cuidado con otros valores personales o compromisos familiares o laborales (Vara-García et al., 2021). Recientemente, Losada et al. (2018) subrayan que una mayor frecuencia de comportamientos disruptivos por parte de la persona cuidada se asocia con mayor ambivalencia en los cuidadores y, a su vez, este sentimiento se asocia con estrategias de afrontamiento desadaptativas, como la evitación experiencial o la supresión emocional. Aunque la investigación empírica sobre los sentimientos ambivalentes de los cuidadores es escasa, la literatura existente pone de manifiesto la importancia de avanzar en el estudio de esta variable, puesto que la ambivalencia se asocia a graves consecuencias para los cuidadores, como sintomatología depresiva y ansiosa (Losada et al., 2017, 2018).

2.3.4. Variables moduladoras

Como se explicaba anteriormente, las variables moduladoras tienen un papel fundamental en el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), puesto que parecen contribuir de manera muy destacada a explicar las diferencias interindividuales en torno a la experiencia del cuidado, así como las diferencias existentes entre la exposición a las variables estresoras ya mencionadas y el impacto que pueden tener en la salud física y emocional de los cuidadores. Si bien el lugar que habitualmente ocupan estas variables en el proceso de estrés, tal y como es descrito en el modelo de estrés y afrontamiento, es previo a las consecuencias asociadas al cuidado, se habla de estas variables en este último subapartado por motivos prácticos dado que permite enlazar de una mejor manera los contenidos tratados en los apartados de la introducción.

Una de las variables moduladores más ampliamente estudiada en población cuidadora es el apoyo social. Esta variable se asocia con menor carga (Han et al., 2014), así como con menores niveles de depresión, y modula los efectos de los estresores en este tipo de consecuencias para los cuidadores (p. ej., Clay et al., 2008). Intervenciones dirigidas a incrementar el apoyo social parecen mejorar la calidad de vida de los cuidadores (Dam et al., 2016; Rodríguez-Pérez et al., 2017). Por otro lado, la literatura es consistente al reconocer la existencia de distintas estrategias de afrontamiento adoptadas por los cuidadores, con distintas consecuencias emocionales para los mismos. Se suele diferenciar entre estrategias centradas en la solución del problema (dirigidas, por ejemplo, a eliminar o reducir los acontecimientos estresantes), estrategias centradas en la emoción (manejando la propia respuesta emocional) o estrategias disfuncionales (evitando, o desenganchándose de la experiencia emocional) (Li et al., 2014). Parece que las estrategias disfuncionales, como las basadas en la evitación de la respuesta emocional se asocian con mayor malestar tanto psicológico (Cooper et al., 2008; Rodríguez-Pérez et al., 2017) como físico (Kim et al., 2008). Por el contrario, las estrategias de afrontamiento basadas en la aceptación emocional parecen ser protectoras y se asocian a una mejor calidad de vida, ya que parecen actuar amortiguando el efecto de los estímulos estresantes en la salud psicológica de los cuidadores (Cooper et al., 2008).

Por último, una variable apenas estudiada en población cuidadora pero que está adquiriendo cada vez mayor relevancia en la literatura es la inflexibilidad psicológica (p.ej. Romero-Moreno et al., 2014; Márquez-González et al., 2010). Se trata de un constructo transdiagnóstico enmarcado en la Terapia de Aceptación y Compromiso (ACT) (Hayes et al., 2011). La inflexibilidad psicológica implica que el comportamiento queda excesivamente controlado por los pensamientos, emociones y otras experiencias internas y ocurre con frecuencia cuando las personas intentan, de forma rígida, evitar, controlar o suprimir esas experiencias, normalmente desagradables, alejándolas de sus valores personales. Y, como resultado, la persona es menos capaz de aceptar experiencias no deseadas, adoptando en cambio una postura cerrada y más crítica hacia ellas (Hayes et al. 2006; Hayes et al. 1996). Esta variable puede tener relación con las estrategias de afrontamiento desadaptativas (Rueda y Valls, 2020). La inflexibilidad psicológica está compuesta a su vez por otros subprocesos o variables transdiagnósticas, siendo especialmente relevantes los constructos de fusión cognitiva y valores personales. Al tratarse de variables centrales para esta tesis doctoral se tratarán con mayor profundidad en el punto 2.5.

2.4 Relevancia de la visión transdiagnóstica en la investigación sobre el cuidado

El hecho de que el cuidado familiar de personas con demencia lleve asociado distintas consecuencias psicológicas, con manifestaciones frecuentemente comórbidas (Joling et al., 2014), sugiere la pertinencia de investigar posibles procesos transdiagnósticos asociados al malestar de los cuidadores, esto es, procesos centrales que pueden asociarse o estar en la base de los distintos problemas psicológicos que sufre este tipo de población. El enfoque transdiagnóstico es una aproximación científica convergente e integradora que pone el foco en procesos cognitivos y conductuales etiopatogénicos que causan y/o mantienen los problemas psicopatológicos y ofrece una base para entender los diferentes síntomas y trastornos desde procesos más o menos comunes y/o generales (p. ej., Barlow et al., 2004; Sandín et al., 2012). Por ejemplo, Brown y Barlow (2009) postulan que la comorbilidad entre los trastornos del estado de ánimo y de ansiedad puede explicarse por las dimensiones de orden superior del afecto negativo y positivo y sugieren que los trastornos del estado de ánimo y de ansiedad surgen de diátesis psicosociales y biológicas/genéticas compartidas. Estudios como el realizado por Brown y Barlow (2009) sirvieron de base para los esfuerzos recientes para desarrollar los llamados protocolos de tratamiento transdiagnóstico (Norton, 2012) o unificados (Barlow et al., 2010) que atraviesan las categorías de diagnóstico para abordar los procesos centrales de los problemas psicológicos, y así desarrollar tratamientos de intervención más parsimoniosos y eficaces (Barlow et al., 2004), algo especialmente relevante en población cuidadora.

2.5 La fusión cognitiva como proceso transdiagnóstico relevante en la investigación sobre el cuidado

En la investigación sobre el cuidado, un enfoque transdiagnóstico que está cobrando cada vez más relevancia es la Terapia de Aceptación y Compromiso (ACT, Hayes et al., 2011). Desde el modelo ACT se argumenta que la inflexibilidad psicológica se encuentra en la base de gran parte de los problemas psicológicos, siendo este un proceso transdiagnóstico (Hayes et al., 2011). Un proceso clave en la inflexibilidad psicológica es la fusión cognitiva, que se refiere al fenómeno por el cual las personas creen como real y literal el contenido de sus pensamientos y emociones, en lugar de como estados internos transitorios (Hayes et al., 2011). La atención y el comportamiento de las personas altamente “fusionadas” con el contenido de sus cogniciones son dominados por este proceso, sin ser conscientes del proceso de pensamiento en sí mismo (Gillanders et al., 2014). De esta forma, la fusión cognitiva se refiere a la tendencia del comportamiento a estar excesivamente regulado e influenciado por los pensamientos. Dicho de otra manera, “la fusión es una forma de dominancia verbal en la regulación de la conducta” (Hayes et al., 2011, p. 93).

La fusión cognitiva tiene que ver con la relación que establece una persona con sus propios eventos cognitivos, en un continuo desde el estado fusionado (dominado por la creencia literal de los propios pensamientos) hasta el defusionado (experimentando los pensamientos como eventos mentales transitorios). Cuando se "fusiona" una persona actúa sobre los pensamientos como si fueran eventos cognitivos literalmente ciertos, sin ser consciente del proceso de pensamiento en sí mismo, pudiendo llegar este proceso a dominar el comportamiento y la experiencia sobre otras fuentes de regulación del comportamiento, alejando a la persona de sus metas y valores relevantes en la vida (Guillanders et al., 2014). En el caso de los cuidadores familiares de personas con demencia, el hecho de fusionarse con pensamientos relacionados con su situación de cuidado, con pensamientos autorreferenciales o catastrofistas, puede tener graves consecuencias.

Así, por ejemplo, la fusión cognitiva se ha asociado con distintas consecuencias psicológicas como la vergüenza o la depresión, (Dinis et al. 2015), trastornos de la conducta alimentaria (Ferreira et al. 2014), así como a sintomatología depresiva y ansiosa en poblaciones y contextos muy diversos (Gillanders et al., 2014). En el caso de cuidadores familiares de personas con demencia, algunos estudios llevados a cabo en esta población sugieren que se trata de una variable relevante relacionada con el malestar psicológico de los cuidadores. Romero-Moreno et al. (2014) encontraron que aquellas personas con niveles altos de fusión cognitiva presentaban a su vez, mayores puntuaciones en sintomatología depresiva, ansiosa y sentimientos de culpa. Además, esta variable se ha relacionado con mayor frecuencia de comportamientos disruptivos por parte del familiar, así como con menores niveles de satisfacción con la vida (Romero-Moreno et al., 2015). Sin embargo, hasta la fecha no se ha estudiado la posible relación entre esta variable y otras variables poco exploradas en la literatura del cuidado, como la sintomatología de ambivalencia o la comorbilidad de sintomatología depresiva y ansiosa, ni el papel predictivo de la fusión cognitiva en este tipo de sintomatología mediante estudios longitudinales. Menos aún se han estudiado los posibles mecanismos por los cuáles la fusión cognitiva se relaciona con el malestar psicológico en cuidadores. Una posible explicación pudiera ir encaminada hacia la pérdida de contacto o satisfacción con los valores personales de los cuidadores.

Por valores se entiende a aquellas direcciones vitales, libremente elegidas, deseadas y elaboradas verbalmente por la persona que ayudan a organizar y dirigir las acciones vitales (Hayes et al., 2011). En población cuidadora son también escasos los estudios que analizan esta variable, a pesar de que, además del valor del cuidado del familiar, hay otros valores importantes para ellos (por ej., ocio y autocuidado), y el bajo compromiso y satisfacción con los mismos se relaciona con malestar psicológico (p.ej., Romero-Moreno et al., 2017; Vara-García, 2021). Diferentes estudios han sugerido que el trabajo con esta variable parece ser de gran relevancia para mejorar el bienestar de los cuidadores (Márquez-González et al., 2010).

Según el modelo ACT (Hayes et al., 2011), todos los subprocesos de inflexibilidad psicológica guardan relación entre sí, y la disminución de fusión cognitiva da como resultado una mayor flexibilidad psicológica y un mayor contacto y avance hacia las direcciones valiosas de la vida. Por el contrario, cuando una persona se encuentra altamente fusionada con sus cogniciones, existe menos “espacio” para dirigirse hacia valores personales y obtener satisfacción de los mismos, lo que, a su vez, repercute en una peor calidad de vida (p.ej., Gillanders et al., 2014).

El proceso contrario a la fusión cognitiva, esto es, la defusión cognitiva, es un componente propio de objetivo de intervención de la terapia ACT (Hayes et al., 2011).

Sin embargo, se ha sugerido que otro tipo de terapias psicológicas, como la terapia cognitivo conductual (TCC), también promueven la defusión cognitiva de forma indirecta, a través de ejercicios como la restructuración cognitiva, puesto que fomentan una perspectiva de observador científico y, por lo tanto, una distancia con los propios pensamientos (Arch et al., 2012). Además, estos mismos autores sugieren que si bien es cierto que la terapia ACT logra mayores niveles de defusión cognitiva que TCC, este proceso terapéutico es relevante en ambos tipos de terapia, puesto que era un mediador importante para variables de resultado tras la tintervención, como ansiedad y satisfacción con la vida (Arch et al., 2012). Este sorprendente resultado sugiere que ambas terapias poseen procesos terapéuticos comunes, en este caso, la defusión cognitiva, lo que podría explicar el hecho de que ambas terapias resultan eficaces y no existan grandes diferencias entre ellas en cuanto a los mecanismos activos de las intervenciones (Arch y Graske, 2008). Por lo tanto, además de estudiar a través de qué procesos actúan las terapias psicológicas, también resultan de mucha utilidad los estudios de moderación, dirigidos a estudiar qué personas, en función de sus características, se benefician en mayor medida de un tipo de terapia u otra. Esto resulta especialmente interesante en el caso de los cuidadores familiares de personas con demencia, dadas las distintas terapias psicológicas existentes para ofrecerles un tratamiento óptimo y eficaz a largo plazo (Cheng et al., 2020). Sin embargo, el rol moderador de la fusión cognitiva en estudios de intervención no ha sido estudiado en cuidadores familiares de personas con demencia.

2.6. Resumen final

El cuidado familiar de una persona con demencia conlleva consecuencias psicológicas negativas (p.ej., Collins y Kishita 2020). La gran mayoría de los estudios dirigidos a analizar el malestar psicológico de los cuidadores han estado centrados en la variable de depresión, y en menor medida en la ansiedad (p. ej., Cooper et al., 2008), ambivalencia y sintomatología comórbida ansioso-depresiva. Sin embargo, parece ser un tipo de sintomatología frecuente que hace preguntarse qué procesos transdiagnósticos comunes subyacen a la comorbilidad en personas que cuidan de un familiar que tienen demencia. Los escasos estudios realizados para investigar la relación entre la variable transdiagnóstica de fusión cognitiva y malestar psicológico en cuidadores han mostrado su relación positiva (Romero-Moreno et al., 2014). Sin embargo, ningún estudio hasta la fecha ha analizado la relación entre esta variable y los sentimientos de ambivalencia y la sintomatología comórbida de los cuidadores de forma transversal ni longitudinal, ni tampoco se ha estudiado el rol moderador de esta variable en distintas terapias psicológicas dirigidas a cuidadores.

A través de la presente Tesis Doctoral se pretende, por lo tanto, ampliar el conocimiento acerca de la variable transdiagnóstica fusión cognitiva, y su relación con el malestar psicológico de los cuidadores a través de distintos diseños y metodologías.

3. Objetivos e hipótesis

3.1. Objetivo general de la Tesis Doctoral

La presente tesis tiene por objetivo general analizar transversal y longitudinalmente, tomando como referencia el marco teórico del modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), el papel de distintas variables y, especialmente de la fusión cognitiva, en el proceso de estrés del cuidado.Se han desarrollado cinco estudios independientes entre sí, cuyos objetivos e hipótesis específicas se exponen a continuación, que comparten como idea central el análisis del papel de la fusión cognitiva en el proceso de estrés del cuidado.

Específicamente, se analizará el papel de la fusión cognitiva en la relación entre comportamientos disruptivos del familiar y el sentimiento de ambivalencia de los cuidadores (estudio 1), así como en la relación entre estrés y sintomatología comórbida depresiva-ansiosa (estudio 2). Por otro lado, se analizará la relación entre fusión cognitiva y sintomatología depresiva y ansiosa a través de la satisfacción con valores (estudio 3). Además, se analizará de forma longitudinal el efecto predictor de la fusión cognitiva sobre la sintomatología depresiva, ansiosa y ambivalencia de los cuidadores (estudio 4) y por último, se analizará el papel de la fusión cognitiva en la predicción de la respuesta a diferentes tratamientos psicológicos para la reducción de la sintomatología depresiva (estudio 5).

3.2 Estudio 1: Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feeling.

Publicado en *Behavioral Psychology/Psicología Conductual* (Barrera-Caballero et al., 2019) con índice de impacto JCR en el año 2020 de 1.017.

3.2.1. Objetivo general

De manera transversal, analizar la relación entre factores estresantes (frecuencia y reacción a comportamientos problemáticos), fusión cognitiva y ambivalencia en cuidadores familiares de personas con demencia.

3.2.2 Objetivos específicos

1) Analizar el papel de la fusión cognitiva en la relación entre los comportamientos disruptivos del familiar cuidado y los sentimientos de ambivalencia de los cuidadores.

2) Analizar el grado en que la fusión cognitiva ejerce un papel mediador en la relación entre los comportamientos disruptivos del familiar cuidado y la experiencia de ambivalencia en los cuidadores.

3.2.3 Hipótesis

1) Una mayor frecuencia de comportamientos disruptivos y reacción asociada a los mismos por parte de los cuidadores se asociará con mayor fusión cognitiva en los cuidadores.

2) La fusión cognitiva se asociará de forma positiva con los sentimientos de ambivalencia de los cuidadores.

3) La fusión cognitiva tendrá un papel mediador en la relación entre la frecuencia y reacción a comportamientos disruptivos del familiar y los sentimientos de ambivalencia de los cuidadores.

3.3. Estudio 2: Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers.

Publicado en *Psychology and Aging* (Barrera-Caballero et al., 2021*)*, con índice de impacto JCR en el año 2020 de 3.34.

3.3.1. Objetivo general

Analizar las diferencias entre perfiles emocionales de los cuidadores (comórbido, depresivo, ansioso y subclínico) en factores demográficos y contextuales, variables de estrés y fusión cognitiva.

3.3.2 Objetivos específicos

1) Analizar las diferencias entre perfiles emocionales de los cuidadores (comórbidos, depresivos, ansiosos, subclínica) en variables contextuales y sociodemográficas (género, edad, parentesco), así como en variables estresoras (tiempo dedicado al cuidado, frecuencia y reacción a conductas disruptivas del familiar) y la fusión cognitiva.

2) Analizar el papel de la fusión cognitiva como variable o proceso transdiagnóstico central en la presentación comórbida de sintomatología depresiva y ansiosa de los cuidadores.

3.3.3 Hipótesis

1) Las mujeres cuidadoras y aquellos cuidadores que informen de un mayor nivel de estrés también presentarán mayor riesgo de sufrir síntomas comórbidos de depresión y ansiedad en comparación con los demás perfiles emocionales.

2) Los cuidadores con niveles elevados de fusión cognitiva presentarán mayor riesgo de sufrir síntomas comórbidos de depresión y ansiedad en comparación con los demás perfiles emocionales.

3.4. Estudio 3: Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values

En segunda revisión para su publicación en *Aging & Mental Health*, con índice de impacto JCR en el año 2020 de 3.658.

3.4.1. Objetivo general

De manera transversal, analizar la relación entre fusión cognitiva, la satisfacción con los valores personales (valor del cuidado y otros valores personales) y la sintomatología depresiva y ansiosa de los cuidadores.

3.4.2 Objetivos específicos

1) Analizar el papel de la satisfacción con los valores personales (valor del cuidado y otros valores personales) en la relación entre la fusión cognitiva y la sintomatología depresiva y ansiosa de los cuidadores.

2) Analizar el grado en que la satisfacción con los valores personales (valor del cuidado y otros valores personales) ejerce un papel mediador en la relación entre la fusión cognitiva y la sintomatología depresiva y ansiosa de los cuidadores.

3.4.3 Hipótesis

1) Mayor satisfacción con los valores personales se asociará con menor sintomatología depresiva y ansiosa de los cuidadores.

2) La satisfacción con los valores personales tendrá un papel mediador en la relación entre la fusión cognitiva y la sintomatología depresiva y ansiosa de los cuidadores. Específicamente, una mayor fusión cognitiva se asociará con una menor satisfacción con los valores personales, y ésta con mayor sintomatología depresiva y ansiosa.

3.5 Estudio 4: Longitudinal effects of cognitive fusion in emotional distress in family caregivers.

En preparación para la revista *Journals of Gerontology*, con índice de impacto JCR en el año 2020 de 6.591.

3.5.1. Objetivo general

Analizar el efecto longitudinal de la fusión cognitiva en el malestar psicológico de los cuidadores familiares de personas con demencia, contralando el papel de otras variables relevantes en el modelo de estrés y afrontamiento adaptado al cuidado.

3.5.2 Objetivos específicos

Analizar el efecto predictor de la fusión cognitiva sobre la sintomatología depresiva, ansiosa y ambivalente.

3.5.3 Hipótesis

Incrementos en la fusión cognitiva predecirán incrementos en la sintomatología depresiva, ansiosa y ambivalente de los cuidadores, una vez controladas las demás variables.

3.6. Estudio 5: Cognitive fusion and treatment response to depression in caregivers of relatives with dementia.

En revisión para *Journal of Contextual and Behavioral Science*, con índice de impacto JCR en el año 2020 de 5.138.

3.4.1. Objetivo general

Analizar si los niveles basales de fusión cognitiva predicen diferentes respuestas al tratamiento en sintomatología depresiva, comparando la Terapia de Aceptación y Compromiso (ACT), la Terapia Cognitiva y Conductual (TCC) y un grupo control.

3.4.2 Objetivo específico

Analizar el papel de la fusión cognitiva como moderador de la eficacia del tratamiento para la sintomatología depresiva, comparando la Terapia de Aceptación y Compromiso (ACT), la Terapia Cognitiva y Conductual (TCC) y un grupo control.

3.4.3 Hipótesis

1) Aquellos cuidadores con mayores niveles basales de fusión cognitiva presentarán mayor cambio en la sintomatología depresiva después del tratamiento.

2) Aquellos cuidadores con mayores niveles basales de fusión cognitiva presentarán mayor cambio en la sintomatología depresiva después del tratamiento, en concreto, en la condición ACT.

4. Metodología General

La presente tesis doctoral está formada por cinco trabajos independientes. Los estudios presentan temáticas relacionadas entre sí y comparten el objetivo principal de analizar el rol transdiagnóstico de la fusión cognitiva en su relación con el malestar psicológico de los cuidadores familiares de personas con demencia, controlando el efecto de otras variables relevantes en el proceso del cuidado.

Como se ha señalado, el primer estudio ("*Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feeling*") se encuentra publicado en la revista Behavioral Psychology/Psicología Conductual, indexada en la base de datos Journal Citation Reports (JCR) en el cuarto cuartil de la categoría de Psicología Clínica (Factor de impacto: 1.017). El segundo estudio ("*Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers*") se encuentra publicado en la revista Psychology and Aging, indexada en la base de datos JCR en el segundo cuartil de la categoría de Gerontología (Factor de impacto: 3.34). El estudio tres ("*Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values*") se encuentra en proceso de revisión para su publicación en la revista Aging and Mental Health. El estudio cuatro ("*Longitudinal effects of stress and cognitive fusion in emotional distress in family caregivers")* se encuentra en proceso de envío a revista. El quinto y último estudio de la presente tesis doctoral ("*Cognitive fusion and treatment response to depression in caregivers of relatives with dementia*") se encuentra en proceso de revisión para su publicación en la revista Journal of Contextual and Behavioral Science.

Aunque cada uno de los estudios mencionados contiene sus propios apartados de Introducción, Método, Resultados, Discusión y Referencias, en esta sección se describen las características metodológicas que comparten todos los estudios, mencionando las especificidades de cada trabajo particular. En primer lugar, se describirán las características relativas a los participantes así como de los procedimientos llevados a cabo para para la recogida muestral. Después se detallarán las principales variables objeto de estudio y los instrumentos utilizados para su medición. Por último, se describirán los procedimientos de análisis de datos utilizados en cada estudio. Para ofrecer una visión general de las principales características de los estudios que componen la presente tesis doctoral así como del estado de éstos, se presenta un cuadro resumen en la Tabla 4.1.

4.1 Participantes y procedimiento

Los criterios de inclusión para participar en los estudios fueron los siguientes:

- Ser mayor de edad.
- Considerarse el cuidador principal e informal (sin remuneración económica directa) del familiar diagnosticado de Alzheimer u otra demencia relacionada.
- Invertir, como mínimo, 1 hora diaria o 7 horas semanales al cuidado del familiar enfermo.
- Llevar al menos 3 meses consecutivos a cargo de la situación de cuidado.

Además, dadas las características particulares del quinto estudio, en el que los cuidadores participaron en una intervención psicoterapéutica, se añadieron los siguientes criterios de inclusión para participar en dicho estudio:

- No haber recibido previamente terapia psicológica para afrontar la situación del cuidado.
- Presentar niveles clínicamente significativos en sintomatología depresiva (puntuaciones mínimas de 16 en la escala CES-D; Radloff, 1977).

Como se señala en la Tabla 4.1, el número final de participantes por estudio varía entre 130 y 553. Esta variabilidad en el tamaño muestral de los diferentes estudios es debida a varios motivos, destacando el hecho de que la presente Tesis Doctoral se ha llevado a cabo en el marco de diferentes proyectos de investigación. Por otro lado, la variabilidad de valores perdidos y los distintos momentos temporales en los que se han desarrollado los distintos estudios explican también las diferencias entre los distintos tamaños muestrales.

En cuanto al procedimiento, para el contacto con los cuidadores participantes de los distintos estudios se contó con la colaboración de diferentes centros pertenecientes a la Comunidad de Madrid (Hospital Gregorio Marañón, Centro de Especialidades Hermanos Sangro, Asociación de Familiares de Enfermos de Alzheimer de Madrid Suroeste (AFAMSO), Ayuntamiento de Madrid -Dirección General de Mayores-, Aulas Kalevi, Servicio de Atención Primaria del centro Miguel Servet de la Comunidad de Madrid, Unidad de Memoria de Cantoblanco, Fundación Cien, Centro de Salud General Ricardos, Centro de Salud García Noblejas, Centro de Salud Benita de Ávila, Centro de Salud Vicente Muzas, Centro Reina Sofía de Cruz Roja, Centro de Psicología Aplicada de la Universidad Autónoma de Madrid, y Servicios Sociales de Getafe). En primer lugar, la información de contacto de los participantes fue remitida al equipo de investigación por parte del personal de los centros colaboradores. El equipo de investigación se encargó posteriormente de realizar una primera llamada telefónica a todas las personas que aceptaron recibir información sobre el proyecto. Los objetivos de esa primera llamada eran comprobar que el cuidador estaba interesado en colaborar con los estudios, que cumplía los criterios de inclusión y, por último, concertar una cita presencial en su centro de referencia para realizar una entrevista cara a cara, individual, en la cual se evaluaban las distintas variables del estudio. Para el estudio longitudinal se realizaron entrevistas durante un período de dos años (tres evaluaciones: línea de base, 12 y 24 meses después de la línea de base).

Cabe señalar que debido a la irrupción de la pandemia a causa del COVID-19, en el caso del estudio longitudinal se realizaron también entrevistas telefónicas. Todos los participantes dieron su consentimiento informado a participar y los estudios fueron aprobados por el Ministerio de Educación (PSI2012-31293), por el Ministerio de Economía, Industria y Competitividad (PSI2012-31239 y PSI2015-65152-C2-1-R), por el Ministerio de Ciencia e Innovación (PID2019-106714RB-C21) así como por el comité de ética de la Universidad Rey Juan Carlos.

Para el quinto estudio, a los participantes que cumplían los criterios de inclusión se les ofrecía participar en un estudio de intervención psicoterapéutica en formato individual de ocho sesiones semanales con grupo control y asignación aleatoria de los participantes a las diferentes condiciones de intervención (ACT, TCC, condición control; Losada et al., 2015; Márquez-González et al., 2020). Tras la finalización de la intervención, los cuidadores realizaron una evaluación post-intervención para la medición de los posibles cambios en las variables evaluadas en la primera evaluación. Aquellas personas que no cumplían los criterios de sintomatología depresiva clínicamente significativa se les ofrecía participar en un taller grupal de una sesión de unas dos horas de duración sobre aspectos de interés relativos al cuidado familiar de personas con demencia.

4.2 Variables e instrumentos de medida utilizados

A continuación se presentan, de forma resumida, las variables objeto de estudio así como los instrumentos de medida utilizados en los estudios que componen la presente Tesis Doctoral (en el Anexo 1 se incluye una copia de cada instrumento de medida utilizado y una descripción más detallada de los mismos).

Siguiendo el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), además de las características sociodemográficas de la muestra (e.g., edad, sexo, parentesco, tipo de demencia, horas y tiempo cuidando), se evaluaron las siguientes variables:

4.2.1 Estresores

Se evaluó la frecuencia de comportamientos disruptivos de la persona cuidada mediante se la subescala de frecuencia de comportamientos disruptivos del Listado de Problemas de Memoria y de Conducta Revisado (Revised Memory and Behavior Problems Checklist) (Teri et al., 1992). En concreto, se utilizó la versión española de esta escala (Nogales-González et al., 2015). Esta subescala está formada por 8 ítems (ej. “durante la semana pasada, ¿con qué frecuencia su familiar se mostró irritable? “) que miden la frecuencia con la que ocurren dichos comportamientos.

La reacción o malestar asociado de los cuidadores ante dichos comportamientos disruptivos del familiar cuidado se midió a través de la subescala de reacción ante los comportamientos disruptivos del familiar del Listado de Problemas de Memoria y de Conducta Revisado (Revised Memory and Behavior Problems Checklist) (Teri et al., 1992), en su versión española (Nogales-González et al., 2015). Ambas subescalas se utilizaron en todos los estudios de la presente tesis doctoral.

El estado de la demencia o severidad de la misma se midió a través de la Escala Global de Deterioro (GDS; Reisberg et al., 1982) y la capacidad funcional de la persona cuidada fue evaluada mediante la escala Barthel (Barthel Index; Mahoney & Barthel, 1965). La escala GDS se utilizó en el segundo y cuarto estudio y la escala Barthel se utilizó en el tercer y cuarto estudio.

4.2.3 Variables moduladoras

El nivel de fusión cognitiva que presentaban los cuidadores fue medido a través de la versión española (Romero-Moreno et al., 2015) de la Escala de Fusión Cognitiva (CFQ) (Gillanders et al., 2014).

Por otro lado, siguiendo el procedimiento descrito en Vara-García et al. (2021), se midió el nivel de satisfacción de los cuidadores con el valor del cuidado así como con otros valores personales (elegidos). En primer lugar, además del valor del cuidado, los cuidadores debían elegir los dos valores personales más importantes para ellos. Después se les evaluaba el grado de satisfacción que presentaban con las acciones que realizaban de forma consistente con dichos valores.

4.2.4 Variables de resultado: Consecuencias psicológicas del cuidado

En primer lugar, los sentimientos de ambivalencia de los cuidadores se evaluaron mediante la Escala de Ambivalencia en el Cuidado (CAS; Losada et al., 2017).

La sintomatología depresiva que presentaban los cuidadores fue medida a través de la Escala de Depresión del Centro Para Estudios Epidemiológicos (CES-D; Radloff, 1977), en su versión española (Losada et al., 2012).

Por último, para medir el grado de sintomatología ansiosa que presentaban los cuidadores se utilizó la subescala de Tensión del Perfil de Estados de Ánimo (POMS; McNair et al., 1971).

4.3 Análisis de datos

A pesar de que en cada uno de los cinco estudios de la presente tesis se detallan los análisis de datos concretos llevados a cabo, se describen a continuación los principales análisis empleados para estudiar los objetivos de la tesis.

Se llevaron a cabo análisis descriptivos y, con el objetivo de analizar la relación entre las distintas variables de los estudios, se realizaron análisis de correlaciones bivariadas de Pearson.

Para analizar el papel mediador de la fusión cognitiva en la relación entre los comportamientos disruptivos del familiar y los sentimientos de ambivalencia de los cuidadores (estudio 1), se empleó la metodología del Análisis de Senderos (Path Analysis). Siguiendo las recomendaciones de Preacher y Hayes (2004), los análisis de mediación fueron realizados mediante una aproximación de “bootstrapping” de 1000 muestras.

En el segundo estudio se analizaron las diferencias entre los perfiles de sintomatología depresiva, ansiosa, comórbida y sin sintomatología clínica y variables sociodemográficas, estresoras y fusión cognitiva mediante ANOVAs (usando el procedimiento Tukey's pairwise de comparaciones para controlar la tasa de error Tipo-I) y análisis de chi-cuadrado. Por último, se realizaron regresiones logísticas multinomiales para identificar los predictores de malestar psicológico en cada grupo. El perfil comórbido se fijó como categoría de referencia en la variable dependiente nominal a comparar con los otros tres perfiles.

En el tercer estudio, el efecto indirecto de la fusión cognitiva sobre el malestar de los cuidadores a través de la satisfacción con los valores personales se analizó a través de la macro PROCESS para SPSS (Hayes, 2018). Se realizaron análisis de regresión jerárquica del efecto total (c), el efecto directo (c') y los intervalos de confianza del 95 % acelerados y corregidos por el sesgo con bootstrapping del efecto indirecto (ab) con 10000 muestras con bootstrap.

En el cuarto estudio se llevaron a cabo análisis de modelos lineales mixtos para analizar el papel predictor de los cambios a lo largo del tiempo en fusión cognitiva así como de la frecuencia y reacción a los comportamientos disruptivos del familiar en la sintomatología depresiva, ansiosa y ambivalencia de los cuidadores, después de controlar otras variables relevantes en la investigación sobre el cuidado, como variables sociodemográficas, la capacidad funcional de la persona cuidada y el cese del cuidado por diferentes motivos (p.ej., otra persona encargada del cuidado, ingreso del familiar en una residencia).

En el quinto estudio se realizaron análisis de ANOVA y chi-cuadrado y una regresión lineal usando el procedimiento de Hayes (2013) para probar el efecto de moderación por parte de los niveles basales de fusión cognitiva en la relación entre la condición de intervención y el cambio pre-post en la sintomatología depresiva. Este procedimiento proporciona puntos de corte para fusión cognitiva baja, media y alta utilizando los percentiles 16, 50 y 84 como valores condicionantes de los valores del moderador para probar la interacción realizando un arranque de 10000 muestras. La condición de intervención (ACT vs TCC vs control) se incluyó como predictor principal;

los niveles basales de fusión cognitiva se incluyeron como variable moderadora, y el cambio pre-post en la sintomatología depresiva se introdujo como variable dependiente.

Para llevar a cabo los análisis citados en esta sección, se utilizaron los programas estadísticos AMOS Graphics v.22, IBM SPSS en su versión 20 en adelante y la macro PROCESS (v.3.5) para SPSS (Hayes, 2013)

Tabla 4.1. Resumen general de las características de los estudios que conforman la Tesis Doctoral

Título	**Autores**	**Estado de publicación**	**Tamaño muestral**	**Diseño**	**Variables**	**Análisis de datos**
Estudio 1 Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feeling	Barrera-Caballero, S., Losada, A., Vara-García, C., Romero-Moreno, R., & Márquez-González, M.	Publicado en la revista *Behavioral Psychology/Psicología Conductual*	N = 364	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas Frecuencia de comportamientos disruptivos de la persona cuidada Reacción del cuidador a comportamientos disruptivos de la persona cuidada Fusión cognitiva Ambivalencia	Correlaciones de Pearson Análisis de mediación
Estudio 2 Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers	Barrera-Caballero, S., Romero-Moreno, R., del Sequeros Pedroso-Chaparro, M., Olmos, R., Vara-García, C., Gallego-Alberto, L., ... & Losada-Baltar, A	Publicado en la revista *Psychology and Aging*	N = 553	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas Frecuencia de comportamientos disruptivos de la persona cuidada Reacción del cuidador a comportamientos disruptivos de la persona cuidada Fusión cognitiva	Correlaciones de Pearson Análisis ANOVAS y Chi-Cuadrado Análisis de regresión logística multinomial

					Sintomatología depresiva y ansiosa	
Estudio 3 Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values	Barrera-Caballero, S., Romero-Moreno, R., Vara-García, C., Márquez González, M., Olazarán, J., & Losada-Baltar, A.	En revisión en *Aging and Mental Health*	N = 287	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas Frecuencia de comportamientos disruptivos de la persona cuidada Reacción del cuidador a comportamientos disruptivos de la persona cuidada Fusión cognitiva Satisfacción con valores Sintomatología depresiva y ansiosa	Correlaciones de Pearson Análisis de regresión jerárquica Análisis de Mediación
Estudio 4 Longitudinal effects of cognitive fusion in emotional distress in family caregivers		En preparación	N= 176	Estudio longitudinal	Variables sociodemográficas Frecuencia de comportamientos disruptivos de la persona cuidada Reacción del cuidador a comportamientos	Análisis de modelos generales lineales mixtos

					disruptivos de la persona cuidada Fusión cognitiva Cese del cuidado Sintomatología depresiva, ansiosa y ambivalencia	
Estudio 5 Cognitive fusion and treatment response to depression in caregivers of relatives with dementia	Barrera-Caballero,S., Romero-Moreno, R., Vara-García, C., Olmos, R., Ricardo Márquez-González, M., & Losada-Baltar, A.	En revision en *The Journal of Contextual Behavioral Science*	N = 130	Estudio de Intervención	Variables sociodemográficas Frecuencia de comportamientos disruptivos de la persona cuidada Reacción del cuidador a comportamientos disruptivos de la persona cuidada Fusión cognitiva Cambios pre-post en sintomatología depresiva	Análisis ANOVASy Chi-Cuadrado Análisis de Moderación

Estudio Uno

Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feelings

Publicado en: Barrera-Caballero, S., Losada, A., Vara-García, C., Romero-Moreno, R., & Márquez-González, M. (2019). Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feelings. *Behavioral Psychology* / *Psicología Conductual*, *27*(3), 499-510.

5. Estudio Uno: Care-recipients' disruptive behaviors and caregivers' cognitive fusion: relevant variables for understanding caregivers' ambivalent feelings

5.1. Abstract

The goal of this study was to analyze the relationship between stressors (frequency of and reaction to disruptive behaviors), cognitive fusion and ambivalence among caregivers, and more specifically to study whether cognitive fusion acts as a mediator in the relationship between stressors and ambivalence. To assess these variables, individual interviews were conducted with a total of 364 caregivers of a relative with dementia. Significant and positive correlations were found among stressors, cognitive fusion and ambivalence ($p < .05$). The model suggests that there is a significant and positive relationship between reaction to disruptive behaviors and ambivalent feelings among caregivers, although it seems to be mediated by cognitive fusion. The final model explains 37% of the variance of ambivalence, and it shows an excellent fit to the data. The results suggest that the relationship between frequency of disruptive behaviors and ambivalence seems to be mediated by reaction to disruptive behaviors and cognitive fusion; consequently this last variable seems to be relevant for understanding emotional ambivalence among caregivers.

Keywords: caregivers, dementia, cognitive fusion, emotional ambivalence, problematic behaviors.

5.2. Introduction

Providing care for a relative with Alzheimer's disease or related disorders has been associated with negative consequences for the caregiver’s mental and physical health (e.g., depression and stress) (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013; Otero, Vázquez, Blanco, & Torres, 2017; Pinquart & Sörensen, 2003). Caregivers are subject to highly demanding tasks while devoting several hours per day over long periods of time. For these reasons, caring for a relative with dementia has been considered a prototypical example of a chronic stressful situation, and the theoretical framework that has received the most empirical support has been the stress and coping model adapted to caregiving (Knight & Sayegh, 2010). According to this approach, the impact of difficult situations and demands (stressors) in caregiver's distress depends on caregivers´ personal and contextual resources that can buffer or accentuate this impact (Knight & Sayegh, 2010).

Among the most significant and important stressors faced by caregivers are the behavioral and psychological symptoms of dementia (BPSD), which consist of a wide variety of patient behaviors, including repetition of questions, depression, physical aggression, and delusions (Ornstein et al., 2013). These symptoms are considered to be among the most difficult stressors that caregivers can face. Within BPSD (e.g., disruptive behaviors, memory problems or depressive symptoms), disruptive behaviors such as aggressiveness turn out to be the stressors that cause the greatest reaction (distress) in caregivers, although they are not the most frequent (Fauth & Gibbons, 2014).

To date, much of the research in the dementia caregiving field has focused on psychological outcome variables such as depression or anxiety. However, a variable that has scarcely been explored in the literature is emotional ambivalence. In the caregiving context, ambivalence has been defined as the simultaneous experience of positive and negative feelings toward the care recipient (Fingerman, Pitzer, Lefkowitz, Birditt, & Mroczek, 2008; Willson, Shuey, & Elder, 2003). It is a complex experience that resembles the feeling of being "divided in two directions" (Pillemer et al., 2007). Although this type of ambivalent attitude or emotion has been studied to a greater extent in other areas (e.g., intergenerational relationships; Birditt, Fingerman, & Zarit, 2010; Pillemer, Munsch, Fuller-Rowell, Riffin, & Suitor, 2012; Pillemer et al., 2007), it is not uncommon for caregivers to report simultaneously experiencing negative and positive emotions associated with care (Shim, Barroso, & Davis, 2012), an internal conflict that is typically perceived as aversive by the individual (Pillemer et al., 2007). Recently, Losada, Pillemer, Márquez-González, Romero-Moreno, and Gallego-Alberto (2017) developed and tested the Caregiving Ambivalence Scale, finding that ambivalent feelings (e.g., feeling both satisfaction and resentment due to caregiving) contributed significantly and positively to the explanation of depressive and anxious symptomatology in caregivers. Apart from this, there are also studies that have found data in favor of ambivalence being especially likely to arise when disruptive behaviors by the person with dementia are frequent and stressful for the caregiver (Pillemer & Suitor, 2005). The association of disruptive behaviors and ambivalence is not surprising because such behaviors often act as triggers of negative emotions in caregivers, mingling with the positive feelings that are frequently associated with the care of a loved relative (Losada et al., 2018). However, although disruptive behaviors of the care recipient seem to be associated with experiencing ambivalent feelings, the process through which this occurs and which variables intervene is unclear.

One of the variables that could be contributing to the effect of disruptive behaviors in the development of ambivalent feelings is cognitive fusion. Cognitive fusion has been defined as the tendency for behavior to be overly regulated and influenced by cognition.

When ‘fused,’ a person acts on thoughts as though they are literally true, cognitive events come to dominate behavior and experience over other sources of behavioral regulation (Gillanders et al., 2014). In recent years there has been a significant increase in interest in the study of cognitive fusion, which has been indicated as a highly relevant variable, significantly and positively related to psychopathological problems such as anxiety (Herzberg et al., 2012) and depression (Dinis, Carvalho, Pinto-Gouveia, & Estanqueiro, 2015). Specifically, recent studies suggest that cognitive fusion may play an important mediating role in the explanation of the relationship between the experience of chronic stressful life events (e.g., cancer) and anxiety (Gillanders, Sinclair, MacLean, & Jardine, 2015). Although cognitive fusion has scarcely been studied among the caregiver population, recent studies have found that caregivers of people with dementia who report a higher frequency of disruptive family behaviors as well as high levels of cognitive fusion also report higher levels of depressive and anxious symptomatology (Romero-Moreno, Márquez-González, Losada, Fernández-Fernández, & Nogales-González, 2015). However, to our knowledge, there are no studies that examine the relationship between cognitive fusion and other outcome variables such as emotional ambivalence.

Taking into consideration the aforementioned issues and following the stress and coping model adapted to caregiving (Knight & Sayeh, 2010), the aim of the present study was to explore the role played by cognitive fusion in the association between care-recipients’ disruptive behaviors and caregivers’ ambivalent feelings. In particular, our aim was to analyze the degree to which cognitive fusion exerts a mediating role in the explanation of the relationship between the disruptive behaviors of people with dementia (frequency of disruptive behaviors and reaction to these behaviors) and the experience of ambivalence in caregivers.

Our hypothesis is that a higher frequency of and reaction to disruptive behaviors of the care-recipient is associated with a higher level of cognitive fusion of the caregivers, that is, the tendency to assume the literality of thought. In turn, high levels of cognitive fusion may be linked to a higher frequency of negative emotions towards the care-recipient, which add to the positive feelings that are usually associated with caring for a loved one, thus increasing emotional ambivalence. In other words, we hypothesized that the variable cognitive fusion could act as a mediator in the relationship between frequency of and reaction to disruptive behaviors and feelings of ambivalence in caregivers.

5.3 Method

5.3.1 Participants

Participants in this study were 364 family caregivers of people with dementia. Inclusion criteria were: a) considering oneself to be the principal caregiver of a relative with dementia, b) devoting at least one hour per day to caring for the family member, c) having been a caregiver for at least three consecutive months, and d) being at least 18 years old. Five extreme cases were obtained in the frequency of and reaction to disruptive behaviors variables. In addition, three multivariate outliers (Mahalanobis distance of $p< .001$) were obtained. Therefore, the sample was reduced to 356 participants. The sociodemographic characteristics of the sample are shown in Table 5.1. The sample consisted mainly of women (76.10%) and had a mean age of 61.53 years (*SD*= 13.70). Participants reported having provided care for a mean of 46.44 months (*SD*= 42.72) and devoting approximately half a day caring for their relative 13.62 (*SD*= 8.06).

Table 5.1. Characteristics of the sample (N=356)

	Total	Male (*n*= 85)	Female (*n*= 271)
Caregivers' age			
M	61.50	64.82	60.46
SD	13.70	15.48	12.95
Range	21-87	29-87	21-86
Time since becoming a caregiver (months)			
M	46.44	47.41	46.13
SD	42.72	55.70	37.87
Range	3-444	3-444	3-300
Daily hours caring			
M	13.62	14.04	13.49
SD	8.06	8.05	8.07
Range	1-24	1-24	1-24

5.3.2. Instruments

Apart from sociodemographic information (gender, caregivers' age, time being a caregiver, and number of daily hours devoted to caregiving), the following variables were measured:

a) *Revised Memory and Behavior Problems Checklist* (Teri et al., 1992), Spanish version by Nogales, Losada, & Romero-Moreno (2015). This checklist measured how often the person with dementia displayed disruptive behaviors and how the caregiver reacted to them using the subscales of frequency of disruptive behaviors and reaction to disruptive behaviors. Both subscales comprise eight Likert-type scale items. In the frequency subscale, each item (e.g., "aggressive to others verbally") is rated on a scale ranging from 0 ("never occurs") to 4 ("occurs daily or more often"). In the reaction to disruptive behavior subscale, each item (e.g., "how much has this bothered or upset you?") is rated from 0 ("not at all") to 4 ("extremely"). A total score is obtained by summing the eight individual frequency and reaction scores, with higher scores reflecting greater severity of disruptive problems. The internal consistency (Cronbach's α) for the frequency of disruptive behaviors and reaction subscales in this sample was .60 and .68 respectively, similar findings to those originally obtained by Teri et al. (1992) and by Nogales et al. (2015).

b) *Cognitive Fusion Questionnaire* (CFQ; Gillanders et al., 2014), Spanish version by Romero-Moreno, Márquez-González, Losada, Gillanders, & Fernández-Fernández (2014). This scale measures the tendency to believe in the literal content of thoughts and feelings. Seven items (e.g., "I feel so trapped in my thoughts that I am unable to do the things I really want to do") are rated on a Likert-type scale ranging from 1 (Never) to 7 (Always). The scores of the items are summed in order to get a total score of the measure, with higher scores reflecting higher cognitive fusion. The internal consistency (Cronbach's alpha) for this scale in the present study was .88.

c) *Caregiving Ambivalence Scale* (CAS, Losada et al., 2017). The CAS measures ambivalent feelings in dementia family caregivers. This is a 5-item scale (e.g., "I have mixed feelings towards my relative [tenderness-rage, love-hate, etc.]") that assesses the degree to which caregivers' feelings toward their relative are mixed or conflicted. Participants are asked to select the option that best describes their feelings during the last month. Each item is rated on a Likerttype scale that ranges from 0 ("Never") to 3 ("Always"). The scores in the five items are summed in order to obtain a total score, with higher scores reflecting more ambivalent feelings. Cronbach's alpha coefficient for this scale was .87 in this study.

5.3.3 Procedure

Participants were recruited through different social services and health care centers of the Community of Madrid (Spain) and through media outreach such as Internet. The first contact was established by telephone to verify if the participants met the inclusion criteria of the study. Once this was established, face-to-face interviews were conducted in the participating centers. Caregivers gave their informed consent to participate in the study, which was approved by the Spanish Ministry of Economy and Competitiveness as well as by The Ethics Committee of Rey Juan Carlos University (Madrid).

5.3.4 Data analisis

Following Tabachnick and Fidell (2001) criteria, analyses for sample normality and outliers (univariate and multivariate) were conducted. Descriptive data (means, standard deviations, ranges, and frequencies) were calculated for the assessed variables.

In order to investigate the relationship between variables, correlation analyses were run. The IBM SPSS Statistics program, version 22.0 (IBM, 2013) was used for all analyses. In order to analyze the association between the variables, a theoretical model was developed, drawing on the stress and coping model adapted to caregiving (e.g., Knight & Sayegh, 2010). The following variables were included: sociodemographic variables (gender, caregivers' age, time since becoming a caregiver, and number of daily hours devoted to caregiving), demands or stressors (frequency of disruptive behaviors and reaction to disruptive behaviors), potential mediator (cognitive fusion) and, as the outcome variable, ambivalent feelings. First, all the associations between variables that had been shown to be significant in the correlation analyses were included as paths in the model. Next, following the model-generation strategy (Joreskog & Sörbom, 1993), only those associations between the variables that were observed as significant once the first path analysis was run were included in the final model. In addition to the chi square ($\chi2$) statistic, the chi square value divided by the degrees of freedom ($\chi2/df$) was considered, with values under or near 3 indicating good model fit (Bollen, 1989). The root mean square error of approximation (RMSEA), the normed fit index (NFI) and the Tucker-Lewis index (TLI) were also evaluated as additional indicators of model fit, considering Hu and Bentler's (1998) indications of values under .06 (RMSEA) and over .95 (NFI and TLI) as indicating excellent fit of the data to the model. Finally, mediation was analyzed following the bootstrapping approach recommended by Preacher and Hayes (2004) using 1000 bootstrap samples. IBM SPSS Amos version 21.0.0 was used for these analyses.

5.4 Results

Correlational analyses

The results of the correlational analyses are shown in Table 5.2. Significant and positive associations between the variables frequency of disruptive behaviors, reaction to disruptive behaviors, cognitive fusion and ambivalence were obtained (in all cases p < .01). Caregivers' age was significantly and negatively correlated with cognitive fusion and ambivalence. The results also showed a positive and significant association between gender (being female), frequency and reaction to disruptive behaviors, cognitive fusion and ambivalence. Time since becoming a caregiver was significantly and negatively correlated with cognitive fusion, but showed no relation to any of the other variables in the model. Finally, the number of daily hours devoted to caregiving showed a significant and negative association with ambivalence.

Table 5.2. Pearson correlations between the assessed variables

Variables	1	2	3	4	5	6	7
1. Gender (0= female)	-						
2. Caregiver age	.14*	-					
3. Time since becoming a caregiver	.01	.17*	-				
4. Daily hours caring	.03	.33**	.01	-			
5. Frequency of disruptive behaviors	-.21**	-.13*	.04	.03	-		
6. Reaction to disruptive behaviors	-.20**	-.13*	.03	-.06	.79**	-	
7. Cognitive fusion	-.26**	-.18**	-.12*	-.04	.21**	.28**	-
8. Ambivalent feelings	-.28**	-.23**	-.04	-.12*	.38**	.48**	.47**

Note: **p*< .05; ***p*< .01.

Path model for explaining relationship between stressors and ambivalent feelings

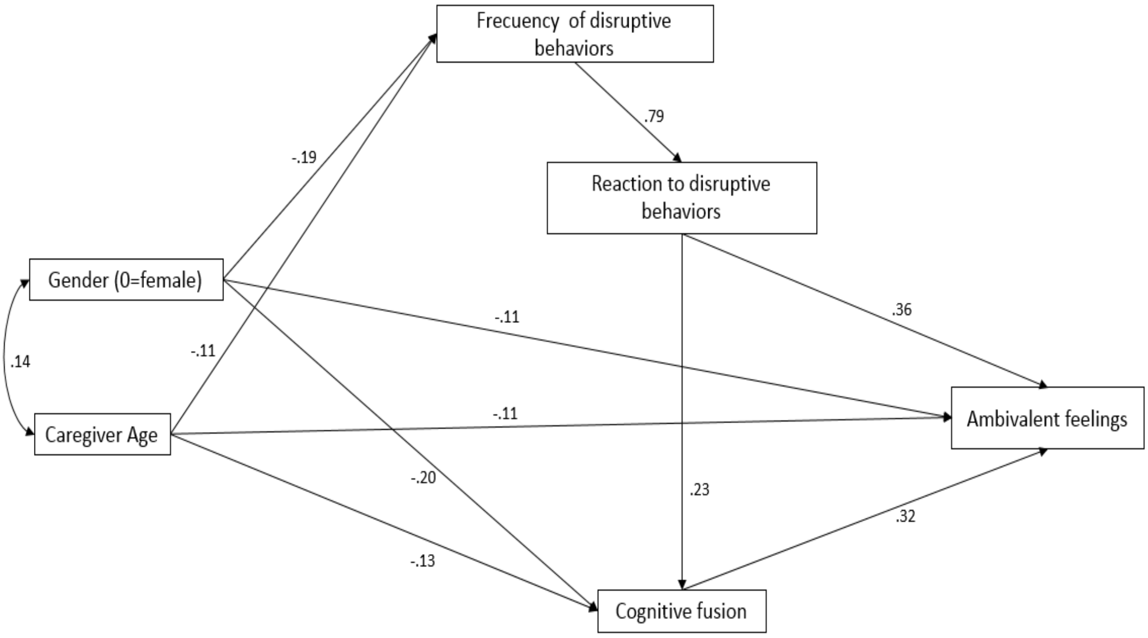
Figure 5.1 shows the associations obtained through the path analysis for ambivalent feelings, including all the significant associations between variables. Time since becoming a caregiver and number of daily hours devoted to caregiving were initially introduced in the model, but were discarded in the final model because no significant associations with the rest of the variables included in the model were obtained.

As can be seen, all the variables (except frequency of disruptive behaviors) have a direct association with ambivalence. Female and younger caregivers, with higher stress reactions to disruptive behaviors and with higher scores in cognitive fusion report more ambivalence.

In addition to the direct associations, additional indirect influences on ambivalence were found. Even though a significant positive association between frequency of disruptive behaviors and ambivalence was observed in the correlation analyses, this association is no longer significant when all the variables are considered together in the model. The results suggest that frequency of disruptive behaviors have an indirect association with ambivalence through its influence on reaction to disruptive behaviors. The results of the bootstrap analysis for testing mediation suggest that this indirect association is significant (standardized indirect effect: .34, $p < .01$, SE= .04, CI= .27-.41). In addition, even though a significant and positive correlation was observed between frequency of disruptive behaviors and cognitive fusion, this association was not significant in the model. The influence of frequency of disruptive behaviors on cognitive fusion is indirect, through its influence on reaction to disruptive behaviors, as was found through the analysis for testing mediation (standardized indirect effect: .18, $p < .01$, SE= .04, CI= .12-.25). These findings suggest that caregivers who experience a higher frequency of disruptive behaviors also have a more stressful reaction to these behaviors and get more cognitively fused. Finally, there is also an indirect influence of reaction to disruptive behaviors on ambivalence through the influence of reaction on cognitive fusion. Again, the results of the bootstrap analysis for testing mediation suggest that this association is significant (standardized indirect effect: .07, *p*< .01, SE=.02, CI= .05-.11). Caregivers who report being more stressed due to their care-recipients' disruptive behaviors are more cognitively fused, and this association seems to increase their ambivalence.

The final model explained 37% of the variance of caregiver's ambivalent feelings. The obtained fit indices suggest an excellent fit of the path model to the data (χ^2= 2.674; *p*= .614; χ^2/df=.669; RMSEA= .000; NFI= .996; TLI= 1.009).

Figure 5.1. Path analysis testing the role of frequency of and reaction to disruptive behaviors and cognitive fusion in caregiver's ambivalent feelings



Note: All associations are significant (*p*< .05). The errors have been omitted for ease of presentation.

5.5 Discussion

The objective of this study was to analyze the role of cognitive fusion in the model of caregiver stress and to explore the role of this variable as a contributor to caregivers' ambivalent feelings. Concretely, our goal was to analyze if cognitive fusion acts as mediator in the relationship between frequency of and reaction to disruptive behaviors and ambivalence in caregivers. To our knowledge, this is the first study that simultaneously analyzes the relationship between the variables frequency of disruptive behaviors, reaction of the caregivers to relative's disruptive behaviors, cognitive fusion and ambivalent feelings.

The results obtained coincide with previous studies in that the frequency of and reaction to disruptive behaviors of the care recipient are significantly and positively associated with caregiver's ambivalent feelings (Losada et al., 2017, 2018). In addition, the results also confirm the relationship observed in previous studies between the frequency of care-recipients' disruptive behaviors and caregivers' cognitive fusion (Romero-Moreno et al., 2014). However, as far as we know, this is the first study that analyses the association between the variable cognitive fusion and ambivalent feelings, variables which, as observed in the results of this study, show a significant and positive relationship. The results also suggest that the frequency of disruptive behaviors is not associated with ambivalence in a direct way, but in an indirect one, with this association being explained through two paths: 1) caregivers´ reaction to disruptive behaviors acts as a mediator in the relationship between the frequency of disruptive behaviors and ambivalence; and 2) the impact of caregiver's reaction to disruptive behaviors on ambivalent feelings is mediated by through cognitive fusion.

In conclusion, it can be said that our initial hypotheses are confirmed. Intense stress reactions to care recipients´ disruptive behaviors are associated with an inadequate cognitive functioning of the caregivers (increased levels of cognitive fusion), thus facilitating the emergence and/or maintenance of negative emotions towards their relative. These negative emotions add to the positive feelings that are usually associated with caring for a loved relative, thus increasing the emotional ambivalence. These findings provide support for the stress and coping model (Knight & Sayegh, 2010), which postulates that the influence of stressors (e.g., disruptive behaviors) on caregiving consequences (in this study, ambivalence) is modulated by other variables (in this study, reaction to disruptive behaviors and cognitive fusion). Although the cross-sectional nature of this study prevents us from reaching causal conclusions, the results obtained suggest an interesting path through which disruptive behaviors can contribute to increasing caregivers´ distress (emotional ambivalence), because more intense reactions to disruptive behaviors seem to be associated with higher levels of cognitive fusion among caregivers.

These results have several implications for practice. In the clinical setting, it can be hypothesized that caregivers' distress may be reduced by intervening in two areas. First, behavioral interventions for decreasing the frequency of care-recipients' disruptive behaviors or the reaction of caregivers to these behaviors (e.g., Bravo-Benítez & Navarro-González, 2018; Logsdon, McCurry, & Teri, 2007) may reduce not only the sources of distress but may also minimize the chances of caregivers getting fused with their thoughts, and the likelihood of the emergence of negative emotions towards the care-recipient. In addition, the use of acceptance-based strategies (e.g., acceptance and commitment therapy, ACT; Hayes, Strosahl, & Wilson, 1999) that include cognitive fusion as a main target of the interventions as well as a mediator of the impact of these interventions (Zettle, Rains, & Hayes, 2011) may be also helpful. According to this idea, ACT-based interventions could be useful in caregivers by promoting the opposite mechanism to cognitive fusion, that is, cognitive defusion; this implies teaching caregivers skills to help them distance themselves from their own thoughts through acceptance, thus diminishing the power their thoughts have over behavior, without directly attempting to modify their content (Losada et al., 2015).

This study presents several limitations that should be mentioned. First, as already noted, the cross-sectional design of the study prevents causal inferences. The direction of the associations that are shown in the model may be different. For example, cognitive fusion may increase the reaction to disruptive behaviors. Therefore, it is necessary to treat the results with caution, and future experimental and longitudinal studies to confirm the data obtained here are recommended. Second, the sample was composed of caregivers who participated voluntarily in this study, which limits the generalization of the results to the rest of the caregiver population. Despite these limitations, the results of this study suggest that the frequency of disruptive behaviors of the care recipient may have not only a direct effect on caregivers' ambivalent feelings. The results suggest that the influence of these behaviors on ambivalence can be mediated by cognitive fusion, as well as by the discomfort associated with the disruptive behaviors of the relatives (reaction to disruptive behaviors). High levels of reaction to disruptive behaviors could place caregivers in a situation of vulnerability to ambivalent feelings, making it difficult for them to distance themselves from their thoughts and develop a more adaptive coping with the stressors and demands associated with caregiving.

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Estudio Dos

Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers

Publicado en: Barrera-Caballero, S., Romero-Moreno, R., del Sequeros Pedroso-Chaparro, M., Olmos, R., Vara-García, C., Gallego-Alberto, L., ... & Losada-Baltar, A. (2021). Stress, cognitive fusion and comorbid depressive and anxiety symptomatology in dementia caregivers. *Psychology and Aging, 36*(5). 667-676. https://doi.org/10.1037/pag0000624

6. Estudio Dos: Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers

6.1. Abstract

Comorbid depression and anxiety is linked to worse outcomes such as increased impairment, distress, and morbidity, as well as worse treatment outcomes. Transdiagnostic variables such as cognitive fusion are considered potential factors for explaining comorbidity. The aim of this study was to analyze the differences between symptom profiles of caregivers (comorbid, depressive, anxiety, and subclinical) in terms of demographic and contextual factors, stress variables, and cognitive fusion. Individual interviews were conducted with 553 caregivers of a relative with dementia. Sociodemographic variables, stressors, cognitive fusion, and depressive and anxiety symptoms were assessed. Caregivers were grouped into four symptom profiles, comorbid (n = 303), depressed (n = 40) anxiety (n = 86), and subclinical (n = 124), based on their depressive and anxiety symptoms. The likelihood of presenting a comorbid profile relative to the subclinical profile was higher in female caregivers. In addition, higher frequency of disruptive behaviors of the care recipient was a risk factor for presenting a comorbid profile relative to the other three profiles, and higher scores in cognitive fusion were a risk factor of comorbidity relative to the other profiles (anxiety, depressive, and subclinical). The findings suggest that the likelihood of presenting comorbid symptomatology is higher for female caregivers and those reporting higher levels of cognitive fusion and higher frequency of disruptive behaviors. These characteristics may describe a vulnerable profile of dementia family caregivers.

Keywords: caregivers, cognitive fusion, comorbid anxiety and depressive symptoms, dementia

6.2. Introduction

Dementia family caregiving involves coping with frequent and diverse situations and tasks that caregivers can find difficult and demanding (Alzheimer's Association, 2018). In addition to time devoted to care or hours caring (Hirst, 2005), the behavioral and psychological symptoms of dementia (BPSD) displayed by their relatives, mostly disruptive behaviors such as aggressiveness, are considered sources of stress for caregivers (e.g., Fauth & Gibbons, 2014; Nogales-González et al., 2015). These issues are frequently associated with negative consequences for caregivers' psychological and physical health (e.g., Gilhooly et al., 2016), even though dementia caregiving may also be related to positive aspects, such as experiencing sense of meaning, personal growth, mastery, or gratitude, associated with better caregiver well-being (Quinn & Toms, 2019). Hence, although dementia caregiving can be a stressful context, not all caregivers experience negative and/or positive consequences in the same way.

Most of the research studying the effects of caregiving on caregivers' psychological health has focused on depressive symptomatology. This may in part be due to the high prevalence of this particular outcome variable in the caregiver population, mostly in female and spousal caregivers (Pinquart & Sörensen, 2003).

Regarding prevalence data of mental health disorders, a recent meta-analysis conducted by Collins and Kishita (2019) showed that the adjusted prevalence estimate of depression among caregivers of people with dementia was 31.24%; thus, around 1 in 3 such caregivers suffer from depression. Even though most of the research on psychological consequences of caregiving has focused on depression or depressive symptoms, anxiety symptoms are also reported as frequent in the caregiver population, although this variable has been less studied than depressive symptoms (Cooper et al., 2008; Kaddour & Kishita, 2020). The recent meta-analysis carried out by Kaddour and

Kishita (2020) reported that clinically relevant levels of anxiety symptoms are present in 42.6% of the caregivers.

Depressive and anxiety symptoms have been very extensively studied as outcome variables in the caregiver population but have mostly been analyzed separately. However, depressive and anxiety symptomatology can also appear simultaneously in caregivers. Mahoney et al. (2005) found that an 8.5% of their sample presented clinically significant levels for both anxiety and depression levels, as assessed through the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and Joling et al. (2015), using a clinical diagnostic interview, found that 32% of spousal caregivers or relatives with dementia presented a comorbid presentation of anxiety and depression. Results in caregiver populations from areas other than dementia have also shown high prevalence of concurrent anxiety and depressive symptoms. For example, similar comorbidity rates have been reported for caregivers of children with cystic fibrosis (Driscoll et al., 2009; Quittner et al., 2014).

Comorbidity is a frequent psychopathological phenomenon, suggesting that clinical mental health symptomatology may share common or transdiagnostic core pathological processes (Hayes & Hofmann, 2018; Newby et al., 2015). For this reason, researchers have developed transdiagnostic (Norton, 2012) or unified (Barlow et al., 2010) approaches, aimed at identifying "cognitive and behavioral processes that are common across a range of depressive and anxiety conditions" (Andersen et al., 2016, p. 674). Psychological inflexibility is considered to be a transdiagnostic process that refers to the rigid attachment to internal experiences (Hayes et al., 2011). The opposite process, that is, psychological flexibility, is defined as "the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends" (Hayes et al., 2006, p. 7). Levin et al. (2014) found in the general population that psychological inflexibility is related more to comorbid depression, anxiety, and substance use disorders than to only having one of these disorders. Therefore, the authors suggest that psychological inflexibility may be a transdiagnostic pathological core process and an important target for interventions.

Psychological inflexibility is a higher order construct, one of its core and transdiagnostic subprocess being cognitive fusion (Hayes et al., 2011). Cognitive fusion is a tendency for behavior that is overly regulated and influenced by cognition, in contrast to distancing from thoughts. “When ‘fused,’ a person acts on thoughts as though they are literally true, cognitive events come to dominate behavior and experience over other sources of behavioral regulation, and he or she becomes less sensitive to direct consequences” (Gillanders et al., 2014, p. 84). The attention and behavior of people with high levels of cognitive fusion are dominated by the verbal content of their thoughts, without being aware of the thought process itself, moving the person away from the relevant personal goals and values of his or her life (Gillanders et al., 2014). Several studies have found a strong and positive association of cognitive fusion with depressive and anxiety symptoms in clinical and subclinical general populations (Carvalho et al., 2019; Gillanders et al., 2014; Herzberg et al., 2012). Gillanders et al. (2015) also highlighted in a crosssectional study that cognitive fusion shows a potential indirect effect in the relationship between the experience of chronic stressful life events (e.g., cancer) and anxiety. In the field of caregiving, cognitive fusion also seems to have a potential indirect effect in the relationship between frequency of disruptive behaviors and caregivers’ ambivalent feelings (Barrera-Caballero et al., 2019). Despite the paucity of studies, caregivers with higher levels of cognitive fusion have been found to show more severe depressive and anxiety symptoms (Romero-Moreno et al., 2014). These findings seem to support the potential relevance of cognitive fusion in explaining both depressive and anxiety symptoms. However, to our knowledge, there are no studies analyzing this transdiagnostic dimension as an explanation of caregivers' comorbid depressive and anxiety symptomatology.

Taking into account the prevalence of comorbidity between depression and anxiety that has been reported in family caregivers of people with dementia (Joling et al., 2015), identifying aspects of the central process of distress in caregivers outlined above could be important for explaining this comorbid manifestation of symptoms, and for helping to make decisions about clinical evaluation and interventions.

The aims of this study were: (a) to analyze the differences between caregivers' symptom profiles (comorbid, depressive, anxiety, and subclinical) in contextual and demographic variables, as well as in stressors (time devoted to care, frequency and reaction to disruptive behaviors, BPSD) and the characteristics of care recipients and caregivers, such as gender, age or kinship, and (b) to analyze the role of cognitive fusion as a central transdiagnostic process in the comorbid presentation of depressive and anxiety symptoms in dementia family caregivers, as compared with depressive, anxiety and subclinical symptoms, but also controlling for the effects of the other assessed variables, which may be related to comorbid depressive and anxiety symptoms.

We hypothesize that caregivers presenting higher levels of cognitive fusion would be at greater risk of suffering comorbid depressive and anxiety symptoms than the other profiles. Also, those reporting higher stress levels would be at greater risk of presenting comorbid symptomatology.

6.3. Methods

6.3.1. Participants and Procedure

A total of 553 face-to-face interviews were conducted with caregivers of relatives suffering from dementia or related disorders. Participants were recruited through social and health centers from the Autonomous Community of Madrid. They were informed about the study by telephone, and an appointment for an interview was arranged if they met the following inclusion criteria: a) considering themselves the main caregiver, (b) devoting at least 1 hr per day for the last three consecutive months to caring tasks, and (c) being at least 18 years old. All participants were recruited in the context of different studies that shared the same design for obtaining baseline data (Losada et al., 2015, 2017; Márquez-González et al., 2020). A total of 673 potential participants were contacted and 120 (17.89%) declined to participate. Caregivers agreed to participate voluntarily in the studies and signed the informed consent. The studies were approved by the Spanish Ministry of Science and Innovation and the Ethics Committee of the Universidad Rey Juan Carlos (Madrid, Spain).

6.3.2 Variables and Measures

Caregivers' data on gender, kinship, and age were obtained, as well as care-recipients' gender and type of dementia diagnosed. Data on care-recipients' gender were not available for 29 subjects. Considering previous studies showing differences between spousal and other caregivers (e.g., adult children and children-in-law; Pinquart & Sörensen, 2011), the kinship variable was recoded in two categories: spouses (wives/husbands) (42.3%) versus others (adult children and other relatives such as sisters, uncles, fathersand mothers-in-law) (57.7%). Daily hours devoted to caregiving, and time since being a caregiver were assessed as potential stressor variables. The stage of the disease of the care recipient was measured through the Global Deterioration Scale (GDS; Reisberg et al., 1982), although data were not available for 41 subjects. In addition, the following variables were assessed.

Frequency and Reaction to Disruptive Behaviors

We used the Spanish version (Nogales-González et al., 2015) of the frequency and reaction subscales of the disruptive behaviors dimension of the Revised Memory and Behavior Problems Checklist (Teri et al., 1992). The frequency subscale consists of eight items measuring how often the person who has dementia behaves disturbingly (e.g., “Destroying property” “Arguing, irritability, and/ or complaining”), ranging from 0 (never occurred) to 4 (occurs daily or more often). The reaction subscale measures caregivers’ reaction to those eight behaviors (e.g., “How much has this behavior upset you?”) with responses ranging from 0 (not at all) to 4 (extremely). In this study, internal consistency (Cronbach’s α) for the frequency of disruptive behaviors subscale was 0.66, and 0.73 for the reaction to these behaviors subscale, similar to those reported in the original study (Teri et al., 1992). Average reaction rating score was calculated following suggestions by Teri et al. (1992) and Roth et al. (2003). For disruptive behavior problems that were not reported, reaction was coded as missing. It is thus possible for caregivers to have high average reaction ratings even when the number ofreported disruptive behaviors is small (Roth et al., 2003).

Cognitive Fusion

The Spanish version (Romero-Moreno et al., 2014) of the Cognitive Fusion Questionnaire (Gillanders et al., 2014) was used. The scale is composed of seven items that measure different facets of cognitive fusion such as reacting emotionally to thoughts (e.g., "My thoughts cause me distress or emotional pain"), behavior being highly regulated by cognitive events (e.g., "I get so caught up in my thoughts that I am unable to do the things that I most want to do") and attempts to control thinking (e.g., "I struggle with my thoughts"). Answers range from 1 (never) to 7 (always). The internal consistency (Cronbach's α) for this study was 0.89.

Depressive Symptomatology

The level of depressive symptomatology was assessed using the Spanish version of the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) validated in dementia family caregivers in Spain (Losada et al., 2012). This is a 20-item scale (e.g., "Ifelt sad"; "I cried sometimes") that assesses how often people felt depressive symptoms during the previous week. Scores for each item range from 0 (rarely or none of the time—less than 1 day) to 3 (most or all of the time—5–7 days) on a Likert-type scale. Scores equal to or over 16 on this scale are associated with clinically significant depressive symptomatology (Radloff, 1977). The internal consistency (Cronbach's α) in this study was 0.89.

Anxiety Symptomatology

The Tension subscale of the Profile of Mood States Scale (POMS; McNair et al., 1971) was used to assess the level of anxiety. This subscale consists of nine items (e.g., "How often have you felt irritable?"), each ranging from 1 (not at all) to 4 (extremely) on a Likert-type scale. Scores equal to or over 13 on this scale are associated with a clinically significant level of anxiety (Losada et al., 2015). The internal consistency (Cronbach's α) in this study was 0.90.

6.3.3. Data Analysis

Following Tabachnick and Fidell (2001) criteria, the sample was checked for normality and presence of univariate and multivariate outliers. Five extreme cases were detected in the scores for frequency of and reaction to disruptive behaviors variables and time since being a caregiver. In addition, five multivariate outliers (Mahalanobis distance of $p < .001$) were detected. We then performed the analysis with and without the inclusion of extreme cases and results were the same. Therefore, we decided to keep the full sample (to gain power and to avoid the arbitrary decision to remove some cases).

Univariate descriptive statistics (means, standard deviations, ranges, and frequencies) and Pearson correlation analyses were analyzed.

The sample was grouped into four symptom profiles of caregivers according to the cut-off point of CES-D (≥16) (Radloff, 1977) and POMS (≥13) (McNair et al., 1971) scales. The following groups or symptoms profiles were created: (a) Comorbid profile: high levels of both depressive and anxiety symptomatology, (b) Depressive profile: high depressive symptoms and low anxiety symptoms, (c) Anxiety profile: low depressive symptoms and high anxiety symptoms, and (d) Subclinical profile: low levels of depressive and anxiety symptomatology. We analyzed potential differences between the four profiles in contextual and sociodemographic factors (caregivers and care-recipients' characteristics), stressors, and cognitive fusion using ANOVAs (using Tukey's pairwise comparisons procedure to control Type-I error rate) and chi-square tests for quantitative and categorical variables, respectively.

6.4 Results

Participant characteristics

The sample was composed of 553 dementia family caregivers, mostly female (72.30%). Participants had been caregivers for a long period (average of 45.96 months, SD: 35.04; range: 3-192), reporting an average of 13.34 daily hours (SD: 8.05; range: 1-24) caring of their relative. The average age of the participants was 61.76 years (SD: 13.74 range: 21-88). Regarding kinship, 42.30% of caregivers provided care for their spouses, 51.90% for their parents, and the rest of the participants (5.8%) took care of other relatives (e.g., sisters, uncles, fathers-in-law and mothers-in-law). Regarding the care recipient characteristics, the majority of them were female (59.5%) and the majority were diagnosed with Alzheimer's disease (66.7%). The remaining care recipients were diagnosed with other dementias (29.3 %) and mild cognitive impairment (4%). Finally, most of the care recipients had moderate or severe cognitive impairment (85.8%).

Most of the caregivers reported comorbid depressive and anxiety symptomatology (comorbid profile; n = 303, 54.8%). The remaining participants were grouped into depressive profile (n = 40, 7.2%), anxiety profile (n = 86, 15.6%) and subclinical profile (n = 124, 22.4%).

Descriptive information and correlational analysis of the assessed variables

Univariate descriptive statistics and Pearson correlations for the study variables are shown in Table 6.1. According to the hypotheses of the study, cognitive fusion was positively associated with both depressive (r = .55; *p* < .001) and anxiety symptoms (r = .56; *p* < .001). In addition, cognitive fusion was also associated with frequency of disruptive behaviors (r = .18; p < .001) and reaction to these behaviors (r = .28; p < .001). Frequency of disruptive behaviors and reaction to these behaviors were positively associated with depressive symptoms (r = .25; p < .001; r = .30; p < .001, respectively) and anxiety symptoms (r = .29; p < .001; r = .31; p < .001, respectively). Depressive and anxiety symptoms were themselves highly positively correlated (r = .71; *p* < .001). Male caregivers reported less frequency and reaction to disruptive behaviors (r = -.15; p < .001; r = -.17; p < .001), cognitive fusion (r = -.21; p < .001), and depressive (r = -.28; p < .001) and anxiety symptomatology (r = -.26; *p* < .001). Caregivers' age was negatively associated with frequency of disruptive behaviors (r = -.12; *p* = .005), cognitive fusion (r = -.20; *p* < .001), and anxiety symptoms (r = -.15; *p* = .001), but positively associated with daily hours caring (r = .36; *p* < .001) and time since being a caregiver (r = .12; p < .001). Also, when the cared person was a male, it was positively associated with caregivers' age (r = .29; p < .001), daily hours caring (r = .18; *p* < .001), and depressive symptoms (r = .13; *p* =.002). Regarding kinship, being a spousal caregiver was associated with being older (r = -.74; p < .001), more daily hours caring (r = -.42; p < .001), lower anxiety levels (r =.14; *p* < .001), and lower cognitive fusion levels (r = .19; *p* < .001).

Table 6.1. Descriptive statistics (range, mean, and standard deviation) and Pearson correlations (N = 553)

Measure	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*Range*	*M*	*SD*
1. Caregiver gender (0 = female)	_										_	_	_
2. Care-recipient gender (0 = female) #	-34**	_									_	_	_
3. Kinship (0 = spouse)	-.17**	-.51**	_								_	_	_
4. Caregivers' age	.15**	.29**	-.74**	_							21-88	61.76	13.74
5. Daily hours caring	.03	.18**	-.42**	.36**	_						1-24	13.34	8.05
6. Time since being a caregiver	-.02	-.03	-.02	.12**	-.03	_					3-192	45.96	35.04
7. Frequency of disruptive behaviors	-.15**	.04	.09*	-.12**	-.01	.01	_				0-28	7.07	5.54
8. Reaction to disruptive behaviors †	-.17**	.08⁎	.09	-.06	-.05	-.06	.30**	_			0-32	14.58	9.45
9. Cognitive fusion	-.21**	-.04	.19**	-.20**	-.06	-.07	.18**	.28**	_		7-49	24.81	10.31
10. Depressive symptoms	-.28**	. 13**	-.00	-.03	.07	-.03	.25**	.30**	.55**	_	0-51	20.67	11.57
11. Anxiety symptoms	-.26**	.04	.14**	-.15**	.00	.01	.29**	.31**	.56**	.71**	0-36	17.78	8.33

*p < .05; ** p <. 01; *M* = Mean; *SD* = Standard deviation; *#N =524; †N = 508; ⁎N = 481.*

Differences between symptom profiles in the assessed variables

Differences between symptom profiles in the sociodemographic and assessed variables are reported in Table 6.2. There were significant differences between symptom profiles in demographic factors. The comorbid profile was significantly associated with being a female caregiver (62.0% vs. 35.9%; Z = 5.5), while the subclinical profile was associated with being a male caregiver (44.4% vs. 14.0%; Z = 7.7). In addition, it was found that subclinical profile was associated with a spousal relationship between caregiver and care recipient compared to parent or other kinship situations (27.8 % vs. 18.5%; Z = 2.6). We found significant differences between the profiles and age: the caregiver comorbid profile was younger than the depressive (p = .025), and subclinical (p = .019) profiles, and the caregiver depressive profile was significantly older than the anxiety profile (p = .046).

In addition, there were significant differences between symptom profiles in frequency and reaction to disruptive behaviors, and in cognitive fusion. Specifically, caregivers in the comorbid profile reported higher frequency of disruptive behaviors of the care recipient than depressive, anxiety and subclinical profiles (p < .001). Also, caregivers in the comorbid profile showed higher reaction to these behaviors than depressive (p =.016), anxiety and subclinical profiles (p < .001). Differences between symptom profiles in daily hours caring and time since being a caregiver were non-significant. Caregivers in the comorbid profile presented higher levels of cognitive fusion than depressive, anxiety and subclinical profile (p < .001).

Table 6. 2. Differences between symptom profiles in the assessed variables (N = 553)

	Comorbid profile (*N* = 303, 54.8%)	Depressive profile (*N*=40, 7.2%)	Anxiety profile (*N*=86, 15.6%)	Subclinical profile (*N* = 124, 22.4%)	*F*, X^2	*p*	*Post-hoc pairwise comparisons (Tukey, α = .05)*
Caregiver gender, n (row %)					62.66	.000**	
Male caregivers	55 (35.9%)	6 (3.9%)	24 (15.7%)	68 (44.4%)			-
Female caregivers	248 (62.0%)	34 (8.5%)	62 (15.5%)	56 (14.0%)			
Kinship, n (row %)					8.43	.038*	
Spouse	122 (52.1%)	18 (7.7%)	29 (12.4%)	65 (27.8%)			-
Son/Daughter and Others	181 (56.7%)	22 (6.9%)	57 (17.9%)	59 (18.5%)			
Age of caregivers, M (SD)	60.66 (13.79)	65.8 (11.08)	60.6 (12.27)	64.0 (14.92)	3.23	.022*	Comorbid < Depressive Comorbid < Subclinical Depressive > Anxiety
Stage of the disease of the care-recipient, M (SD)	4.75 (1.18)	4.89 (1.18)	4.55 (1.21)	4.71 (1.17)	0.95	.415	-
Daily hours caring, M (SD)	13.6 (8.02)	13.57(8.19)	12.30 (8.52)	13.1 (7.77)	.69	.555	-

Time since being a caregiver, M (SD)	46.11 (35.97)	41.52 (26.55)	44.51 (36.61)	48.00 (34.29)	.40	.750	-
Care-recipient gender, n (row %)#					7.16	.067	
Male care-recipient	169 (51.4%)	22 (6.7%)	55 (16.7%)	83 (25.2%)			-
Female care-recipient	121 (62.1%)	15 (7.7%)	24 (12.3%)	35 (17.9%)			
Frequency of disruptive behaviors, M (SD)	8.32 (5.98)	4.32 (4.25)	5.90 (4.37)	5.67 (4.70)	15.78	.000**	Comorbid > Depressive Comorbid > Anxiety Comorbid > Subclinical
Reaction to disruptive Behaviors, M (SD) †	16.90 (8.97)	12.69 (9.77)	12.46 (9.14)	10.46 (9.06)	17.81	.000**	Comorbid > Depressive Comorbid >Anxiety Comorbid > Subclinical
Cognitive fusion, M (SD)	29.42 (9.19)	21.22 (9.09)	21.64 (8.38)	16.93 (8.29)	65.66	.000**	Comorbid > Depressive Comorbid > Anxiety Comorbid > Subclinical Anxiety >Subclinical Depressive > Subclinical

*p < .05; ** p <. 01; M = Mean; SD = Standard deviation; *#N =524; †N = 508: Comorbid profile (N = 290, 57.1%); Depressive profile (N=30, 5.9%); Anxiety profile (N=78, 15.3%); Subclinical profile* (N = 110, 21.7%)

Determinants of comorbid depressive and anxiety symptomatology profile versus depressive, anxiety, or subclinical profile

As it has been described in the data analysis section, we conducted two multinomial regressions: a first one including as predictors all the assessed variables except reaction to disruptive behaviors, and a second one adding as a predictor reaction to disruptive behaviors. The sample size for the first regression was larger (N = 524) than the model which includes reaction to disruptive behaviors (N = 481) because the latter model shows the coefficient for reaction for those reporting problem behaviors. The likelihood ratio chi-square test (LR) for reaction to disruptive behaviors (LR(3) = 6.765, p = .080) did not reach statistical significance. As the effect of reaction to disruptive behaviors did not contribute beyond and above the predictors included in the previous regression model, we only show the regression model without this predictor (Table 6.3). Table 6.3 shows the coefficients (adjusted *odds ratio*) and their 95% confidence intervals predicting the subclinical, anxiety, and depressive profiles vs. the reference comorbid profile. ORs significantly higher than 1 indicates a higher likelihood of being in the subclinical, anxiety or depressive profile, relative to the comorbid profile, and vice versa for OR below 1. The examined predictors were demographic factors, frequency of disruptive behaviors of care-recipient, and cognitive fusion.

Significant results were found for caregivers gender (LR(3) = 26.163; p < .001) and caregivers' age (LR(3) = 8.663; p = .034). With regard to stressors, frequency of disruptive behaviors had a significant relationship with the symptom profile (LR(3) = 23.064; p < .001). Cognitive fusion (LR(3) = 136.315; p < .001) also made a significant contribution.

Men were more likely than women caregivers to be included in the subclinical profile, relative to the comorbid profile (OR = 3.765; 95%; CI [1.949 – 7.274]). Being older was associated with a higher likelihood of being in the depressive profile relative to the comorbid profile (OR = 1.079; 95%; CI [1.023 – 1.138]). In addition, frequency of disruptive behavior is a risk factor to be in the comorbid profile relative to subclinical profile (OR = .925; 95% CI [.877 – .976]), anxiety profile (OR = .923; 95% CI [.874 – .974]) and depressive profile (OR = .852; 95% CI [.778 – .933]). Finally, cognitive fusion was also a risk factor in each comparison. Higher cognitive fusion was associated with a higher likelihood of being in the comorbid profile relative to the other three profiles. In particular, the likelihood of being in the subclinical profile (relative to the comorbid profile) decreased by 14.8% per unit increase in cognitive fusion (OR = .852; 95% CI [.824 – .881]). The likelihood of being in the anxiety profile decreased by 9% per unit increase in cognitive fusion (OR = .910; 95% CI [.882 – .939]). Finally, the likelihood of being in the depressive profile decreased by 9.1% per unit increase in cognitive fusion (*OR* = .909; 95% CI [.872 – .948]).

Table 6.3. Multinomial logistic regression analyses of determinants of symptom profile (N=524) in caregivers of people with dementia

	Subclinical vs. Comorbid profile	Anxiety vs. Comorbid profile	Depressive vs. Comorbid profile
Factors	OR (95% CI)	OR (95% CI)	OR (95% CI)
Caregiver gender (0 = female)	**3.765 (1.949, 7.274)**	1.141 (0.560, 2.329)	0.279 (0.069, 1.130)
Care-recipient gender (0 = female)	0.724 (0.345, 1.521)	0.597 (0.271, 1.313)	0.436 (0.114, 1.668)
Kinship (0 = spouse)	1.154 (0.403, 3.308)	1.509 (0.507, 4.493)	2.174 (0.389, 12.135)
Caregivers' age	1.011 (0.978, 1.045)	1.012 (0.979, 1.047)	**1.079 (1.023, 1.138)**
Daily hours caring	0.970 (0.934, 1.007)	0.975 (0.940, 1.012)	0.981 (0.934, 1.030)
Time since being a caregiver	0.999 (0.991, 1.006)	0.997 (0.990, 1.005)	0.991 (0.979, 1.003)
Cognitive fusion	**0.852 (0.824, 0.881)**	**0.910 (0.882, 0.939)**	**0.909 (0.872, 0.948)**
Frequency of disruptive behaviors	**0.925 (0.877, 0.976)**	**0.923 (0.874, 0.974)**	**0.852 (0.778, 0.933)**
-2*LL*	942.34 (24)		

Statistically significant coefficients *($p < .05$)* are highlighted in bold.

6.5 Discussion

The main objectives of this study were to analyze the possible differences between caregivers' symptom profiles in terms of demographic factors, potential stress variables, and cognitive fusion and to examine which caregivers were more vulnerable to comorbid depressive and anxiety symptomatology, compared to those with depressive, anxiety or subclinical symptoms. The effects of other important contextual and demographic variables were controlled for. To our knowledge, this is the first study to analyze the differences between caregivers with comorbid depressive and anxiety symptoms and other symptom profiles and to identify possible correlates of these differences.

The results show a high prevalence of comorbid symptoms in family caregivers of people with dementia, with more than half of the participants showing simultaneously significant levels of depressive and anxiety symptomatology (54.8%). It is worth mentioning that the cutoffs for the measures used in this study undoubtedly influence the number of caregivers being classified as depressed or anxious. However, as reported in Footnote 1 and supplemental materials, the obtained rate of comorbid symptoms was also high (29.1%) using different cut-off points for the CES-D (Vázquez, Blanco, & López, 2007) and for the POMS (McNair, Lorr, & Droppleman, 2003). The obtained comorbidity rate, although large, was not unexpected, considering the findings reported by Joling et al. (2014), who found that during a two-year follow-up period, 60% family caregivers of people with dementia developed a depressive and/or anxiety disorder (32% comorbid). The present study also reveals that clinically relevant anxiety symptoms were very prevalent among caregivers, with almost 70.4% of the caregivers of our sample suffering this problem (alone or comorbid with clinically relevant depressive symptoms). Joling et al. (2014) also reported a larger proportion of anxiety problems compared to depressive problems. Despite this prevalence for clinically relevant symptoms of anxiety, it is surprising that anxiety has received far less attention than depressive symptomatology in the scientific literature (Kaddour & Kishita, 2019).

In non-caregiving populations, the comorbid presentation of mood and anxiety disorders is associated with worse outcomes, such as a higher severity and chronicity of the specific psychopathology, lower psychosocial functioning, higher likelihood of suicidal behavior, and lower treatment efficacy and greater relapse (e.g., Bronisch & Wittchen, 1994; Brown, Antony, & Barlow, 1995; Brown, Schulberg, Madonia, & Shear, 1996; Sareen, Houlahan, Cox, & Asmundson, 2005). Our findings suggest that a high proportion of family caregivers of people with dementia has a comorbid presentation of clinically relevant levels of depressive and anxiety symptomatology, and so caregivers may be especially vulnerable to the described outcomes.

In relation to sociodemographic factors, the findings of this study show that female caregivers would report more comorbid symptoms than male caregivers, a finding coherent with other studies that report higher levels of distress for female caregivers (Collins & Kishita, 2019; Joling et al., 2014; Kaddour & Kishita, 2019). These findings may be related to their more vulnerable situation in terms of exposure to stressors (Pinquart & Sörensen, 2006), and to having higher cognitive fusion than men. With respect to age, the findings suggest that caregivers in the comorbid group are younger than caregivers in the depressive and subclinal profiles.

With respect to potential caregiving stressor variables, the results of the present study suggest that both frequency and reaction to care-recipients' disruptive behaviors are associated with distress (depressive and anxiety symptoms) in caregivers, in line with other studies (Feast, Moniz-Cook, Stoner, Charlesworth, & Orrell, 2016; Nogales-Gonzalez et al., 2015). Regarding our hypothesis on comorbidity and stressors, it is partially supported. Firstly, caregivers who reported a comorbid symptomatology presented higher frequency of behavior problems and reaction associated with these behaviors than those caregivers who reported depressive symptoms, anxiety symptoms, and subclinical symptomatology. However, only frequency of disruptive behaviors, differentiated between the comorbid profile and the other symptom profiles.

The findings of this study suggest that care recipients' disruptive behaviors may be especially relevant in terms of understanding the comorbid presence of depressive and anxiety symptoms in caregivers. It is worth mentioning that dementia per se (the illness) is not the only factor contributing to the development and maintenance of BPSD. These difficulties occur in the context of a relationship. Consequently, caregiver factors, environmental triggers, and interactions between the caregiver and the care-recipient are also relevant (Kales, Gitlin, & Lyketsos, 2015), and so future studies should analyze the potential role of these factors in the development of BPSD and the comorbid presentation of depressive and anxiety symptoms in caregivers.

One variable that also seem to be relevant for understanding the comorbid presentation of depressive and anxiety symptoms in family caregivers of people with dementia is cognitive fusion. While the association between cognitive fusion and depressive or anxiety symptoms has already been described in previous studies (Romero-Moreno et al., 2014; 2015), this study offers the first evidence that cognitive fusion seems to be an important correlate of comorbidity in caregivers. Our hypothesis is supported by the results showing that caregivers in the comorbid profile had higher levels of cognitive fusion or a greater tendency to be regulated by the meaning of their thoughts than those caregivers with depressive, anxiety, and subclinical symptoms profiles, after controlling for the remaining distress predictors (demographic and stressors variables). Moreover, there was no difference in cognitive fusion between the depressive and anxiety profiles, which provides additional empirical support to the consideration of cognitive fusion as a transdiagnostic process. In this line, the obtained results are consistent with previous studies showing that psychological inflexibility, which includes cognitive fusion, is related to a range of comorbid psychological problems such as depressive, anxiety, eating or substance use disorders (e.g., Levin et al. 2012; 2014; Rawal, Park, & Williams, 2010; Venta, Sharp, & Hart, 2012). This variable may be a common process across emotional problems.

The results suggest a high rate of comorbidity between depressive and anxiety symptoms in family caregivers, most of them female caregivers. This fact may be relevant considering the high increase in the prevalence of dementias worldwide, as well as the high number of family caregivers who continue to be the main source of care for community-dwelling older adults suffering from dementing conditions (e.g., Alzheimer's Association, 2018; Stokes, Combes, & Stokes, 2015). The identification of correlates of comorbidity such as cognitive fusion and care recipient's disruptive behaviors may be useful for identifying potential relevant assessment and intervention targets.

Several limitations of the present study should be considered. First, the correlational and cross-sectional nature of the study prevents causal inferences. It would be necessary to carry out experimental and longitudinal studies to confirm that disruptive behaviors, cognitive fusion, and caregivers' gender contribute to explain comorbid depressive and anxiety symptomatology in family caregivers of people with dementia. Longitudinal studies may also help to elucidate the core process of comorbid anxiety and depression across time, and also, whether anxiety precede the onset of depression in family caregivers of people with dementia, as previous studies have suggested in non-caregiver clinical samples (Brown, Campbell, Lehman, Grisham, & Mancill, 2001). The sociodemographic characteristics of our sample are similar to those described in other studies done with caregivers (e.g., in terms of gender or age distribution); however, since the sample was composed of caregivers who volunteered to participate, the results cannot be generalized to the general population of caregivers. Also, participants in this study reported many hours devoted to caregiving tasks and a high degree of cognitive impairment of the care-recipient. Studies done with other caregiver samples are needed to replicate the obtained results.

Furthermore, the subclinical profile group comprised caregivers whose scores were not severe enough to cross the threshold. However, some of them may have had symptoms warranting clinical attention or intervention. It is also worth mentioning that the high level of depressive and anxiety symptoms in the sample could be explained by other reasons. In this study, cut-off scores were the only criteria used to define the symptom profiles and it is possible that levels of clinically significant symptoms were overestimated for this reason. Future studies could consider not only cut-off scores but also diagnostic criteria (e.g., Joling et al., 2014). In addition, even though the selected measures for depressive and anxiety symptoms have good psychometric properties, they may not capture differences in the way these conditions are manifested differently in older people, compared with younger adults (i.e., Brenes, 2006; Hybels, Landerman, & Blazer, 2012). Furthermore, the high levels of symptomatology in our sample could be associated with low availability of resources for caregivers, such as government financial or social support (Schulz, 2020).

Despite these limitations, the findings of this study suggest that comorbid depressive and anxiety symptomatology is an important issue that deserve further research given its high prevalence in family caregivers of people with dementia. Cognitive fusion as well as care recipient’s disruptive behaviors are important factors to be considered for a deeper understanding and more rational treatment of the comorbidity in dementia family caregivers.

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Estudio Tres

Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values

Barrera-Caballero, S., Romero-Moreno, R., Vara-García, C., Márquez González, M., Olazarán, J., & Losada-Baltar, A. Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values. En revisión en *Aging and Mental Health.*

7. Estudio Tres: Cognitive fusion and distress in family caregivers: The role of satisfaction with personal values.

7.1 Abstract

Cognitive fusion (the tendency towards behavior that is overly regulated and influenced by cognition) and dissatisfaction with personal values are central processes of psychological inflexibility and are related to distress. Being cognitively fused may interfere with achieving satisfaction from personal values. This study analyzed the role of satisfaction with the value of caregiving and other personal values (e.g., personal growth) in the relationship between cognitive fusion and caregivers' distress. 287 dementia family caregivers participated in this quantitative study carried out in Madrid, Spain, from January 2016 to February 2020. We measured sociodemographic and stressor variables, cognitive fusion, caregivers' satisfaction with values and depressive and anxiety symptoms. The indirect effect of cognitive fusion on distress through caregivers' satisfaction with caregiving value and with other personal values was tested. Four hierarchical regression models were analyzed: the role of satisfaction with the caregiving value in the association between cognitive fusion and depressive (Model 1a) and anxiety (Model 1b) symptoms; and the role of satisfaction with other personal values in the association between cognitive fusion and depressive (Model 2a) and anxiety (Model 2b) symptoms. The results showed an indirect effect of cognitive fusion on both depressive and anxiety symptoms only through satisfaction with other personal values. Those reporting higher cognitive fusion reported lower satisfaction with other personal values, and this association was related to higher scores in depressive and anxiety symptoms (Models 2a and 2b). Cognitive fusion could be a variable that interferes in obtaining satisfaction from personal values, something that increases caregivers' distress.

Keywords: Anxiety symptoms, Caregivers, Cognitive fusion, Depressive symptoms, Satisfaction with Personal Values.

7.2 Introduction

Informal care is the most frequent form of caring for people with dementia, a disease with rising prevalence (Livingston et al., 2020). Frequently, such caregivers are relatives that provide support over years for many hours daily, dealing with different stressful situations, such as care-recipient disruptive behaviors, which are related to caregivers' distress (Cheng, 2017). Taking this into account, it is not surprising that research shows caregivers of people with dementia experiencing high levels of burden, a multi-dimensional biopsychosocial reaction (Given et al., 2001) resulting from the caregiver's perception that caregiving has had a negative impact upon their emotional and physical health, and social or financial status (Zarit et al., 1986). According to the stress and coping model adapted to caregiving (Knight & Sayegh, 2010), the impact of difficult situations and demands (e.g., neuropsychiatric symptoms including disruptive behaviors of the care-recipient) on caregivers' distress depends on caregivers' personal and contextual variables that can buffer or emphasize this impact (Knight & Sayegh, 2010). Given the high prevalence of depressive and anxiety symptoms (and comorbid presentations) in caregivers (e.g., Barrera-Caballero et al., 2021; Collins & Kishita, 2019), it may be necessary to study the dispositional variables that are at the core of emotional distress in caregivers and may be important targets for treatment.

Dysfunctional coping strategies, such as avoidant coping strategies, are associated with greater psychological (Cooper et al., 2008; Rodríguez-Pérez et al., 2017) and physical problems (Kim et al., 2007) in family caregivers. These strategies are related to the wider process of psychological inflexibility that, in addition to avoidance, involves other sub-processes underlying psychopathological problems, including cognitive fusion and actions oriented towards values (Hayes et al., 2011), that have scarcely been studied in the caregiving literature. Psychological inflexibility is defined as "the rigid dominance of psychological reactions, over chosen values and contingencies, in guiding action" (Bond et al., 2011, p. 678). This variable is gaining more and more relevance in the scientific literature, being suggested as a central component of different forms of psychopathology. Specifically, it has been considered as a higher order transdiagnostic construct, key for understanding depressive and anxiety symptoms (Hayes at al., 2011). As already mentioned, this construct involves other core sub-processes, including cognitive fusion (Hayes et al., 2006), which refers to a process in which behavior is overly regulated and influenced by cognition. People with high levels of cognitive fusion tend to believe in the literal content of their thoughts and act as though they are literally true, instead of distancing from thoughts (Hayes et al., 2006). Recent studies carried out with family dementia caregivers show direct associations between cognitive fusion and caregivers' distress and comorbid depressive and anxiety symptomatology (Barrera-Caballero et al., 2021; Romero-Moreno et al., 2014). However, to date, there are no studies analyzing the mechanisms through which this variable is related to distress in caregivers.

A further essential subprocess of psychological inflexibility is the incoherence, dissatisfaction or disconnection of personal values. "Values are freely chosen, verbally constructed consequences of ongoing, dynamic, evolving patterns of activity, which establish predominant reinforcers for that activity that are intrinsic in engagement in the valued behavioral pattern itself" (Wilson & DuFrene, 2009, p.64). Concretely, the degree to which people live in accordance with the most important values in their lives, that is, commitment to personal values, is a key process in psychological health (Wilson et al., 2010). In the family caregiving context, looking after their loved relative could be very relevant in caregivers' lives. Gallego-Alberto et al. (2017) found that higher commitment to the caregiving role and leisure predicted less caregivers' guilt. Apart from the caregiving value, other personal values (e.g., personal growth, friendship, spirituality etc.) can also be relevant for them, and caregivers' commitment to other personal values has been associated with better psychological outcomes (Romero-Moreno et al., 2017). Vara-García et al. (2021) reported that those caregivers who have a "personal" values profile (e.g., personal growth) showed lower satisfaction with life and higher anxiety levels than those caregivers with a family values profile.

Psychological inflexibility processes are interrelated, and these relationships may explain psychological outcomes such as depression and anxiety (Hayes et al., 2011). However, in the caregiving population, possible explanatory mechanisms of why fusion is related to caregivers' emotional distress have not been explored. Along these lines, it has been suggested that people with high cognitive fusion may feel a lack of vital sense or loss of vital direction (Hayes et al., 2011). Disconnection from values could thus be a mechanism through which cognitive fusion is related to caregivers' distress because highly fused caregivers may have fewer chances to derive satisfaction from their own values, and this could provoke distress. In a study carried out with caregivers of people with dementia, Romero-Moreno et al., (2017) found support for the association between cognitive fusion and lower commitment to values, additionally suggesting that cognitive fusion is associated with lower satisfaction with life. However, the role of satisfaction with caregiving value as well as the role of satisfaction with other personal values in the relationship between cognitive fusion and caregivers' distress has not been studied.

The main objective of this study was therefore to analyze the role of satisfaction with values (caregiving value and other personal values) in the relationship between cognitive fusion and caregiver's depressive and anxiety symptoms. More specifically, we set out to analyze the possible indirect effect of cognitive fusion on depressive and anxiety symptoms in caregivers through satisfaction with caregiving value as well as through satisfaction with other personal values.

7.3 Method

7.3.1 Participants and procedure

A total of 287 family caregivers of a relative with dementia participated in the study. Participants were recruited and informed about the study through health and social centers in the Autonomous Community of Madrid. To participate in this study, they had to be 18 years of age or older, to identify themselves as the main caregiver and to dedicate at least one hour daily to caring tasks during at least three consecutive months. If they met the inclusion criteria, face-to-face assessments were carried out with the participants using the questionnaires described below. All participants signed an informed consent indicating that they agreed to participate voluntarily in the study, which was approved by the (blinded information) Ministry of Economy and Competitiveness and the Ethics Committee at (blinded information).

7.3.2 Measures

Caregivers' demographic data regarding age and gender, as well as care recipients' disease and type of relationship with the caregiver were obtained. The illness of the care-recipients was diagnosed by a neurologist or reported by the caregivers through their relative's medical reports. In addition, we assessed time since becoming a caregiver, hours per day devoted to care-related tasks, care recipients' functional capacity (measured through the Barthel index; Mahoney, 1965), and frequency and reaction to disruptive behaviors (measured through the Spanish version (Nogales-González et al.,

2015) of the disruptive behaviors scale of the Revised Memory and Behavior Problems Checklist (RMBPC; Teri et al., 1992)).

Cognitive fusion. The Spanish version (Romero-Moreno et al., 2015) of the Cognitive Fusion Questionnaire (Gillanders et al., 2014) was used. This scale consists of seven items that measure the tendency to believe in the literal content of thoughts and feelings (e.g., “I get angry with myself for thinking in a particularly way”; “I fight with my thoughts”) on a Likert-type scale ranging from 1 (never) to 7 (always). The internal consistency (Cronbach’s α) for the scale in this study was 0.92.

Depressive symptomatology. To assess caregivers’ depressive symptomatology, the Spanish version (Losada et al., 2012) of the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) was used. It consists of 20 items that measure how often people felt depressive symptoms during the previous week (e.g., “I felt sad”; “I cried sometimes”) through a Likert-type scale with scores ranging from 0 (rarely or none of the time – less than one day) to 3 (most or all of the time – 5-7 days). For the present study, Cronbach’s alpha was 0.88.

Anxiety symptomatology. Caregivers’ level of anxiety symptomatology was assessed through the Tension subscale of the Profile of Mood States Scale (POMS; McNair et al., 1971). This is a nine-item subscale (e.g., “How often have you felt irritable?”) in which each item is measured on a Likert-type scale, ranging from 1 (not at all) to 4 (extremely). In this study, the internal consistency (Cronbach’s α) was 0.89.

Caregivers' satisfaction with values (caregiving value and other personal values). To assess caregivers' satisfaction with caregiving value as well as caregivers' satisfaction with other personal values, we used the procedure described in Vara-García et al. (2021). Firstly, apart from the caregiving value, caregivers had to choose the two most important values from a list of eight (1-being a good spouse, 2-being a good parent, 3-professional growth, 4-personal growth, 5-leisure, 6-self-care, 7-citizenship, or 8-spirituality). After this, caregivers were asked about their satisfaction with the commitment to the caregiving value and the other two chosen values (other personal values) ("Which is the current degree of satisfaction with what you are currently doing for your value ______?"). This item is ranked using a 5-point Likert scale from 1 ("Not at all") to 5 ("A lot"). The score from the answer to the caregiving value as well as the mean score from the answers to the other two chosen values was computed to establish a measure of 1) Satisfaction with caregiving value and 2) Satisfaction with other personal values.

7.3.3 Data analysis

Descriptive data and Pearson correlation analyses were conducted. The indirect effect of cognitive fusion on caregivers' distress through satisfaction with values was tested through the PROCESS method for SPSS script (Hayes, 2018). Hierarchical regression analyses of total effect (c), direct effect (c'), and bootstrapped bias-corrected and accelerated 95% confidence intervals of the indirect effect (ab) were conducted with 10000 bootstrapped samples. Four models were analyzed: 1) testing the possible mediational role of satisfaction with the caregiving value in the association between cognitive fusion and depressive symptoms (Model 1a) and between cognitive fusion and anxiety symptoms (Model 1b); and 2) testing the possible mediational role of satisfaction with other personal values in the association between cognitive fusion and depressive symptoms (Model 2a) and between cognitive fusion and anxiety symptoms (Model 2b). The outcome variables for the models were depressive and anxiety symptoms. All these interactions were tested after controlling for the same important covariates in each model: caregivers' gender and age, kinship (spouses vs. others), daily hours and time caring, care-recipient's functional capacity, care-recipient's frequency of disruptive behaviours and caregivers' reaction to these behaviours, following the stress and coping model adapted to care (Knight & Sayegh, 2010).

In order to test confidence intervals (CI), the bias-corrected and accelerated bootstrapping method was used. The bias-corrected bootstrapping method does not assume symmetry or normality of the sampling distribution of the indirect effect and offers relatively greater power and better type I error rates when compared to other mediation approaches (Mackinnon et al., 2004).

7.4 Results

Sociodemographic data

The study sample was mainly composed of female family caregivers (67.9%) who mostly took care of a parent (50.6%) or a spouse (45.6%); their mean age was 63.33 years (SD = 12.79). Participants took care of their relatives for an average of 13.20 daily hours (SD: 7.80; range: 1–24) for a mean of 50.41 months (SD: 40.11; range: 3–360). Most of the care-recipients were diagnosed with Alzheimer's disease (55.4%) and the remaining with other dementias.

Correlational analysis

Table 7.1 shows the univariate descriptive statistics and Pearson correlations for the analyzed variables. Cognitive fusion was negatively associated with satisfaction with other personal values (r = -.23; p < .001) as well as with satisfaction with the caregiving value (r = -12; p = .03), and positively associated with depressive (r = .61; p < .001) and anxiety symptoms (r = .60; p < .001). Satisfaction with other personal values was positively associated with satisfaction with the caregiving value (r = .47; p < .001) and it was negatively associated with both depressive (r = -.32; p < .001) and anxiety symptoms (r = -.33; p < .001). Also, satisfaction with the caregiving value was negatively associated with depressive (r = -.19; p < .001) and anxiety symptoms (r = -.13; p = .02). Finally, depressive and anxiety symptoms were highly positively correlated (r = .71; p < .001).

Table 7.1. Descriptive information and correlational analysis

Measure	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*	*11*	*12*	*13*	*Range*	*M/%*	*SD*
1. Caregiver sex (0 = woman)	_													_	67.9%	_
2. Caregivers' age	.21**	_												28-88	63.33	12.79
3. Kinship (0 = spouses)	-.24**	-.75**	_											_	45.6%	_
4. Daily hours caring	.02	.39**	-.37**	_										1-24	13.20	7.80
5. Time since being a caregiver	-.03	.05	-.06	-.03	_									3-360	50.41	40.12
6. Care-recipient functional capacity	.10	.06	-.20**	.04	-.27**	_								0-100	69.06	26.69
7. Frequency of disruptive behaviors	-.13*	-.12*	.07	.00	.02	-.10	_							0-28	6.54	5.30
8. Reaction to disruptive behaviors	-.17**	-.21**	.19**	-.07	-.04	-.05	.79**	_						0-26	5.94	5.94
9. Satisfaction with personal values	.13*	.39**	-.41**	.22**	-.05	.07	-.08	-.10	_					1-5	3.67	.99
10. Satisfaction with caregiving value	.01	.17**	-.10	.06	.06	-.16**	-.07	-.06	.47**	_				1-5	4.05	.82

11. Cognitive fusion	-.18**	-.24**	.24**	-.09	-.04	.01	.16**	.31**	-.23**	-.12*	_			7-49	22.79	10.55
12. Depressive symptoms	-.16**	-.16**	.13*	-.11*	-.02	-.09	.24**	.28**	-.32**	-.19**	.61**	_		0-51	17.33	10.74
13. Anxiety symptoms	-.25**	-.25**	.22**	-.08	.07	-.02	.26**	.33**	-.33**	-.13*	.60**	.70**	_	0-36	16.21	7.86

*$p < .05$; ** $p <. 01$; *M* = Mean; *SD* = Standard deviation

Models 1a and 1b – Effects of satisfaction with caregiving value in the association between cognitive fusion and caregivers' depressive and anxiety symptoms

First, the relationship between satisfaction with the caregiving value and cognitive fusion was analyzed. As this association was found to be non-significant (B = -.00; df = 9-277, p =.14, C.I. = -.017 - .002), no further analyses were conducted for these models.

Model 2a - Effects of satisfaction with other personal values in the association between cognitive fusion and caregivers' depressive symptoms

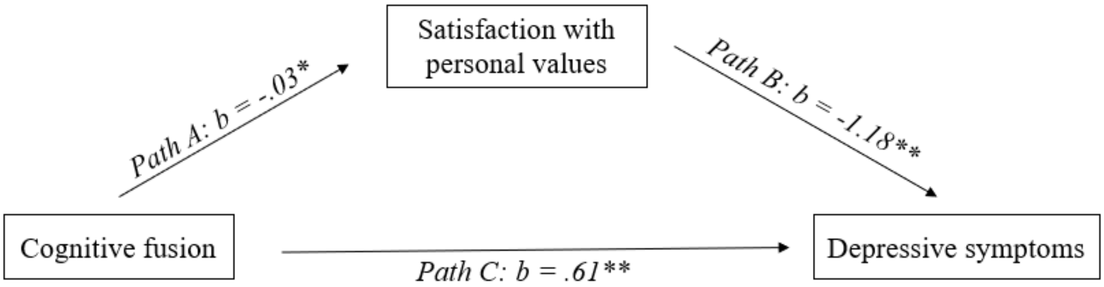
The relationship between satisfaction with other personal values and cognitive fusion was analyzed. Results (Table 7.2) showed that higher levels of cognitive fusion were significantly associated with lower satisfaction with other personal values (B = -.03; df = 9-277, p = .01, C.I. = -.048 - -.005). In addition, results revealed that lower satisfaction with other personal values was significantly associated with higher levels of depressive symptoms (B = -1.18, df = 276, p < .001; C.I. = -1.734 - -0.650). Finally, results showed that higher levels of cognitive fusion showed a significant direct (B = .58; df = 276, p < .001; C.I. = .480–.676), and indirect effect (B = .03; df = 277, p < .001; bootstrapping C.I. = .005–.070) through satisfaction with other personal values, on higher levels of caregivers' depressive symptoms (Figure 7.1).

Table 7.2. Regression analyses on depressive and anxiety symptoms

Dependent variable: **depressive symptoms**							Dependent variable: **anxiety symptoms**					
Independent variable	Beta	Product of coefficients			Bootstrapping CI		Beta	Product of coefficients			Bootstrapping CI	
		SE	t	p	95% lower	95% higher		SE	t	p	95% lower	95% upper
Cognitive fusion	.58	.05	11.61	.00	.48	.67	.38	.03	10.41	.00	.31	.45
Satisfaction with other personal values	-1.18	.27	-4.35	.00	-1.72	-.65	-.71	.20	-3.56	.00	-1.11	-.32
Sex (0 = woman)	-.98	1.07	-.91	.36	-3.09	1.13	-1.77	.79	-2.25	.02	-3.32	-.22
Caregivers’ age	-.00	.06	-.05	.96	-.12	.11	-.03	.04	-.66	.50	-.11	.05
Kinship (0 = spouses)	-3.68	1.57	-2.34	.02	-6.78	-.59	-.48	1.15	-.42	.67	-2.76	1.78
Time since being a caregiver	-.01	.01	-1.26	.21	-.04	.01	.02	.01	2.05	.04	.00	.03
Daily hours caring	-.10	.06	-1.52	.13	-.23	.03	.02	.05	.41	.68	-.07	.11
Care-recipient functional capacity	-.05	.02	-2.48	.01	-.09	-.01	.01	.01	.70	.48	-.02	.03
Frequency of disruptive behaviours	.26	.15	1.73	.08	-.03	.56	.13	.11	1.23	.22	-.08	.36
Reaction to disruptive behaviours	-.02	.14	-.14	.88	-.29	.25	.09	.10	.89	.37	-.11	.29

C.I.: Confidence Interval. Significance of variables is determined when zero is not contained in the 95% CI.
Beta (non-standardized)

Figure 7.1. Effects of cognitive fusion on depressive symptoms through caregivers' satisfaction with other chosen personal values

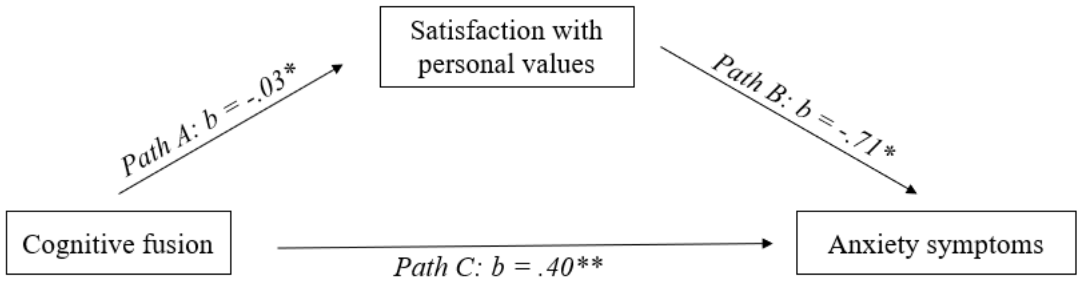


Indirect effect (*ab*): *b* = .03, Boot SE = .02, CI95% = .005–.070

Model 2b – Effects of satisfaction with other personal values in the association between cognitive fusion and caregivers' anxiety symptoms

The relationship between satisfaction with other personal values and cognitive fusion was analyzed. Again, results (Table 7.2) revealed that higher levels of cognitive fusion were significantly associated with lower satisfaction with other personal values (B = -.03; df = 9-277, p = .01, C.I. = -.048 - -.005). In addition, results showed that lower satisfaction with other personal values was significantly associated with higher levels of anxiety symptoms (B = -.71, df = 10-276, *p* < .001; C.I. = -1.106 - -.318). Finally, results showed that higher levels of cognitive fusion showed a significant direct (B = .38; df = 10-276, p < .001; C.I. = .308–.452), and indirect effect (B = .02; df = 10-276, *p* < .001; bootstrapping C.I. = .003–.040) through satisfaction with other personal values, on higher levels of caregivers' anxiety symptoms (Figure 7.2).

Figure 7.2. Effects of cognitive fusion on anxiety symptoms through caregivers' satisfaction with other chosen personal values



Indirect effect (*ab*): *b* = .02, Boot SE = .01, CI95% =. 003–.040

7.5 Discussion

This is the first study to explore the indirect effect of cognitive fusion on both caregivers' depressive and anxiety symptoms through the satisfaction with caregiving value as well as through satisfaction with other personal values. In line with our hypothesis, the results showed that there was an indirect effect of cognitive fusion on caregivers' distress through satisfaction with values. However, the hypothesis is only partially confirmed. Only satisfaction with caregivers' other chosen personal values (not satisfaction with caregiving value) showed an indirect effect in the relationship between cognitive fusion and depressive and anxiety symptoms. A possible explanation for this finding may have to do with the fact that although the caregiving value is not, in general, freely chosen by many caregivers, they may be more satisfied with this value than with other values (e.g., due to social desirability). Therefore, regardless of their levels of cognitive fusion, they can dedicate themselves to their caregiving value and feel satisfied with this work. Vara et al. (2021) reported that one of the most frequently chosen values is self-care, which has been highlighted as an area unattended in favor of dementia caregiving tasks (Wang et al., 2019). Regarding other chosen values, in addition to not being satisfied with them because they may not be able to dedicate time to them due to caregiving tasks, being fused means that they cannot enjoy or derive satisfaction from those other chosen values. This is consistent with the study by Trindade et al. (2016), who suggested that cognitive fusion is a maladaptive process which may be associated with insensitivity to the opportunities of engaging in valued actions in a meaningful way.

These findings should be analyzed with caution due to several limitations. First, this is a cross-sectional study, which prevents causal inferences. Future longitudinal or experimental studies are needed to confirm the obtained findings. In addition, the convenience nature of the sample may make generalization of these results to the general population difficult. In addition, future studies should be conducted in different cultures that may have different values to further understand the complex relationships of cognitive fusion, depressive and anxiety symptoms in dementia caregivers (Knight & Sayegh, 2010; Losada et al., 2010). Finally, our measure of the caregiving value may be limited, and this construct may underlie a higher complexity (e.g., caregiving values may contain diverse beliefs such as "that my relative has a good health" and "being a loving and affectionate caregiver for my loved one"). Future studies should replicate the results obtained in this study with assessment instruments that provide a broader view of the construct of caregiving value.

Despite these limitations, the clinical implications of this study may be important, given the high rates of depressive and anxiety symptomatology in the population (Collins & Kishita, 2019; Kaddour & Kishita, 2020). The findings provide support to the transdiagnostic role of cognitive fusion and satisfaction with personal values in dementia family caregivers. For this reason, these processes should be considered as potential intervention targets to reduce caregivers' distress. A transdiagnostic intervention that focuses specially on these constructs is Acceptance and Commitment Therapy (ACT), which has shown positive effects in caregivers (Collins & Kishita, 2019). Apart from this psychological intervention, cognitive fusion may be modified through non-ACT interventions, as is the case with Cognitive and Behavioral Therapy (CBT; Arch et al., 2012), which has also shown positive results in family caregivers (Cheng et al., 2020). In addition, considering the association between disruptive behaviors of the care recipient and caregivers' levels of cognitive fusion (e.g., Barrera-Caballero et al., 2021), caregivers' cognitive fusion may be targeted by non-psychotherapist led interventions aimed at reducing the frequency of disruptive behaviors (Logsdon et al., 2007). As the findings of this study suggest, decreasing cognitive fusion may help caregivers to be more satisfied with their personal values, thereby decreasing their distress. From the perspective of this model, encouraging caregivers to adopt a more flexible way of responding to their thoughts through strategies such as cognitive defusion may be important. Finally, even despite being fused, focusing on their values and trying to find satisfaction in them could be crucial for caregivers' psychological health.

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Estudio Cuatro

Longitudinal effects of cognitive fusion in depressive, anxiety, and ambivalent symptoms of family caregivers of people with dementia

En preparación para la revista *Journals of Gerontology*.

8. Estudio Cuatro: Longitudinal effects of cognitive fusion in depressive, anxiety, and ambivalent symptoms of family caregivers of people with dementia.

8.1 Abstract

Family dementia caregiving has been commonly associated with negative psychological distress for caregivers. Cognitive fusion, that is, the tendency for been overly influenced by cognition, has been linked to psychological distress in caregivers in cross-sectional studies. However, longitudinal analysis of predictors of caregiver's levels of depressive, anxious and ambivalent feelings are lacking, with no available study analyzing the longitudinal effects of cognitive fusion on caregivers' mental health. The objective of this study is to analyze the longitudinal effect of cognitive fusion in depressive, anxiety and ambivalent caregivers' symptoms after controlling for caregivers' age and gender, daily hours and time caring, care-recipient functional and cognitive status and cessation of caregiving. Study participants were 176 family dementia caregivers. Face to face assessments were conducted in three yearly assessments. Linear mixed models analysis were used to analyze the associations between time-varying values for frequency and reaction to care-recipient behavioral problems, cognitive fusion, and depressive, anxiety and ambivalent symptoms. The results suggest that increases in cognitive fusion predicted depressive, anxious and ambivalent caregivers' feelings. Reaction to care-recipients behavioral problems and being a female caregiver significantly predicted increases in anxiety and ambivalent symptoms over time. Results suggest that cognitive fusion may constitute a core dysfunctional mechanism involved in depressive, anxiety and ambivalence symptoms. Psychological strategies aimed at reducing cognitive fusion and stress levels may be especially helpful for reducing caregivers' distress.

Keywords: ambivalent feelings, anxiety, caregivers, cognitive fusion, depressive symptoms, stress, longitudinal analysis

8.2 Introduction

People with dementia, a rising illness that result in progressive cognitive and functional decline, show complex problems and symptoms in many domains (Livingston et al., 2020). All people with dementia need help for facing daily live, and most of them are cared by relatives (e.g., Friedman et al., 2015; Livingston et al., 2020). According to the stress and coping model adapted to caregiving (Knight & Sayegh, 2010), caregiving for a relative with dementia has been considered as a chronically stressful situation, as it can be highly demanding for family caregivers, who in addition to offer practical support in daily tasks, usually provide support in the context of changes in personality and challenge behaviors of the cared person (e.g., Cheng, 2017).

Although caregiving may be associated to positive aspects (Quinn & Toms, 2019), research typically links this situation to negative consequences on caregivers' well-being (Sallim et al., 2015). Depressive symptoms in caregivers are relevant and one of the most studied outcomes in this population. Specifically, a recent metanalysis carried out by Collins and Kishita (2020) revealed that 31.24% caregivers showed depressive problems. Although anxiety has been less studied in dementia caregiving (Cooper et al., 2008), 42.6% caregivers suffer from anxiety symptoms (Kaddour & Kishita, 2020). Also, caregivers usually report at the same time positive and negative feelings towards their care-recipient or the caregiving process. Although having ambivalent feelings is related with high levels of psychological distress (Losada et al., 2017; 2018), research in caregiving ambivalence is sparse. In the mentioned metanalysis most studies used cross-sectional designs, with few examples of longitudinal studies, especially for anxiety and ambivalence.

Due to the high prevalence of psychological distress and even the high prevalence of comorbid depressive and anxious symptomatology (Barrera-Caballero et al., 2021) among caregivers, there is a need of studying variables that may longitudinally predict caregivers' distress, as they may be important intervention targets to treat emotional distress in a more efficient way. In the general psychological literature, transdiagnostic processes have been shown to be significant predictors of distress. Transdiagnostic processes make reference to mechanisms that are relevant for understanding the development and maintenance of different sets of disorders (Sauer-Zavala et al., 2017). The identification of mechanistically transdiagnostic processes is relevant to develop more efficient treatments, as targeting underlying mechanisms across comorbid conditions with the same core vulnerabilities has been found to be associated with clinical improvement (e.g., Farchione et al., 2012).

One transdiagnostic process that has received significant attention in the scientific literature is cognitive fusion. It is a central component of psychological inflexibility that refers to the regulation of behavior by cognition. Specifically, being cognitively fused implies that thoughts are interpretated as literal truths that dominate emotional and behavioural regulation to the exclusion of other contextual variables (Hayes, Strosahl, & Wilson, 2011). Crossectional studies carried out in caregivers' populations supported the transdiagnostic role of this variable, showing a positive relationship between cognitive fusion and depressive and anxiety levels (Romero-Moreno et al., 2014) and ambivalent feelings (Barrera-Caballero et al., 2018). A recent study by Barrera-Caballero et al. (2021) found that people highly fused with their thoughts and emotions showed more likely comorbid depressive and anxious symptoms (Barrera-Caballero et al., 2021).

In non-caregiving clinical and subclinical populations, different studies have shown the association between cognitive fusion and depressive and anxiety symptoms (e.g., Gillanders et al., 2014; Herzberg et al., 2012), including longitudinal studies highlighting the predicting effect of cognitive fusion in distress. For example, a recent study carried out with women with chronic pain, showed that cognitive fusion, but not pain intensity nor pain-related functional impairment, predicted changes in depressive symptoms over one year period (Carvalho et al., 2019). Other study demonstrated that cognitive fusion longitudinally impacted on physical and mental health of patients with inflammatory bowel disease (Trindade et al., 2018). However, longitudinal analysis of predictors of caregivers' levels of distress are sparse, with no available study analyzing the longitudinal effect of cognitive fusion on caregivers' depressive and anxious symptoms, as well as ambivalent feelings. Thus, the current study expands on previous literature by exploring the role of cognitive fusion on changes in depressive, anxiety and ambivalent symptoms.

The aim of this study was to analyze the longitudinal effect of cognitive fusion in depressive, anxiety and ambivalent symptoms of family dementia caregivers, after controlling for other relevant variables related to distress in caregivers, such being female and being exposed to more stressors such as behavioral and psychological symptoms of dementia. We hypothesized that increases in cognitive fusion over time would predict increases on caregivers' depressive, anxiety and ambivalence symptoms.

8.3 Method

8.3.1 Participants and Procedure

A total of 176 caregivers of relatives suffering from dementia or related disorders participated in this study. Face to face interviews were conducted each year through a two-year period (three assessments: baseline, 12 and 24 months after baseline). Baseline characteristics of the sample are shown in Table 8.1.

Participants were contacted through social and health centers from the Autonomous Community of Madrid. Participants were informed by telephone about the objectives of the study, and those who met the inclusion criteria were scheduled for an individual interview conducted by a trained psychologist. The inclusion criteria were: a) being 18 years old or older, b) identifying themselves as the main caregiver, and c) devoting at least 1 daily hour per day for the last three consecutive months to caregiving tasks. The exclusion criterium was having participated in a regular psychological intervention in the last six months. All caregivers participated voluntarily in the study and provided informed consent before the interview. The study was approved by the Spanish Ministry of Science and Innovation and the Ethics Committee of the Universidad Rey Juan Carlos (Madrid, Spain).

8.3.2 Variables and Measures

Sociodemographic variables: caregivers' age and sex, daily hours and time since care begin (months), care-recipient functional capacity and cognitive impairment and cessation of caregiving.

Frequency and reaction to disruptive behaviors. The Spanish version (Nogales-González et al., 2015) of the disruption subscale from the Revised Memory and Behavior Problems Checklist (Teri et al., 1992) was used. It consists of an eight-item subscale that assesses the frequency of disruptive behaviors in dementia patients (e.g., "During the past week, how often did your relative destroy property or threaten to hurt others?") as well as the caregivers' reaction to those behaviors (e.g., "How much has this behavior upset you?"). Scores for frequency subscale range from 0 = "never occurred" to 4 = "occurs daily or more often" and for reaction subscale scores range from 0 = "not at all" to 4 =

"extremely." Internal consistency (Cronbach's α) of this subscale in this study was .57 for frequency subscale and .73 for reaction subscale.

Cognitive fusion: This variable was assessed using the Spanish version (Romero-Moreno et al., 2014) of the Cognitive Fusion Questionnaire (Gillanders et al., 2014). It is a 7-item scale assesses the degree to which caregivers' present the tendency to believe in the literal content of thoughts and feelings and other facets of this variable (e.g., "I get so caught up in my thoughts that I am unable to do the things that I most want to do"). The answers are rated on a 7-point Likert-scale from 1 (never) to 7 (always). Cronbach's alpha for this scale was .92 for the present study.

Anxiety symptoms. Anxiety symptoms were assessed using The Tension subscale of the Profile of Mood States Scale (P OMS; McNair et al., 1971). It consists of nine items (e.g., "How often have you felt nerv ous?"). Scores range from 1 "not at all" to 4 "extremely" on a Likert-type scale. The internal consistency (Cronbach's α) in this study was .89.

Depressive symptoms: Spanish version (Losada et al., 2012) of The Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) was used. This scale is composed of consists of 20 items assessing the frequency of depressive symptoms over the previous week (e.g. "I thought my life had been a failure"; "I felt sad"). Scores range from 0 "rarely or none of the time" to 3 "most or all the time." In the present study, the internal consistency (Cronbach's α) for the scale was .89.

Ambivalent feelings: The Caregiving Ambivalence Scale (CAS, Losada et al., 2017) was used to assess the degree to which caregivers' attitudes and feelings toward their relatives are mixed or conflicted. This scale is composed of 5 items (e.g., "I have mixed feelings toward my relative (tenderness-rage, love-hate, etc). Scores are rated on a 4-point Likert-scale from 0 (never) to 3 (always). Cronbach's alpha for this scale was .76 for the present study.

8.3.4 Data analysis

With the aim of examining the correlation of predictors of depressive, anxiety and ambivalent symptoms over time, three linear mixed models were used, one for each of the dependent variables (depressive symptoms, anxiety symptoms and ambivalent feelings). The three models were fitted with a random intercept and used restricted maximum- likelihood (REML) estimation to handle missing data. The linear variables were centered at their grand means to increase the regression coefficients' interpretability and to reduce multicollinearity problems. The whole models included time-varying covariates (caregivers' age and sex, daily hours, and time caring, care-recipient functional capacity and cognitive impairment and cessation of caregiving), stressors and cognitive fusion as predictors and the dependent variables: 1) depressive, 2) anxiety and 3) ambivalent symptoms. In addition, the models included the time in variant main effect for sex which was dummy coded as "0" = female and "1" = male. Finally, models included random intercepts and random slopes.

Table 8.1. Sample characteristics at baseline

	M	SD	RANGE	%	*n*
Sex					
Male caregivers				35,2	62
Female caregivers				64,8	114
Age of caregivers	62.60	12.12	32-87		
Daily hours caring	13.41	8.20	1-24		
Time since being a caregiver	53.52	41.35	3-300		
Care-recipient functional capacity	69.88	26.77	0-100		
Care-recipient cognitive impairment	4.66	1.24	2-7		
Frequency of disruptive behaviors	6.16	4.74	0-21		
Reaction to disruptive behaviors	5.63	5.83	0-26		

Cognitive fusion	21.82	10.71	7-49
Depressive symptoms	15.92	10.73	0-44
Anxious symptoms	15.47	7.87	0-33
Ambivalent feelings	3.75	3.32	0-15

M = Mean; SD = Standard deviation

8.4 Results

Dropouts / missing data

176 participants enrolled in the study. Of these, data were available for 139 caregivers (79%) at the 1-year follow-up, and, at the 2-year follow-up assessment, data were available for 116 caregivers (65.91%). Therefore, 37 participants were lost to the 1-year follow-up assessment (21%), due to difficulties to reach participants (59,4%) and declined to participate (40,6%). Finally, 23 participants were lost to the 2-year follow-up assessment (34,09%): mainly due to difficulties to reach participants (41,6%), declined to participate (46,6%) and caregiving cessation (e.g., death or institutionalization of care-recipient) (11,8%). To test if missing data occurred at random, we analyzed differences between those caregivers who dropped out at any assessment point and those who remained in the study, independent samples t-tests were conducted. No significant differences were found between caregivers who missed the 1-year follow up and those who did not in their scores on any of the assessed variables at baseline ($p > 0.05$), as well as no significant differences were found between caregivers who missed the 2-year follow-up assessment and those who did not in their scores on any of the assessed variables at baseline and at the 1-year follow-up ($p > 0.05$).

Changes over time in depressive symptoms

The results of the linear mixed model conducted to analyze the relationship between sociodemographic, stressor variables, cognitive fusion and depressive symptoms are shown in Table 8.2. Only the time-varying value for cognitive fusion (t = 11.38, df = 306,30, p < 0.01) showed a significant association with variability in depressive symptoms, reflecting that those caregivers with increases in cognitive fusion over time also showed greater depressive symptoms over time. No significant effects were found for the other assessed variables.

Changes in anxiety symptoms over the time

The results of the linear mixed model conducted to analyze the relationship between sociodemographic, stressor variables, cognitive fusion and anxiety symptoms are shown in Table 8.2. The effect of sex was significant (t= -2.14; df=93.82; p=0.034), reflecting that male and female caregivers showed significant differences in mean anxiety symptoms scores across time, with higher scores on anxiety reported for female caregivers. Time varying values in reaction to disruptive behaviors (t = 2.12, df = 314,25, p = 0.035) and cognitive fusion showed (t =9.55, df = 306,78, p < 0.01) a significant association with variability in anxiety symptoms, indicating that those caregivers with increases in reaction to disruptive behaviors and those caregivers with higher scores in cognitive fusion over time also showed greater anxiety symptoms over time. The estimate for “time” referred to the slope when sex was coded as “0” (the slope for female). Results show that the coefficient for “time” was significant (t=-2.14; df=93.82; p =0.04), indicating that female caregivers showed significant changes in anxiety over time. No significant effects were found for of the other assessed variables.

Changes in ambivalent feelings over the time

The results of the linear mixed model conducted to analyze the relationship between sociodemographic, stressor variables, cognitive fusion and ambivalent feelings are shown in Table 8.2. The effect of age was significant (t=-2.34, df=193.46; p=0.20), indicating that younger caregivers reported higher ambivalent feelings over time. Also, time varying values in reaction to disruptive behaviors (t = 3.22, df =309.98, p = 0.01) and cognitive fusion (t =5.20, df =304.49, p < 0.01) showed a significant association with variability in ambivalent symptoms, indicating that those caregivers with increases in reaction to disruptive behaviors and those caregivers with increases in cognitive fusion over time also showed greater ambivalent feelings over time. No significant effects were found for the other assessed variables.

Table 8.2. Linear mixed-effects model for depressive, anxious and ambivalent symptoms over time

OUTCOME: DEPRESSIVE SYMPTOMS						95% CONFIDENCE INTERVAL	
VARIABLE	ESTIMATE	SE	*t*	p	df	LOWER BOUND	UPPER BOUND
Intercept	16.56	1.14	14.53	<.01	208.904	14.31	18.81
Time	-.63	.51	-1.24	.22	125.22	-1.64	.38
Sex (0=female)	-.43	1.08	-.40	.69	139.76	-2.58	1.71
Caregiver's age	-.01	.05	-.24	.81	182.11	-.11	.08
Daily hours caring	.00	.06	.05	.95	304.15	-.12	.12
Time caring	.00	.01	.43	.67	168.89	-.02	.03
Frequency of behavioral problems	.16	.13	1.21	.23	304.63	-.10	.42
Reaction to behavioral problems	.23	.12	1.93	.05	314.66	-.00	.47
Care-recipient functional capacity	-.04	.02	-1.91	.06	279.45	-.07	.09

Care-recipient cognitive impairment	-.15	.46	-.33	.73	292.24	-1.07	.76
Cessation of caregiving	.38	1.15	.33	.53	154.03	-1.89	2.66
Cognitive fusion	.53	.04	11.38	<.01	306.30	.44	.63

OUTCOME: ANXIOUS SYMPTOMS						95% CONFIDENCE INTERVAL	
VARIABLE	ESTIMATE	SE	*t*	p	df	LOWER BOUND	UPPER BOUND
Intercept	16.46	.86	19.14	<.01	183.174	14.77	18.16
Time	-.86	.40	-2.14	.04	93.82	-1.65	-.06
Sex (0=female)	-1.92	.90	-2.13	.03	154.44	-3.70	-.14
Caregiver’s age	-.07	.04	-1.78	.08	199.11	-.15	.00
Daily hours caring	.03	.05	.73	.46	315.22	-.06	.13
Time caring	.00	.01	.64	.52	182.27	-.01	.02
Frequency of behavioral problems	-.00	.10	-.01	.98	314.05	-.22	.21
Reaction to behavioral problems	.21	.10	2-12	.03	314.25	.01	.41

Care-recipient functional capacity	-.00	.01	-.13	.89	293.42	-.03	.03
Care-recipient cognitive impairment	.05	.38	.14	.89	298.68	-.70	.81
Cessation of caregiving	1.17	.94	1.24	.21	162.68	-.69	3.05
Cognitive fusion	.36	.04	9.54	<.01	306.79	.29	.44

OUTCOME: AMBIVALENCE FEELINGS						95% CONFIDENCE INTERVAL	
VARIABLE	ESTIMATE	SE	*t*	p	df	LOWER BOUND	UPPER BOUND
Intercept	2.96	.36	8.009	<.01	200.67	2.24	3.68
Time	-.14	.15	-.96	.33	107.86	-.45	.15
Sex (0=female)	-.07	.35	-2.13	.83	153.36	-.77	.61
Caregiver’s age	-.04	.01	-2.34	.02	193.47	-.07	-.05
Daily hours caring	.02	.02	1.11	.26	296.76	-.02	.06
Time caring	-.00	.01	-.25	.80	182.69	-.01	.00
Frequency of behavioral problems	.00	.04	.05	.96	288.59	-.08	.08

Reaction to behavioral problems	.13	.04	3.20	.00	309.98	.05	.20
Care-recipient functional capacity	.01	.01	1.28	.19	293.42	-.04	.02
Care-recipient cognitive impairment	-.02	.15	-.12	.89	314.65	-.32	.28
Cessation of caregiving	.44	.37	1.18	.24	168.15	-.29	1.19
Cognitive fusion	.08	.01	5.20	<.01	304.49	.05	.11

8.5 Discussion

The current study explored, for the first time, if increases in cognitive fusion predicted increases in depressive, anxious and ambivalent caregivers' symptoms over a two-year period, controlling for relevant variables in the caregiving process such as caregivers' sex and stressors (frequency and reaction to disruptive behaviors, functional capacity and care-recipient cognitive impairment and caregiving cessation).

As we hypothesized, the results of this study showed that increases in scores in cognitive fusion were associated with increased depressive, anxious and ambivalent feelings over time, after controlling for the rest of variables. It was the only variable that predicted changes in all the outcome variables, suggesting its transdiagnostic role for the explanation of caregivers' emotional distress. Cognitive fusion may be a core target of interventions for dementia caregivers since it seems to be a common predictor of the different outcome variables of emotional distress analyzed in this study. Previous cross-sectional studies already showed that a higher tendency of behavior to be regulated by cognition, that is cognitive fusion, was associated with greater depressive, anxious and ambivalent caregivers' symptomatology (Barrera-Caballero et al., 2021). So, the current study adds to findings by conducting a more robust statistical procedure to analyze the role of cognitive fusion in the longitudinal prediction of caregivers' distress.

Regarding caregivers' depressive symptoms, the results showed no significant sex differences mean depression over time, a result in line with the findings obtained by Romero-Moreno et al. (2012), but in contrast with (Pillemer et al., 2018) who highlighted that female caregivers showed higher levels of depressive symptoms than male caregivers. Regarding caregivers' anxious symptoms, this study reveals that female caregivers' report higher anxiety levels over time, consistently with other studies (Kaddour and Kishita, 2019). Regarding stressors, reaction to disruptive behaviors predicted increases in ambivalent and anxious caregivers' symptomatology, in line with Nogales-González et al. study, (2015), but not depressive symptoms. So, according to the stress and coping model adapted to caregiving (Knight y Sayegh, 2010), reaction to disruptive behavior is a relevant variable, although it seems that cognitive fusion has a stronger contribution to caregivers' distress as increases in this variable over time predicted increases across depressive, anxiety and ambivalent symptoms. These results contribute to moving forward the understanding of the role of psychological processes in the etiology of depressive, anxious and ambivalent symptoms in caregivers.

The obtained findings have important clinical implications for the management of distress in family caregivers of people with dementia. Caregivers dealing with depressive, anxious and ambivalent feelings could be benefited from interventions that target tackling unhelpful entanglement with thoughts and emotions, rather than being overly focused on reducing stress and distress. Specifically, integrating transdiagnostic approaches in available interventions for dementia family caregivers, such as Acceptance and Commitment therapy (Losada et al., 2015), seem to be useful to reduce cognitive fusion by increasing cognitive defusion (a core process in psychological flexibility), through deliteralization techniques that promote perspective taking, such as mindfulness-based practices. By promoting cognitive defusion caregivers could learn how to distance oneself from their negative internal experiences. Also, the results suggest that strategies aimed at reducing stress associated to care-recipient disruptive behaviors could be useful, especially for those caregivers' experiencing anxiety and ambivalent symptoms.

There are some limitations in this study which should be acknowledged. Firstly, the sample size of the study could be considered small, and all the caregivers participated voluntary in the study, something that could prevent the generalization of the results to the general caregiving population. In addition, despite the longitudinal design of this study, experimental studies are needed to demonstrate causality. Finally, although the current results show the predictive role of cognitive fusion in depressive, anxiety and ambivalent symptoms, no information regarding the mechanisms of action of these relationships is provided. Also, in addition to cognitive fusion other variables could contribute to understand caregivers' distress- Future studies should analyze the interplay of cognitive fusion with variables such as experiential avoidance, rumination or leisure in order to better understand the processes that lead to caregivers' distress.

Despite the mentioned limitations, given de high expected prevalence of family caregivers, the economic cost associated with care, and the negative psychological and physical consequences for caregivers, this study contributes to the available literature by suggesting the relevant transdiagnostic role of the variable cognitive fusion for understanding worsening in caregivers' distress. Psychological strategies aimed at reducing cognitive fusion and stress levels may be especially helpful for reducing caregivers' distress.

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Estudio Cinco

Cognitive fusion and treatment response to depression in caregivers of relatives with dementia.

Publicado en: Barrera-Caballero,S., Romero-Moreno, R., Vara-García, C., Olmos, R., Ricardo Márquez-González, M., & Losada-Baltar, A. Cognitive fusion and treatment response to depression in caregivers of relatives with dementia. En revision en *Journal of Conteztual and Behavioral Science.*

9. Estudio Cinco: Cognitive fusion and treatment response to depression in caregivers of relatives with dementia

9.1 Abstract

Caring for a relative with dementia is associated with negative psychological consequences for the caregivers, such as depression. Cognitive fusion is considered a key process of psychological inflexibility, associated with psychological distress. The aim of this study is to analyze whether baseline levels of cognitive fusion predict different treatment response of depressive symptoms, comparing individual Acceptance and Commitment Therapy (ACT), Cognitive and Behavioral Therapy (CBT) and a control group. A total of 130 family caregivers participated in the study: ACT intervention (N= 49), CBT intervention (N= 41) and control group (N = 40). Moderation analyses were conducted. The results show a significant effect of the interaction between baseline levels of cognitive fusion and the treatment condition ($p < .05$) on depressive symptoms. Specifically, caregivers in the CBT condition presented higher change in depressive symptoms than those in the control group when their baseline levels of cognitive fusion were low, medium and high. Participants in the ACT condition showed a greater change in depressive symptoms than participants in the control group when their baseline levels of cognitive fusion were medium and high. Finally, the findings suggest that caregivers in the ACT condition showed a greater change in depressive symptoms than those in the CBT condition when their baseline levels of cognitive fusion were high. These results seem to support the use of cognitive fusion as a screening tool for intervention assignment in clinical practice with dementia caregivers.

Keywords: Caregivers, Change in depressive symptoms, Cognitive fusion, Acceptance and Commitment Therapy, Cognitive Behavioral Therapy, Moderator of treatment Mechanism of change.

9.2 Introduction

Globally around 50 million people have dementia, and this number is expected to almost triple by 2050 (Patterson, 2018). Most of the unpaid care received by people with dementia is provided by informal caregivers, mostly relatives, who provide care for many years, assuming the main substantial proportion of dementia care costs (in low-to-middle-income countries the assumed cost reaches up to 70–90%, while in high-income countries this figure is about 40%; Prince et al., 2015). Caregivers usually deal with neuropsychiatric symptoms including disruptive behaviors (e.g., agitation, aggression, and sleep disturbances), which are the most distressing for caregivers. These aspects, linked to other daily difficulties (e.g., coping with other roles and family conflicts), put caregivers in a vulnerable chronically stressful situation (Cheng, 2017). Although people often choose to care for a relative and also find positive outcomes, such as a sense of meaning or personal growth (Quinn & Toms, 2019), caring for a relative with dementia is generally associated with negative psychological consequences (e.g,. Sallim et al., 2015; Kaddour & Kishita, 2019). One of most studied is depression, due to its high prevalence, with an adjusted frequency of 31.24% of depressive symptoms in caregivers of people with dementia (Collins & Kishita, 2020).

Several meta-analytic studies on the efficacy of interventions in reducing caregiver distress (e.g., Cheng et al., 2019; Kishita et al., 2018) find that symptoms of depression can be significantly reduced through psychotherapeutic interventions such as cognitive-behavioral approaches (e.g., START, STrAtegies for RelaTives, Livingston et al., 2020) and Acceptance and Commitment Therapy (ACT) (e.g., Losada et al., 2015). Although CBT interventions have strong empirical support for managing depression in caregivers, there is variability in the effect size. The interest in ACT approaches is growing due to its benefits in reducing distress in caregivers of people with dementia (Kishita et al., 2018).

Both CBT and ACT interventions train behavioral strategies for managing sources of distress (Hofmann & Asmundson, 2008); however, while changes in dysfunctional thoughts and behavior are the main mechanisms of action of CBT, acceptance of unavoidable sources of distress combined with doing actions towards important areas of values for the caregiver are the main mechanisms of action of ACT (Márquez-González et al., 2010). In a similar way, both models differ regarding the role of cognitions in behavior change. While CBT models focus on modifying the content of dysfunctional thoughts, ACT interventions view thoughts as a form of behavior, and focus on identifying and modifying its function (Hayes, 2004). ACT interventions do not attempt to decrease emotional distress by changing maladaptive cognitions, but through the acceptance of unpleasant emotions and thoughts as well as through cognitive defusion strategies (Hayes, 2004). The opposite, that is cognitive fusion, or acting on the literal meaning of one's thoughts, is the tendency to allow behavior to be excessively regulated and influenced by one's thoughts, instead of maintaining a distance between thoughts and actions, and is a key process targeted by ACT (Hayes, 2004).

Given that previous research has already shown both CBT and ACT therapies to work well for some family caregivers of people with dementia (Losada et al., 2015; Márquez-González et al., 2020), there may now be a need to study which intervention work best for whom. One way to achieve such a goal is by identifying moderators of treatment effects which can be measured before therapy (Kraemer et a., 2006) in order to provide people with the best treatment option. Previous studies have reported some moderators for dementia family caregiver interventions. For example, Rabinowitz et al. (2006) found that lower baseline levels of self-efficacy better predicted positive response to treatment in a cognitive-behavioral psychoeducational intervention compared to an enhanced support group. In another study, Kim et al. (2012) found that kinship with the care-recipient also affected the response to intervention. Specifically, they found that both wife and daughter caregivers had lower depressive symptoms after using an adult day service compared to those who did not (Kim et al., 2012).

In the present study, the role of cognitive fusion as a moderator of treatment efficacy is analyzed. Previous research has suggested cognitive fusion as a key variable for identifying caregivers with high levels of symptoms of depression, anxiety, and comorbid depression and anxiety (Barrera-Caballero et al., 2021). In addition, an intervention study with a non-caregiver population conducted by Arch et al. (2012) showed that cognitive defusion mediated treatment effects in a traditional CBT intervention and an ACT intervention, with ACT resulting in greater cognitive defusion than CBT.

Drawing upon the previously mentioned studies, the aim of this study is to test for the first time whether baseline cognitive fusion levels moderate the relationship between the intervention condition (ACT or CBT versus control) and improvement in depressive symptoms in a sample of dementia caregivers, hypothesizing that those with higher baseline cognitive fusion will show a higher decrease in depressive symptoms after the intervention. In addition, our hypothesis is that this effect will be stronger for those caregivers allocated in the ACT intervention than in the other two intervention conditions (CBT or control) since cognitive fusion is a central process and mechanism of action of ACT-based interventions.

9.3 Methods

9.3.1 Participants and procedure

Participants were 130 family caregivers of people with dementia who participated in two previous randomized controlled trials that shared the pre-postintervention design (Losada et al., 2015; Márquez-González et al., 2020). They were recruited through different social and health centers in the Community of Madrid, Spain. The inclusion criteria were: a) identifying themselves as the main caregiver, b) devoting at least one hour per day for at least three consecutive months to caregiving tasks; c) being at least 18 years old; d) presenting clinical depressive symptomatology (scores higher than 16 in the Center for Epidemiologic Studies-Depression (CES-D) Scale), Radloff, 1977) at baseline; and e) giving informed consent to voluntary participation in one of the two intervention studies (Losada et al., 2015; Márquez-González et al., 2020). The studies were approved by the Spanish Ministry of Science and Innovation and the Ethics Committee of the Universidad Rey Juan Carlos (Madrid, Spain).

The ACT intervention, described in detail in Márquez-González et al. (2010), consisted of eight weekly two-hour individual sessions. Based on Hayes et al. (1999) and McCurry (2006), the main therapeutic aims of these sessions were training caregivers to accept rather than avoid aversive feelings and thoughts and clarifying and orienting behavior towards meaningful personal values. On the other hand, the CBT intervention, described in detail in Losada et al. (2006), also consisted on eight weekly two-hour individual sessions. Based on a cognitive-behavioral model (Gallagher-Thompson et al., 2000; Losada et al., 2006), the objectives of this intervention were increasing the frequency of pleasant activities, modifying dysfunctional thoughts related to caregiving, training in assertiveness skills and relaxation techniques. Finally, the control condition consisted of a two- to three-hour workshop of psychoeducation on dementia, conducted in a group format.

The results from the main studies (Losada et al., 2015; Márquez-González et al., 2020) showed that when comparing change in depressive symptoms between the three study conditions, significantly greater changes were obtained favoring the CBT and ACT interventions compared to the control condition. No significant differences were obtained when comparing CBT and ACT outcomes on depressive symptoms.

Data from these three conditions of the two projects were selected and merged for conducting the analyses of this study. Concretely, data from pre- and post-intervention were available for 41 family caregivers for the CBT intervention, 49 for the ACT intervention, and 40 for the control group. Because the Spanish version (Romero-Moreno et al., 2014) of the Cognitive Fusion Questionnaire (Gillanders et al., 2014) was not (could not be) included until after its validation, data on cognitive fusion were not available for 14 subjects.

9.3.2 Variables and measures

Information on caregivers' gender, age, kinship with the care-recipient, daily hours devoted to caring tasks and time since being a caregiver was collected. Also, care recipients' age and functional capacity (measured through the Barthel index; Mahoney and Barthel, 1965) were reported by the caregivers. In addition to these sociodemographic and stressor variables, the following variables were assessed:

Frequency and reaction to disruptive behaviors. The Spanish version (Nogales-González et al., 2015) of the Revised Memory and Behavior Problems Checklist (Teri et al., 1992), measuring frequency and reaction subscales (both consisted of eight items) of the disruptive behaviors dimension. The frequency subscale assesses how often from 0 (never occurred) to 4 (occurs daily or more often) the care-recipient shows eight behaviors (e.g., “Arguing, irritability, and/or complaining”). The reaction subscale measures caregivers’ reaction to those eight behaviors (e.g., “how much has this behavior upset you?”), ranging from 0 (not at all) to 4 (extremely). The internal consistency (Cronbach’s α) in this study was 0.69 for the frequency subscale, and 0.74 for the reaction subscale.

Cognitive fusion. We used the Spanish version (Romero-Moreno et al., 2014) of the Cognitive Fusion Questionnaire (Gillanders et al., 2014). This is a seven-item scale that assesses the tendency to believe and react to the literal content of thoughts and feelings (e.g., “I fight with my thoughts “I get angry with myself for thinking in a particularly way”). Responses on a Likert-type scale range from 1 (never) to 7 (always). The internal consistency (Cronbach’s α) for this study was 0.84.

Depressive symptomatology. The Spanish version (Losada et al., 2012) of the (CES-D; Radloff, 1977) was used. It consists of twenty items that measure how often during the previous week caregivers felt depressive symptoms. (e.g., “I felt sad”; “I cried sometimes”). The answers to the items ranged from 0 (rarely or never – less than one day) to 3 (most or all of the time – 5-7 days) on a Likert-type scale. In this study, Cronbach’s alpha was .81.

9.3.3 Data analysis

We first used descriptive data, analyzing baseline differences between conditions and changing from pre–to post treatment (2-months-after baseline levels) in cognitive fusion in the different intervention conditions through independence (χ^2) and ANOVA analysis. We then conducted linear regression analyses using the Hayes (2013) procedure to test the moderation effect of baseline levels of cognitive fusion on the relationship between the intervention condition and pre-post change in depressive symptomatology. This procedure provides cut-off scores for low, medium and high cognitive fusion using 16th, 50th and 84th percentiles as conditioning values of the moderator values for testing the interaction conducting a bootstrapping of 10000 samples. Intervention condition (ACT vs CBT vs control) was included as our main predictor; baseline levels of cognitive fusion was included as the moderator variable and change from pre- to post treatment (2-months-after baseline levels) in depressive symptomatology was introduced as the dependent variable. Frequency of care-recipients' disruptive behaviors and caregivers′ baseline levels of depressive symptoms were entered in the model as covariates. Finally, we tested for differences in depressive symptomatology between treatment conditions (control, CBT and ACT), controlling for levels of cognitive fusion (low, medium and high) using repeated measures ANOVA. All analyses were conducted using the IBM SPSS program (v.27) and the PROCESS macro (v.3.5) for SPSS (Hayes, 2013).

9.4 Results

Differences between intervention conditions in the assessed variables at baseline and change from pre to post treatment in cognitive fusion

Table 9.1 shows the characteristics of the sample (means, standard deviations or samples and percentages). There were no differences between groups in any sociodemographic characteristic prior to the intervention. Nor were differences found in reaction to care-recipients' disruptive behavior or in depressive symptomatology. Caregivers in the ACT intervention reported a higher frequency of care-recipients' disruptive behavior than caregivers in the CBT and control groups, and higher levels of cognitive fusion than the control group. Finally, those caregivers in the ACT intervention showed higher change from pre to post treatment in cognitive fusion than caregivers in the CBT and control groups.

Table 9.2. Participants sociodemographic and caregiving characteristics in each group

	Control (n=40)	Acceptance and Commitment Therapy (ACT) (n=49)	Cognitive and Behavioural Therapy (CBT) (n=41)	F/X2	p	Post hoc pairwise comparisons (Tukey, α =.05)
Caregivers' age	60.10 (12.67)	59.08 (15.76)	62.34 (11.13)	.66	.515	
Gender (% female)	82.25	82.24	82.26	4.48	.107	
Care-recipient kinship (% spousal)	39.25	39.38	39.26	5.12	.883	
Time being a caregiver (months)	14.04 (23.08)	13.23 (19.06)	16.69 (31.47)	.23	.794	
Daily hours caring	14.88 (8.60)	13.53 (7.68)	12.56 (8.01)	.81	.444	
Care-recipient's age	78.80 (9.42)	78.81 (8.67)	79.05 (8.88)	.10	.903	

Care-recipient functional capacity	62.62 (26.53)	65.14 (28.79)	69.80 (27.01)	.71	.492	
Frequency of disruptive behaviours	6.82 (5.13)	9.85 (5.75)	6.51 (5.87)	4.91	.009	ACT > Control ACT > CBT
Reaction to disruptive behaviors	18.62 (7.83)	21.91 (6.18)	18.53 (7.50)	2.94	.057	
Depressive symptomatology	26.40 (9.34)	28.45 (8.96)	27.00 (9.27)	2.61	.078	
Cognitive fusion	25.23 (10.38)	30.77 (8.55)	27.11 (9.08)	3.72	.027	ACT > Control
Change pre- to post treatment cognitive fusion	1.07 (8.31)	5.53 (8.35)	1.86 (8.02)	3.28	.041	ACT > Control ACT > CBT

The moderator role of baseline cognitive fusion levels in the associations between intervention conditions and change in depressive symptomatology

The obtained cut-off scores for cognitive fusion based on the linear regression model for testing moderation using the percentiles of the interaction model (16th: 17; 50th: 30; 84th: 37; Hayes et al., 2013) were: low cognitive fusion: <17; medium cognitive fusion: 18-37; and high cognitive fusion: >38. Mean depression levels for each treatment condition considering cognitive fusion levels are shown in Table 9.2. Participants in the ACT condition with high levels of cognitive fusion showed a greater change in depression than those with low and medium levels. No differences were found for participants in the CBT and control conditions.

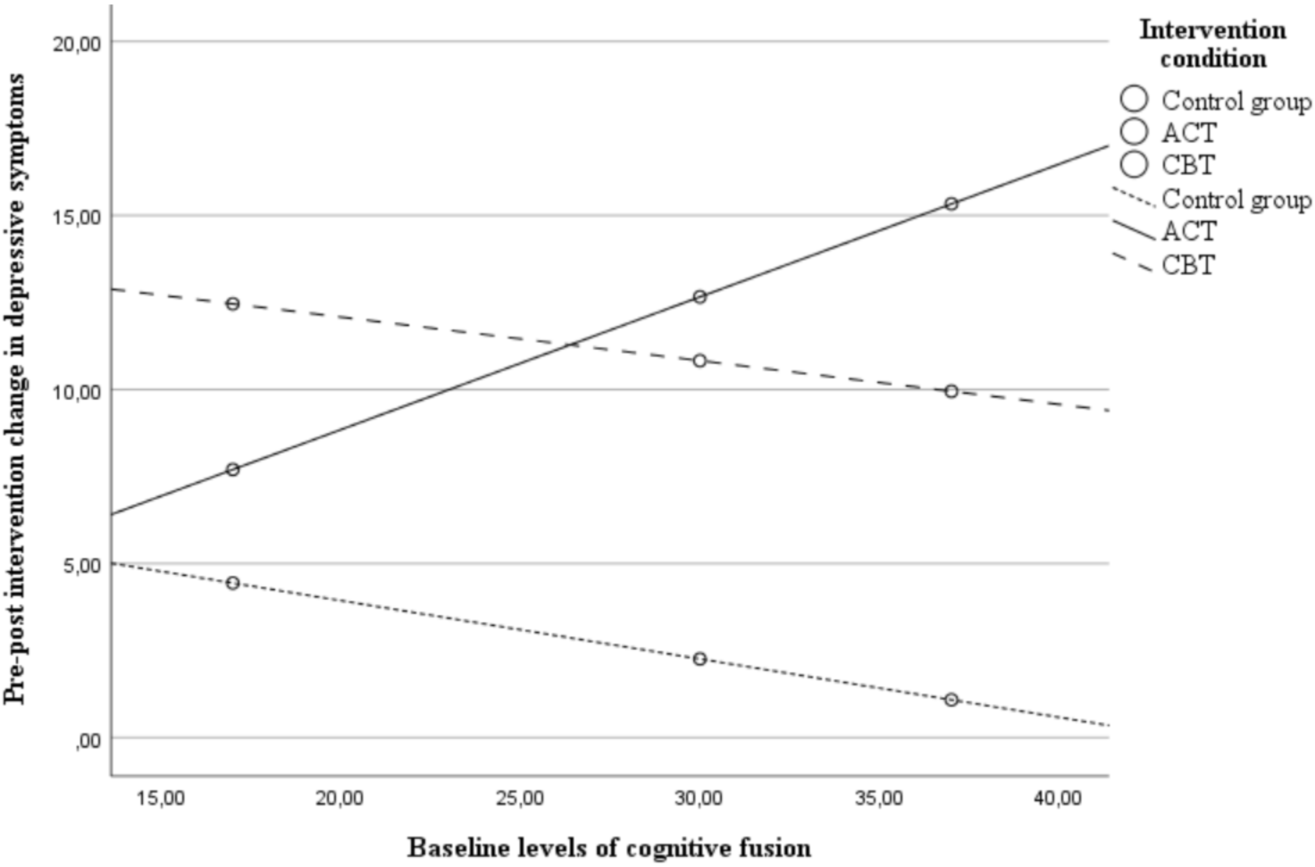
The moderation model results showed that the interaction between intervention condition and baseline levels of cognitive fusion had a significant effect (F (2, 104) = 4.36, p = .015) on change in depressive symptoms. Specifically, as Figure 9.1 illustrates, the analyses revealed that participants in the CBT condition showed a greater change in depressive symptoms than participants in the control group when baseline cognitive fusion was low (standardized effect = 8.02, p = .006, t = 2.82, SE = 2.84, CI 95%= 2.38 -13.66), medium (standardized effect = 8.57, p < .01, t = 3.96, SE = 2.16, CI 95% = 4.28 -12.85), and high (standardized effect = 8.86, p = .004, t = 2.92, SE = 3.03, CI 95% = 2.85 -14.87). In addition, participants in the ACT condition presented greater change in depressive symptoms than the control group when baseline levels of cognitive fusion were medium (standardized effect = 10.40, p < .01, t = 5.03, SE = 2.07, CI 95% = 6.30 - 14.50). No differences were observed between CBT and ACT when baseline levels of cognitive fusion were medium. Participants in the ACT condition showed a greater change in depressive symptoms than participants in the CBT (standardized effect = 5.38, p =.003, t = 2.07, SE = 2.59, CI 95% = .23 -10.54) and participants in the control group for high baseline levels of cognitive fusion (standardized effect = 14.86, p < .01, t = 5.21, SE = 2.73, CI 95% = 8.82 - 19.67).

Table 9.2. Baseline and postintervention scores in depressive symptomatology controlling for cognitive fusion (CF) levels and treatment condition

	Low cognitive fusion		Medium cognitive fusion		High cognitive fusion		F	p	Post hoc pairwise comparisons (Tukey, α =.05)
	Baseline depressive symptoms	Postintervention depressive symptoms	Baseline depressive symptoms	Postintervention depressive symptoms	Baseline depressive symptoms	Postintervention depressive symptoms			
Control	22.36 (2.52; 17-45)	19.00 (12.24; 11-50)	22.66 (2.3; 16 – 36)	20.00 (6.89; 11-30)	32.54 (8.44; 19-47)	30.81 (8.75; 14-43)	-.21	.81	-

CBT	20.00 (4.14; 16-28)	9.33 (7.96; 3-23)	24.06 (7.82; 16-41)	14.06 (9.16; 1-42)	33.78 (9.57; 18-51)	20.92 (12.12; 5-39)	.36	.69	-
ACT	25.50 (8.26; 16-35)	17.50 (12.61; 9-36)	21.68 (6.06; 16-40)	14.66 (8.27; 5-29)	32.78 (9.05; 16-51)	15.00 (7.95; 0-36)	10.43	<.05	High cognitive fusion > low cognitive fusion High cognitive fusion > medium cognitive fusion

Figure 9.3. Linear regression model



9.5 Discussion

The main objective of this study was to analyze the degree to which baseline levels of cognitive fusion moderated dementia family caregivers' responses to change in depressive symptoms in the context of two randomized trials comparing an individual ACT intervention, an individual CBT intervention and a control group.

In line with our hypothesis, the results of this study suggest that baseline cognitive fusion levels have a moderator effect in the relationship between the intervention condition and change in depressive symptoms. Those caregivers participating in a CBT intervention showed a higher change in depressive symptoms compared with the control group when baseline levels of cognitive fusion were low. Those caregivers presenting medium and higher baseline levels of cognitive fusion showed a higher change in depressive symptoms both in the ACT and the CBT interventions as compared to the control group. Furthermore, those caregivers in the ACT condition reported a greater change in depressive symptoms than caregivers in the CBT condition when baseline levels of cognitive fusion were high. The results suggest that caregivers with high levels of cognitive fusion benefit more from ACT than from CBT. Also, the results showed that those caregivers in the ACT intervention reported higher change from pre- to post-treatment in cognitive fusion than caregivers in the CBT and control groups. This finding provides construct validity to the ACT intervention, as change in cognitive fusion is supposed to be one of its main mechanisms of action, which is consistent with previous research (Levin et al., 2020).

The obtained results add cognitive fusion to previous studies reporting moderators of caregiver interventions (e.g., self-efficacy; Rabinowitz et al. 2006). The study conducted by Rabinowitz et al. (2006) showed that caregivers' low levels of self-efficacy predicted better treatment responses in a cognitive behavior psychoeducational intervention. Consistently with this study, the present study shows that high cognitive fusion (which can be considered also as a measure of maladaptive coping similar to low levels of self-efficacy), predicted better treatment responses in the CBT and ACT conditions compared to the control group. In other study with a non-caregiver population, a higher baseline level of psychological inflexibility, which included cognitive fusion, predicted a higher improvement in distress symptoms and functional impairment in the context of an ACT intervention for clinical perfectionism in comparison with a waitlist group (Ong et al., 2019).

Given that from the ACT theoretical framework, increased psychological inflexibility is key to understanding psychological distress (Hayes et al., 1999), it is theoretically predictable that those caregivers presenting higher levels of cognitive fusion at baseline might show a higher change in depressive symptoms after the intervention. As these therapies are focused directly on that process (Hayes et al., 2006), caregivers with higher levels of cognitive fusion may experience a more notable benefit from ACT-based interventions. On the other hand, it might be also reasonable to think that baseline levels of cognitive fusion may moderate the relationship between CBT intervention and depressive symptoms, even though cognitive fusion is not a target of this kind of intervention. It has been shown in the literature that techniques like cognitive restructuring, commonly used in CBT interventions, may indirectly deal with this variable (Arch & Craske, 2008). However, in this study, our data suggest that when baseline levels of cognitive fusion are high, people seem to benefit more from an ACT intervention than a CBT intervention. Hence, this kind of therapy (CBT) does not seem as efficient as ACT for caregivers that tend to fuse with their own thoughts and emotions. A possible explanation for this finding could be that, in people with high cognitive fusion levels, cognitive fusion possibly acts as a central mechanism that maintains their symptoms

(Barrera-Caballero et al., 2021), while in those with low or medium levels of cognitive fusion, other central mechanisms may be involved (e.g., leisure and dysfunctional thoughts, Losada et al., 2015), in which case it would be helpful to identify these.

Some limitations of the present study should be considered. First of all, the sample included volunteer caregivers with clinical depressive symptomatology who wanted to participate in an intervention program. Additional studies conducted with larger sample sizes and additional time points are necessary in order to provide support for the findings obtained. Another important limitation is that, although it was found that change in cognitive fusion is associated with greater change in depressive symptoms in ACT when compared to CBT and control, we have not verified that ACT acts on cognitive fusion.

Despite these limitations, the present study may claim to make a unique contribution to the literature because as far as we are aware, this is the first study showing that considering baseline levels of cognitive fusion is important, not only because it is related to emotional distress in caregivers but also because it may influence how caregivers respond to different types of interventions, even after controlling for baseline depressive symptoms. The study also presents important clinical implications. It supports the use of cognitive fusion as a screening tool for appropriate caregiver intervention assignment. These results provide support for the validity of the increasingly more frequent recommendation that interventions with distressed caregivers must be tailored to address the specific needs of each caregiver and adapt the concrete mechanisms involved in each case, and which can be appropriately identified by a comprehensive functional assessment (Márquez-González et al., 2020). Finally, the use of cognitive fusion as a screening tool for appropriate intervention assignment could be useful not only for caregivers but also for other populations.

This study highlights the role of caregivers' cognitive fusion levels in the influence it has on caregivers' response to specific treatments, a crucially important issue considering the growing worldwide impact of dementia as well the number of family caregivers (Alzheimer's Association, 2018) and its negative consequences for them.

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10. Discusión General

En este apartado se discuten los resultados y aportaciones de los estudios que conforman la presente tesis doctoral. Primeramente se analizan las características de la muestra con el objetivo de valorar la capacidad de generalización de los resultados obtenidos en los diferentes estudios a la población cuidadora, en comparación con los resultados obtenidos por otras investigaciones nacionales e internacionales. Posteriormente se exponen los hallazgos obtenidos en cada estudio, analizando los objetivos e hipótesis planteadas, destacando las aportaciones principales que se derivan de cada uno de los trabajos. Seguidamente se realiza una reflexión que engloba las aportaciones principales de todos los estudios que conforman esta tesis doctoral. Tras esta reflexión se analizan las implicaciones prácticas más importantes del conjunto de los estudios, así como las limitaciones existentes y las posibles futuras líneas de investigación. Por último, para concluir la presente tesis doctoral, se presenta una conclusión general derivada de las principales aportaciones comentadas en la discusión.

10.1 Características sociodemográficas de la muestra

De forma global, las características sociodemográficas de los participantes que encontramos en los distintos estudios de la presente tesis doctoral se asemejan a las que se encuentran en otros estudios tanto nacionales como internacionales. Específicamente, se observa que el cuidado es mayoritariamente femenino (en torno al 70%), puesto que la muestra de participantes de los estudios de la tesis estaba compuesta principalmente por mujeres, coincidiendo con Abellán et al. (2017), quienes informan de que el perfil prototípico de cuidador familiar en España se corresponde con ser mujer (76%). Otros estudios internacionales también ponen de manifiesto que las responsabilidades de cuidar a alguien con demencia a menudo recaen en las mujeres, ya que aproximadamente dos tercios de las personas cuidadoras son mujeres (Alzheimer's Association, 2019; WHO, 2012). Según la Alzheimer’s Association Women and Alzheimer’s Poll (2014), que encuestó tanto a hombres y mujeres, de aquellas personas que cuidaban de 21 a más de 60 horas a la semana, el 67 % eran mujeres (Alzheime’s Association, 2014).

En cuanto al parentesco, se encuentra que las personas cuidan de forma mayoritaria de su padre o madre o de su esposo o esposa, en línea con lo reportado por Abellán et al. (2017) y otros estudios nacionales e internacionales (p. ej., Alzheimer's Association, 2019; Friedman et al., 2015).

Respecto a las características de la persona cuidada, estas no difieren con las expuestas en otros estudios internacionales (p.ej., Alzheimer's Association, 2019; Livingston et al., 2020). Concretamente, los diferentes estudios de la tesis muestran que los cuidadores se encuentran sometidos a altas demandas, al atender a sus familiares, mayoritariamente afectados por una demencia tipo Alzheimer (en torno al 70%), durante un elevado número de horas diarias (más de 10 horas diarias) durante un tiempo prolongado (más de tres años de media).

En definitiva, las características sociodemográficas de las muestras de los diferentes estudios de la tesis parecen asemejarse con las de otras investigaciones llevadas a cabo con cuidadores familiares de personas con demencia. Por tanto, con ciertas garantías, los resultados que se derivan de esta tesis doctoral podrían ser discutidos y comparados respecto a la literatura científica del cuidado.

10.2 Principales aportaciones de los estudios incluidos en la tesis

Teniendo como referencia el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), el objetivo principal de la presente tesis doctoral fue analizar de forma transversal y longitudinal el papel de distintas variables y, especialmente, de la fusión cognitiva, en el proceso de estrés del cuidado.

Específicamente, en el primer estudio se analizó el papel de la fusión cognitiva en la relación entre los comportamientos disruptivos del familiar y el sentimiento de ambivalencia de los cuidadores. En el segundo estudio se analizaron las diferencias entre perfiles emocionales de los cuidadores (comórbidos, depresivos, ansiosos, subclínica) en variables contextuales y sociodemográficas (género, edad, parentesco), así como en variables estresoras (tiempo dedicado al cuidado, frecuencia y reacción a conductas disruptivas del familiar) y la fusión cognitiva. Además de esto, se analizó el papel de la fusión cognitiva como variable o proceso transdiagnóstico central en la presentación comórbida de sintomatología depresiva y ansiosa de los cuidadores. En el tercer estudio se analizó la relación entre fusión cognitiva y sintomatología depresiva y ansiosa a través de la satisfacción con valores personales. El cuarto estudio tuvo como objetivo analizar de forma longitudinal el efecto predictor de la fusión cognitiva sobre la sintomatología depresiva, ansiosa y los sentimientos de ambivalencia de los cuidadores, controlando el papel de otras variables relevantes en el modelo de estrés y afrontamiento adaptado al cuidado. Por último, en el quinto y último estudio se analizó el papel moderador de la fusión cognitiva en el análisis de la eficacia del tratamiento para la sintomatología depresiva, comparando la Terapia de Aceptación y Compromiso (ACT), la Terapia Cognitiva y Conductual (TCC) y un grupo control.

A continuación se analizan las aportaciones principales que se derivan de cada estudio de la presente tesis doctoral. Para un análisis más profundo se remite a la discusión propia de cada uno de los estudios anteriormente expuestos.

Estudio uno

Los resultados del primer estudio mostraron que, de acuerdo con las hipótesis planteadas, las variables frecuencia y reacción ante los comportamientos disruptivos del familiar, fusión cognitiva y sentimientos de ambivalencia se relacionan de forma positiva y significativa. Los resultados sugieren que la frecuencia de conductas disruptivas del familiar no se asocia de forma directa con los sentimientos de ambivalencia de los cuidadores, sino que esta asociación podría explicarse a través de dos vías indirectas: 1) la reacción de los cuidadores ante las conductas disruptivas del familiar podría actuar como mediador en la relación entre la frecuencia de las conductas disruptivas y la ambivalencia; y 2) el impacto de la reacción del cuidador ante las conductas disruptivas sobre los sentimientos ambivalentes podría estar mediado a su vez por la fusión cognitiva. La principal aportación de este estudio hace referencia a que la reacción de estrés de los cuidadores ante las conductas disruptivas de su familiar podría asociarse con un proceso cognitivo desadaptativo de los cuidadores (aumento de los niveles de fusión cognitiva), facilitando así el surgimiento y/o mantenimiento de emociones negativas hacia su familiar, que junto con los sentimientos positivos derivados del cuidado de un familiar querido, se manifestaría como ambivalencia emocional. Estos hallazgos respaldan el modelo de estrés y afrontamiento (Knight & Sayegh, 2010), que postula que la influencia de los estresores (p. ej., conductas disruptivas) en las consecuencias del cuidado (en este estudio, ambivalencia) está modulada por otras variables (en este estudio, reacción a conductas disruptivas y fusión cognitiva).

Estudio dos

En primer lugar, los resultados de este estudio sugieren que existe una alta prevalencia de síntomas comórbidos en los cuidadores familiares de personas con demencia, presentando más de la mitad de los participantes (54,8%) simultáneamente niveles significativos de sintomatología depresiva y ansiosa. El presente estudio también revela que, en línea con Joling et al. (2014), los síntomas de ansiedad clínicamente significativos fueron muy prevalentes entre los cuidadores (70,4%). Las principales aportaciones de este estudio son, por un lado, que una alta proporción de cuidadores familiares de personas con demencia tienen una presentación comórbida de niveles clínicamente relevantes de sintomatología depresiva y ansiosa. Por otro lado, los hallazgos de este estudio muestran que las mujeres cuidadoras informan de más síntomas comórbidos que los hombres cuidadores, resultados coherentes con otros estudios que informan de mayores niveles de angustia para las mujeres cuidadoras (Collins & Kishita, 2019; Joling et al., 2014; Kaddour y Kishita, 2019). Por otra parte, los hallazgos de este estudio sugieren que los comportamientos disruptivos de los familiares pueden ser especialmente relevantes en términos de comprender la presencia comórbida de síntomas depresivos y de ansiedad en los cuidadores. Por último, si bien la asociación entre fusión cognitiva y síntomas depresivos o ansiosos ya ha sido descrita en estudios previos (Romero-Moreno et al., 2014; Romero-Moreno et al., 2015), la principal aportación de este estudio es que ofrece la primera evidencia de que la fusión cognitiva parece ser una variable importante asociada a la comorbilidad ansioso-depresiva en los cuidadores En esta línea, los resultados obtenidos son consistentes con estudios previos que muestran que la inflexibilidad psicológica está relacionada con problemas psicológicos comórbidos como trastornos depresivos, de ansiedad, alimentarios o por uso de sustancias (p.e., Levin et al. 2012 ; Levin et al., 2014; Rawal et al., 2010; Venta et al., 2012).

Estudio tres

Los resultados de este estudio mostraron, en línea con lo hipotetizado, que hubo un efecto indirecto de la fusión cognitiva sobre el malestar emocional de los cuidadores a través de la satisfacción con los valores personales. Sin embargo, la hipótesis se confirma parcialmente. Solo la satisfacción con otros valores personales elegidos por los cuidadores (no la satisfacción con el valor del cuidado) mostró un efecto indirecto en la relación entre la fusión cognitiva y los síntomas depresivos y ansiosos de los cuidadores. La principal aportación de este estudio hace referencia a que tener alta fusión cognitiva puede asociarse a menor satisfacción con valores, puesto que "estar dominado" por el contenido de los pensamientos hace que la conducta esté demasiado regulada por la cognición, lo que repercute en que no se "beneficien" de las contingencias ambientales o no obtengan satisfacción de los valores, lo que a su vez, se relaciona con mayores niveles de síntomas depresivos y de ansiedad de los cuidadores. Estos resultados son consistentes con lo encontrado por Trindade et al. (2016), quienes sugirieron que la fusión cognitiva es un proceso desadaptativo que puede estar asociado con la insensibilidad a las oportunidades de participar en acciones valiosas de manera significativa.

Estudio cuatro

En línea con las hipótesis planteadas, los resultados de este estudio longitudinal reflejan que incrementos en los niveles de fusión cognitiva predijeron incrementos en la sintomatología depresiva y ansiosa, así como en los sentimientos de ambivalencia de los cuidadores, tras controlar variables relevantes destacadas en la literatura del cuidado (por ejemplo sociodemográficas y estresoras). La fusión cognitiva fue la única variable que predijo cambios en las tres variables de malestar, demostrando su papel transdiagnóstico. En cuanto a la sintomatología depresiva, soló la fusión cognitiva predijo cambios. En cuanto a la sintomatología ansiosa, este estudio revela que son las mujeres cuidadoras quienes presentan mayores niveles de ansiedad a lo largo del tiempo, en concordancia con otros estudios (Kaddour y Kishita, 2019). Por otra parte, aumentos en los niveles de reacción a las conductas disruptivas del familiar también predijeron aumentos en la sintomatología ansiosa de los cuidadores. En cuanto a la ambivalencia, este estudio revela que quienes presentan mayores niveles de ambivalencia a lo largo del tiempo son las personas de menos edad y las que informan de mayor reacción a los comportamientos del familiar y de mayores niveles de fusión cognitiva. La principal aportación de este estudio es que la mayor tendencia a que la conducta sea regulada por la cognición, es decir la fusión cognitiva, se asoció con una mayor sintomatología depresiva, ansiosa y ambivalente de los cuidadores, lo cual es consistente con estudios transversales previos (Barrera-Caballero et al., 2021) y con estudios longitudinales en otras poblaciones (Carvalho et al., 2019). Por lo tanto, los resultados actuales se suman a estudios previos, pero los refuerzan dado que en este caso se han llevado a cabo a través de una metodología longitudinal. Estos resultados contribuyen a avanzar en la comprensión del papel de la fusión cognitiva en la etiología de los síntomas depresivos, ansiosos y ambivalentes en los cuidadores

Estudio cinco

En línea con lo hipotetizado, los resultados de este estudio sugieren que los niveles basales de fusión cognitiva tienen un efecto moderador en la relación entre la condición de intervención en la que participan los cuidadores y el cambio en los síntomas depresivos o la repuesta a la intervención. Los cuidadores que participaron en una intervención cognitivo-conductual (TCC) mostraron un mayor cambio en los síntomas depresivos en comparación con el grupo de control cuando los niveles iniciales de fusión cognitiva eran bajos. Aquellos cuidadores que presentaban niveles basales medios y altos de fusión cognitiva mostraron un mayor cambio en los síntomas depresivos tanto en las intervenciones de aceptación y compromiso (ACT) como en la TCC en comparación con el grupo control. Además, los cuidadores en la condición ACT informaron un mayor cambio en los síntomas depresivos que los cuidadores en la condición TCC cuando los niveles iniciales de fusión cognitiva eran altos. Los resultados sugieren que los cuidadores con altos niveles de fusión cognitiva se benefician más de ACT que de TCC. Además, los resultados mostraron que los cuidadores en la intervención ACT informaron de un mayorcambio pre-posttratamiento en la fusión cognitiva que los cuidadores en los grupos de TCC y control. Este hallazgo proporciona apoyo empírico a la validez de constructo a la intervención ACT, ya que teóricamente el cambio en la fusión cognitiva es uno de sus principales mecanismos de acción, lo que es consistente con investigaciones previas (Levin et al., 2020).

La principal aportación de este estudio hace referencia a que los resultados sugieren que es importante considerar los niveles iniciales de fusión cognitiva antes de la intervención terapéutica, no solo porque está relacionado con el malestar emocional en los cuidadores sino también porque puede influir en la forma en que los cuidadores responden a diferentes tipos de intervenciones psicológicas. Los resultados de este estudio apoyan el uso de la fusión cognitiva como una herramienta de detección para la toma de decisión clínica sobre cuál es la intervención más adecuada para el cuidador en función de sus niveles previos en esta variable transdiagnóstica. Estos resultados respaldan la validez de la recomendación, cada vez más frecuente, de que las intervenciones con cuidadores deben adaptarse a las necesidades específicas de cada cuidador y adaptar los mecanismos concretos involucrados en cada caso, y que pueden identificarse adecuadamente mediante una evaluación funcional (Márquez-González et al., 2020).

10.3 Conclusiones generales de los cinco estudios

10.3.1 Perfil de vulnerabilidad psicológica ante el malestar psicológico

A lo largo de los cinco estudios incluidos en esta tesis, a través de diferentes diseños y análisis estadísticos, se ha puesto de manifiesto que los cuidadores que informaban de mayores niveles de estrés y de fusión cognitiva experimentaban a su vez un mayor malestar emocional. Específicamente, quienes informaban de mayor fusión presentaban mayor sintomatología depresiva y ansiosa así como sentimientos de ambivalencia y sintomatología comórbida ansioso-depresiva, variables dependientes escasamente estudiadas en población cuidadora. Por otro lado, a lo largo de los diferentes estudios de la tesis se ha puesto de manifiesto la importancia de otras variables enmarcadas en el modelo de estrés y afrontamiento adaptado al cuidado y que, a su vez, presentan relación con la fusión cognitiva, como la frecuencia de comportamientos disruptivos de la persona cuidada, y la reacción de estrés por parte de los cuidadores ante dichos comportamientos. Es por ello por lo que, de acuerdo con las conclusiones de los estudios de la presente tesis, se podría establecer un perfil de vulnerabilidad de cuidadores a presentar malestar psicológico.

En los diferentes estudios que componen la tesis doctoral se observa la relevancia del género en la comprensión del proceso de estrés del cuidado, como demuestran numerosas investigaciones en relación al cuidado (p.ej., Kaddour y Kishita, 2020; Xiong et al., 2020). Como avalan los estudios de la presente tesis (1, 2, 4), las mujeres parecen presentar mayores niveles de ambivalencia, así como mayor sintomatología depresiva, ansiosa y comórbida. También las mujeres presentan mayor fusión cognitiva y reportan mayor frecuencia y reacción ante los comportamientos disruptivos del familiar. Por su parte, el estrés, y en concreto los comportamientos problemáticos disruptivos, tienen un papel central en la explicación del malestar emocional de los cuidadores, en concordancia con otros estudios (p.ej., Cheng et al., 2017; Livingston et al., 2020), incluyendo variables poco exploradas, como ambivalencia y comorbilidad. Tal y como postula el modelo propuesto por Losada et al. (2018), los comportamientos problemáticos parecen ser predisponentes de la sintomatología de ambivalencia (que se confirman en los estudios 1 y 4), así como de ansiedad y comorbilidad ansioso-depresiva (que se confirman en los estudios 2 y 4). A su vez, los estudios que componen la tesis muestran la importante relación entre estos comportamientos y la fusión cognitiva. De hecho, los resultados del estudio 1 sugieren que el estrés podría ser predisponente de los niveles de fusión cognitiva.

El hecho de que el género, el estrés y la fusión cognitiva predigan malestar psicológico y, en concreto, comorbilidad ansioso-depresiva, es especialmente relevante dadas las consecuencias que se derivan de esta manifestación comórbida. Como se ha mencionado anteriormente, la presentación comórbida de trastornos del estado de ánimo y ansiedad se asocia con graves consecuencias, puesto que se relaciona con una mayor gravedad y cronicidad del curso de problemáticas de salud mental, e incluso se asocia con una mayor mortalidad en condiciones médicas como la enfermedad cardíaca (p.ej., Doering et al., 2010; Gili et al., 2013).

A modo de resumen, los resultados de esta tesis reflejan un perfil de vulnerabilidad a presentar malestar psicológico en personas que cuidan de familiares con demencia: mujeres, de menor edad, que presentan mayor frecuencia y reacción ante los comportamientos disruptivos de su familiar y que presentan, a su vez, niveles elevados de fusión cognitiva. Por su parte son también las mujeres de menor edad con elevados niveles de estrés las que parecen presentar mayor tendencia a fusionarse con sus experiencias internas. La importancia de factores culturales como la connotación femenina del cuidado y el hecho de presentar potenciales conflictos de rol o sentimientos negativos como culpa por no alcanzar las exigencias deseables podrían servir de explicación ante la vulnerabilidad de este perfil.

10.3.2 La fusión cognitiva como variable transdiagnóstica en el proceso de estrés del cuidado

El cuidado familiar de personas con demencia es una fuente importante de malestar para quienes cuidan, y parece que hay variables transdiagnósticas que se relacionan con el desarrollo y mantenimiento de distintos tipos de sintomatología emocional, incluyendo la comorbilidad. Los resultados derivados de la tesis doctoral, obtenidos a través de distintos diseños de investigación y metodologías sugieren que la fusión cognitiva podría ser un proceso compartido por aquellos cuidadores que presentan malestar psicológico, medido a través de distintos tipos de sintomatología: ansiedad, depresión, ambivalencia y comorbilidad ansioso-depresiva, y parece ser un predictor clave a lo largo del tiempo del proceso del cuidado, siendo el único que es común a las distintas variables resultado que se han medido en la tesis. El modelo transdiagnóstico, que tienen en cuenta los procesos compartidos y en la base de distintos problemas, es compatible con el modelo de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), en el que las variables moduladoras adquieren un papel clave en el estudio sobre el cuidado. Por otro lado, el hecho de que en el estudio 3 se encuentre que la fusión cognitiva influye tanto en la sintomatología ansiosa como en la depresiva a través de la baja satisfacción con los valores personales también denota este rol transdiagnóstico de ambas variables de inflexibilidad psicológica.

10.4 Implicaciones prácticas

Teniendo en cuenta el creciente impacto mundial de la demencia, así como el número en aumento de cuidadores familiares y las consecuencias psicológicas asociadas al cuidado (Alzheimer's Association, 2018; Collins & Kishita, 2019; Kaddour & Kishita, 2020), como demuestran los estudios de la presente Tesis Doctoral, los resultados derivados de la misma presentan importantes implicaciones prácticas.

En primer lugar, los resultados de la presente Tesis Doctoral ponen de manifiesto la relevancia de la fusión cognitiva en el proceso de estrés del cuidado y la necesidad de estudios dirigidos a su análisis e intervención. Además, dada la alta tasa de comorbilidad de sintomatología depresiva y ansiosa hallada en el estudio 2 y las consecuencias negativas asociadas a tal comorbilidad, la identificación de correlatos de comorbilidad como la fusión cognitiva y los comportamientos disruptivos de la persona cuidada cuidado resulta útil para identificar posibles objetivos relevantes de evaluación e intervención.

Una intervención transdiagnóstica que se enfoca especialmente en el constructo de la fusión cognitiva es la Terapia de Aceptación y Compromiso (ACT) (Hayes et al., 1999). Esta terapia se dirige principalmente a la inflexibilidad psicológica, promoviendo un modo más flexible de enfrentarse a las experiencias negativas internas, a través de dos aspectos fundamentales: la aceptación de eventos internos negativos (emociones, pensamientos, etc.) y la realización de acciones comprometidas con valores importantes para la persona. A pesar de que la fusión cognitiva parece tratarse de un constructo transdiagnóstico y, como avala el estudio 5, personas con niveles medios de fusión cognitiva pueden beneficiarse también de otro tipo de terapias, como la Terapia Cognitivo Conductual (Arch et al., 2012), parece que la forma más eficaz de tratar la fusión cognitiva es de forma directa mediante la terapia ACT. La literatura previa avala la eficacia de terapia ACT a largo plazo para tratar el malestar psicológico (ansiedad, depresión, culpa) de los cuidadores familiares de personas con demencia (Collins y Kishita, 2018; Losada et al., 2015).

Las intervenciones basadas en ACT podrían ser útiles en los cuidadores al promover el mecanismo opuesto a la fusión cognitiva, es decir, la defusión cognitiva. El trabajo en defusión cognitiva implica entrenar a los cuidadores en habilidades que les ayuden a distanciarse de sus propios pensamientos a través de la aceptación, disminuyendo así el poder que tienen sus pensamientos sobre la conducta, sin intentar directamente modificar su contenido (Losada et al., 2015). Otras estrategias específicas para fomentar la defusión cognitiva pueden ser las técnicas de desliteralización del lenguaje, que promueven la toma de perspectiva, como las prácticas basadas en la atención plena que incluyen técnicas de mindfulness, o las que fomentan el yo como contexto, es decir, mediante la activación de otros procesos de inflexibilidad psicológica, al tener estos procesos relación entre sí (Hayes et al., 2011)

Trabajar en favor de la defusión cognitiva pasa por trabajar con los cuidadores en la capacidad de percibir estas experiencias internas como transitorias, con una postura de aceptación y no reacción ante ellas. Esta capacidad de darse cuenta de las experiencias internas sin una reacción automática puede, en última instancia, ampliar su repertorio de comportamientos, lo que abre la posibilidad de que una persona que cuida de su familiar con demencia active comportamientos y participe en experiencias valiosas y significativas, obteniendo satisfacción de las mismas, a pesar de su situación como cuidador. Según sugieren los resultados del estudio 4, la disminución de la fusión cognitiva puede ayudar a los cuidadores a estar más satisfechos con sus valores personales, disminuyendo así sus niveles de sintomatología depresiva y ansiosa. El trabajo en valores parece recomendable para los cuidadores, y desde la intervención ACT se propone que el trabajo en esta área es un pilar crucial (Márquez-González, Romero-Moreno y Losada, 2010). Por tanto, en el caso de los cuidadores, incluso a pesar de estar fusionados con pensamientos y emociones relacionadas con su situación de cuidado o su familiar, centrarse en valores personales diferentes al cuidado y tratar de encontrar satisfacción en ellos podría ser muy relevante para su salud psicológica.

Por otro lado, los resultados de los estudios también destacan la influencia de los comportamientos disruptivos en el malestar de los cuidadores y su relación con la fusión cognitiva (estudios 1, 2,4), por lo que demuestran la importancia de trabajar en su reducción para minimizar el impacto de la frecuencia de las conductas disruptivas de los familiares. En este sentido, intervenciones dirigidas a disminuir la frecuencia de las conductas disruptivas del familiar o la reacción de los cuidadores a estas conductas (p. ej., Bravo-Benítez & Navarro-González, 2018; Logsdon et al., 2007) podrían ser útiles y, además, minimizar las posibilidades de que los cuidadores, en condiciones de estrés elevadas, presenten también elevada tendencia a estar fusionados.

Del estudio 5 también se deriva la importancia de considerar la fusión cognitiva como una herramienta de cribado en la elección de la intervención a implementar. Los resultados de este estudio sugieren que considerar los niveles basales de fusión cognitiva, previos a la intervención podría ser importante, no solo porque está relacionado con la angustia emocional en los cuidadores, sino también porque puede influir en cómo los cuidadores responden a diferentes tipos de intervenciones. Los resultados apoyan el uso de la fusión cognitiva como una herramienta de detección para la asignación de intervención adecuada para el cuidador, lo que podría ser útil no solo para los cuidadores sino también para otras poblaciones. Aquellas personas que presentaran niveles medios o elevados de fusión podrían beneficiarse en mayor medida de la terapia de Aceptación y Compromiso para reducir su malestar emocional, mientras que las personas con niveles bajos y también medios de fusión cognitiva, podrían beneficiarse en mayor medida de la Terapia Cognitivo Conductual. Estos resultados respaldan la recomendación, cada vez más frecuente, de que las intervenciones con cuidadores con malestar emocional deben adaptarse a las necesidades específicas de cada cuidador y adaptar los mecanismos concretos que intervienen en cada caso, y que pueden identificarse adecuadamente mediante una evaluación funcional (Márquez-González et al., 2020).

A modo de conclusión, los cuidadores que lidian con síntomas depresivos y ansiosos y comórbidos, así como con sentimientos de ambivalencia, podrían beneficiarse de intervenciones psicológicas, que integren procesos transdiagnósticos, como la terapia ACT (Hayes et al., 1999), que se centren más en abordar el estrés y la fusión cognitiva, lo que produciría cambios en el malestar psicológico.

10.5 Limitaciones de los estudios

A pesar de las ya mencionadas aportaciones e implicaciones prácticas que se derivan de los estudios de la presente tesis doctoral, existen una serie de limitaciones asociadas a los mismos que deben discutirse.

En primer lugar, si bien es cierto que las características sociodemográficas son similares a las de otros estudios (p.ej., referencia del equipo), las muestras recogidas en los distintos estudios de la tesis están formadas por cuidadores que de forma voluntaria accedieron a participar, reclutados principalmente a través de centros de la Comunidad de Madrid. Por ello, se trata de muestras de conveniencia y los resultados derivados de los estudios no serían representativos y no pueden, por tanto, extrapolarse a toda la población cuidadora.

Por otra parte, a pesar de que el tamaño muestral de los estudios es adecuado, se recomienda que futuros estudios utilicen tamaños muestrales mayores para la correcta extrapolación de los datos. Por otro lado, los estudios 1, 2 y 3 comparten la limitación de la transversalidad del diseño de investigación, por lo que no se pueden realizar inferencias causales entre las variables que los componen, pudiendo darse una bidireccionalidad entre las asociaciones planteadas. A pesar de que en el estudio longitudinal se confirma que la fusión cognitiva predice cambios en la sintomatología depresiva y ansiosa, así como en los sentimientos de ambivalencia de los cuidadores, sería conveniente realizar estudios experimentales y longitudinales, llevando a cabo otro tipo de análisis estadísticos (por ej., de moderación y mediación) que permitan confirmar también las direcciones las relaciones y los resultados de los estudios incluidos.

Una limitación adicional tiene que ver con la utilización de medidas de autoinforme para la evaluación de las variables de la presente tesis, dado que a pesar de ser ampliamente utilizadas en la investigación psicológica, conllevan una serie de problemas que podrían afectar a los resultados finales de los estudios, como los sesgos de respuesta, la deseabilidad social o las dificultades de acceso a la experiencia subjetiva (Podsakoff et al., 2003).

Por otro lado, y a pesar de que en los estudios se han controlado variables relevantes en la investigación del cuidado, existen otras variables que no se han tenido en cuenta, como la culpa, los pensamientos disfuncionales o el familismo, que pueden contribuir también a la explicación de los resultados (p.ej., Gallego-Alberto, 2020; Losada et al., 2010). Por otro lado, existen indicadores o variables de inflexibilidad psicológica diferentes y potencialmente complementarios con los evaluados en esta tesis que podrían estar influyendo en los resultados obtenidos, como el mindfulness o la evitación experiencial, por lo que sería conveniente que futuros estudios incluyeran estas variables. Además, no resulta infrecuente que la fusión cognitiva se asocie a otros constructos, como la rumiación (Romero-Moreno et al., 2015).

Por último, en relación a la intervención psicológica con personas que cuidan de familiares con demencia, aunque se encontró que el cambio en la fusión cognitiva se asocia con un mayor cambio en los síntomas depresivos en la terapia ACT en comparación con TCC y el grupo control, son necesarios estudios futuros que permitan obtener respaldo empírico a si intervenciones como la terapia ACT incluida en este estudio actúa de forma directa (efecto mediador) sobre la fusión cognitiva, puesto que no se ha estudiado su efecto mediador.

10.6 Futuras líneas de estudio

La presente tesis doctoral, al mismo tiempo que arroja nuevos resultados sobre la importancia que tiene para los cuidadores familiares de personas con demencia reducir sus niveles de fusión cognitiva para su salud mental, plantea nuevas cuestiones de investigación y líneas de actuación.

En primer lugar, sería conveniente que se realicen estudios experimentales y longitudinales donde se analicen las direcciones de las relaciones entre las variables, mediante análisis de mediación y moderación y se confirme, de manera similar a los hallazgos de Carvalho et al. (2019) en personas con dolor crónico, el carácter mediador de la fusión cognitiva en el malestar psicológico de los cuidadores familiares de personas con demencia. A pesar de que los datos de la presente tesis subrayan la importancia de determinadas variables en el malestar de los cuidadores, es preciso que futuros estudios profundicen en los mecanismos a través de los cuales estas variables, en concreto, la fusión cognitiva, impactan en la salud mental de los cuidadores. Por otra parte, como se mencionó en el apartado anterior, sería interesante analizar el efecto de otras variables relevantes en el proceso del cuidado sobre el malestar psicológico, como variables culturales y contextuales que están cobrando cada vez mayor relevancia, como el familismo, el apoyo social, los pensamientos disfuncionales o la disponibilidad de recursos económicos o de ayuda gubernamentales (Schulz, 2020), profundizando en la influencia de estas variables en la sintomatología comórbida y en la ambivalencia, puesto que se trata de variables muy poco estudiadas en la literatura sobre el cuidado.

Además, a pesar de que a raíz de los resultados de la presente tesis se puede dibujar un perfil de vulnerabilidad psicológica al malestar psicológico, caracterizado por niveles elevados defusión cognitiva, resulta necesario que futuros estudios analicen, mediante diseños experimentales y longitudinales, los factores que predisponen a presentar elevados niveles de fusión cognitiva. Sería conveniente que se analice el efecto de la fusión cognitiva controlando el efecto de otras variables que guardan relación con este constructo, como la metamemoria o la rumiación (Romero-Moreno et al., 2015) o el decentring (Hadash et al., 2017). Por otra parte, sería importante analizar el papel de la fusión cognitiva en las trayectorias y evolución del proceso del cuidado (p. ej., en el cese del cuidado, en la institucionalización, en el uso de apoyo formal y social, etc), aspecto poco explorado; así como el efecto de otras variables que dan lugar a inflexibilidad psicológica, como la falta de contacto con el momento presente o la evitación experiencial (Hayes et al., 2011; Losada et al. 2014).

Por otro lado, en línea con lo expuesto por Gillanders et al. (2014), debido a que la escala de fusión cognitiva utilizada en los estudios de la tesis (CFQ: Gillanders et al., 2014) mide pensamientos generales, independientemente del contenido, sería interesante que futuros estudios diseñen una escala propia de fusión cognitiva en relación con pensamientos concretos derivados de la situación de cuidado, como pensamientos relacionados con la culpa o la claudicación. Estudios recientes también subrayan la necesidad de emplear una escala de fusión cognitiva “estado”, donde se mida el nivel de fusión cognitiva en el momento de la medida, usando el método de evaluación ecológica momentánea para analizarlo en tiempo real, y como afecta al estado de ánimo (Bolderston et al., 2019). Por otra parte, dadas las limitaciones derivadas de los tradicionales métodos de evaluación consistentes en el autoinforme, sería interesante que futuros estudios aplicaran otro tipo de herramientas de medición, como medidas objetivas de salud física (p. ej., biomarcadores) o medidas implícitas, dado que medir esta variable puede requerir de cierta capacidad metacognitiva por parte de los cuidadores.

Por último, sería de interés que se desarrollen estudios de intervención donde se comparen, de forma similar a lo realizado en el estudio cinco de la presente tesis, las diferencias entre dos intervenciones que están recibiendo respaldo empírico sobre la eficacia para tratar el malestar de los cuidadores (TCC y ACT) (Cheng et al., 2017) analizando, además del papel moderador de la fusión cognitiva, el papel mediador de la fusión cognitiva en ambas terapias, analizando los cambios que se producen en cada sesión y su relación con la mejoría clínica.

11. General Conclusions

Drawing upon the sociocultural stress and coping model, the current doctoral thesis proposes that cognitive fusion is a transdiagnostic variable that has a significant influence on caregivers' mental health. Despite its limitations, and as far as we are aware, no other studies have analyzed the influence of this variable in the caregiving stress process in association with ambivalent and comorbid depressive and anxious caregivers' symptoms, neither through cross-sectional nor longitudinal designs. Also, it is the first study analyzing the moderating role of the variable cognitive fusion in different psychological interventions. Throughout the five studies and through different designs and statistical analyses, it has been shown that caregivers who reported higher levels cognitive fusion also experienced higher emotional distress. On the other hand, throughout the different studies of the thesis, the importance of other variables framed in the stress and coping adapted to caregiving (Knight & Sayegh, 2010), that are also associated with cognitive fusion, has been highlighted. Based on the conclusions of the studies of this thesis, a vulnerability profile of caregivers to present psychological distress can be described: female caregivers, who experienced greater frequency and reaction to the disruptive behaviors of their relative, and who present higher levels of cognitive fusion. Potential implications of the findings of this doctoral thesis for the analysis of interventions to reduce cognitive fusion and stress have been proposed, with the final aim of finding ways to alleviate and prevent the negative psychological consequences that caring for a relative that has dementia has for their family caregivers.

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ANEXOS

Anexo I: Instrumentos de Evaluación

Subescala de frecuencia y reacción ante comportamientos disruptivos.

(Nogales-González et al., 2015; Teri et al., 1992).

Ahora me gustaría realizarle una serie de preguntas para evaluar si su familiar tiene problemas de conducta y de qué tipo son. Para ello, de cada problema de conducta voy a hacerle dos preguntas, la primera es para saber si el problema se da y con qué frecuencia. La segunda es para saber cuánto le estresa a usted que esta conducta ocurra. Para ello, use la siguiente escala:

Frecuencia
0 = nunca ocurrió
1 = Ocurrió, pero no la semana pasada
2 = 1 ó 2 veces la semana pasada
3 = de 3 a 6 veces la semana pasada
4 = diariamente o más a menudo

Reacción
0 = no me estresó nada
1 = Me estresó un poco
2 = me estresó moderadamente
3 = me estresó mucho
4 = me estresó extremadamente

Conducta	Frecuencia	**Reacción**
1- ¿Hace la misma pregunta una y otra vez?	0 1 2 3 4	0 1 2 3 4
2- ¿Tiene dificultades para recordar eventos recientes?	0 1 2 3 4	0 1 2 3 4
3- ¿Tiene dificultades para recordar eventos importantes del pasado?	0 1 2 3 4	0 1 2 3 4
4- ¿Pierde o cambia cosas de lugar?	0 1 2 3 4	0 1 2 3 4
5- ¿Olvida qué día es hoy?	0 1 2 3 4	0 1 2 3 4
6- ¿Empieza tareas que no termina?	0 1 2 3 4	0 1 2 3 4
7- ¿Tiene dificultades para concentrarse en una tarea?	0 1 2 3 4	0 1 2 3 4
8- ¿Destruye la propiedad?	0 1 2 3 4	0 1 2 3 4
9- ¿Hace cosas que le hacen pasar vergüenza?	0 1 2 3 4	0 1 2 3 4
10- ¿Le despierta a usted u otros miembros de la familia durante la noche?	0 1 2 3 4	0 1 2 3 4

Conducta	Frecuencia	**Reacción**
11- ¿Habla demasiado alto o demasiado rápido?	0 1 2 3 4	0 1 2 3 4
12- ¿Parece ansioso o preocupado?	0 1 2 3 4	0 1 2 3 4
13- ¿Realiza acciones que son potencialmente peligrosas para él o para otros?	0 1 2 3 4	0 1 2 3 4
14- ¿Amenaza con dañarse a sí mismo?	0 1 2 3 4	0 1 2 3 4
15- ¿Amenaza con dañar a otros?	0 1 2 3 4	0 1 2 3 4
16- ¿Es agresivo verbalmente con otras personas?	0 1 2 3 4	0 1 2 3 4
17- ¿Parece triste o deprimido?	0 1 2 3 4	0 1 2 3 4
18 ¿Expresa sentimientos de desesperanza o tristeza respecto al futuro?	0 1 2 3 4	0 1 2 3 4
19- ¿Llora?	0 1 2 3 4	0 1 2 3 4
20- ¿Hace comentarios sobre su muerte o la de otros?	0 1 2 3 4	0 1 2 3 4
21- ¿Habla de sentimientos de soledad?	0 1 2 3 4	0 1 2 3 4
22- ¿Hace comentarios acerca de “sentirse una carga”?	0 1 2 3 4	0 1 2 3 4
23- ¿Hace comentarios acerca de sentimientos de fracaso?	0 1 2 3 4	0 1 2 3 4
24- ¿Discute, se muestra irritable o presenta otro tipo de queja?	0 1 2 3 4	0 1 2 3 4

Grado de Deterioro Cognitivo.

Escala Global de Deterioro (GDS; Reisberg, Ferris, de Leon y Crook, 1982)

GDS-1, ausencia de alteración cognitiva

Se corresponde con el individuo normal: Ausencia de quejas subjetivas, ausencia de trastornos evidentes de la memoria.

GDS-2, disminución cognitiva muy leve. Se corresponde con el deterioro cognitivo subjetivo: quejas subjetivas de defectos de memoria, sobre todo en:

a) Olvido de dónde ha colocado objetos familiares.

b) Olvido de nombres previamente bien conocidos.

No hay evidencia objetiva de defectos de memoria en el examen clínico, no hay defectos objetivos en el trabajo o en situaciones sociales. Hay pleno conocimiento y valoración de la sintomatología.

GDS-3, defecto cognitivo leve. Se corresponde con el deterioro cognitivo leve: Primeros defectos claros: manifestaciones en una o más de estas áreas:

a) El paciente puede haberse perdido en un lugar no familiar.

b) Los compañeros detectan rendimiento laboral pobre.

c) Las personas más cercanas detectan defectos en la evocación de palabras y nombres.

d) Al leer un párrafo de un libro retiene muy poco material.

e) Puede mostrar una capacidad muy disminuida en el recuerdo de las personas nuevas que ha conocido.

f) Puede haber perdido o colocado en un lugar erróneo un objeto de valor.

g) En la exploración clínica puede hacerse evidente un defecto de concentración.

Un defecto objetivo de memoria únicamente se observa con una entrevista intensiva. Aparece un decremento de los rendimientos en situaciones laborales o sociales exigentes. La negación o desconocimiento de los defectos se hace manifiesta en el paciente. Los síntomas se acompañan de ansiedad discreta-moderada.

GDS-4, defecto cognitivo moderado. Se corresponde con una demencia en estadio leve: defectos claramente definidos en una entrevista clínica cuidadosa en las áreas siguientes:

a) Conocimiento disminuido de los acontecimientos actuales y recientes.

b) El paciente puede presentar cierto déficit en el recuerdo de su propia historia personal.

c) Defecto de concentración puesto de manifiesto en la sustracción seriada de sietes.

d) Capacidad disminuida para viajes, finanzas, etc.

Frecuentemente no hay defectos en las áreas siguientes:

a) Orientación en tiempo y persona.

b) Reconocimiento de personas y caras familiares.

c) Capacidad de desplazarse a lugares familiares. Incapacidad para realizar tareas complejas, la negación es el mecanismo de defensa dominante, disminución del afecto y abandono en las situaciones más exigentes.
GDS-5, defecto cognitivo moderado-grave. Se corresponde con una demencia en estadio moderado: el paciente no puede sobrevivir mucho tiempo sin alguna asistencia. No recuerda datos relevantes de su vida actual: su dirección o teléfono de muchos años, los nombres de familiares próximos (como los nietos), el nombre de la escuela, etc. Es frecuente cierta desorientación en tiempo (fecha, día de la semana, estación, etc.) o en lugar. Una persona con educación formal puede tener dificultad contando hacia atrás desde 40 de cuatro en cuatro, o desde 20 de dos en dos. Mantiene el conocimiento de muchos de los hechos de mayor interés concernientes a sí mismo y a otros. Invariablemente sabe su nombre, y generalmente el de su esposa e hijos. No requiere asistencia en el aseo ni en la comida, pero puede tener cierta dificultad en la elección de los vestidos adecuados
GDS-6, defecto cognitivo grave. Se corresponde con una demencia en estadio moderadamente grave: ocasionalmente puede olvidar el nombre de la esposa, de la que, por otra parte, depende totalmente para sobrevivir. Desconoce los acontecimientos y experiencias recientes de su vida. Mantiene cierto conocimiento de su vida pasada, pero muy fragmentario. Generalmente desconoce su entorno, el año, la estación, etc. Puede ser incapaz de contar desde 10 hacia atrás, y a veces hacia adelante. Requiere cierta asistencia en las actividades cotidianas. Puede tener incontinencia o requerir ayuda para desplazarse, pero puede ir a lugares familiares. El ritmo diurno está frecuentemente alterado. Casi siempre recuerda su nombre. Frecuentemente sigue siendo capaz de distinguir entre las personas familiares y no familiares de su entorno. Cambios emocionales y de personalidad bastante variables, como: a) Conducta delirante: puede acusar de impostora a su esposa, o hablar con personas inexistentes, o con su imagen en el espejo. b) Síntomas obsesivos, como actividades repetitivas de limpieza. c) Síntomas de ansiedad, agitación e incluso conducta violenta, previamente inexistente. d) Abulia cognitiva, pérdida de deseos, falta de elaboración de un pensamiento para determinar un curso de acción propositivo.
GDS-7, defecto cognitivo muy grave. Se corresponde con una demencia en estadio grave: Pérdida progresiva de las capacidades verbales. Inicialmente se pueden verbalizar palabras y frases muy circunscritas; en las últimas fases no hay lenguaje, únicamente gruñidos. Incontinencia de orina. Requiere asistencia en el aseo y en la alimentación. Se van perdiendo las habilidades psicomotoras básicas, como la deambulación. El cerebro es incapaz de decir al cuerpo lo que ha de hacer. Frecuentemente aparecen signos y síntomas neurológicos generalizados y corticales.

Capacidad funcional de la persona cuidada.

(Barthel index; Mahoney & Barthel, 1965).

Hasta qué punto su familiar es capaz de realizar las siguientes actividades:

1. COMER:

(10) Independiente. Capaz de comer por sí solo y en un tiempo razonable. La comida puede ser cocinada y servida por otra persona.
(5) Necesita ayuda. Para cortar la carne o el pan, extender la mantequilla, etc., pero es capaz de comer solo.
(0) Dependiente. Necesita ser alimentado por otra persona.

2. LAVARSE (BAÑARSE):

(5) Independiente. Capaz de lavarse entero. Incluye entrar y salir del baño. Puede realizarlo todo sin estar una persona presente.
(0) Dependiente. Necesita alguna ayuda o supervisión.

3. VESTIRSE:

(10) Independiente. Capaz de ponerse y quitarse la ropa sin ayuda.

(5) Necesita ayuda. Realiza solo al menos la mitad de las tareas en un tiempo razonable.

(0) Dependiente.

4. ARREGLARSE:

(5) Independiente. Realiza todas las actividades personales sin ninguna ayuda. Los complementos necesarios pueden ser provistos por otra persona.
(0) Dependiente. Necesita alguna ayuda.

5. DEPOSICIÓN:

(10) Continente. Ningún episodio de incontinencia.
(5) Accidente ocasional. Menos de una vez por semana o necesita ayuda para enemas y supositorios.
(0) Incontinente.

6. MICCIÓN (Valorar la semana previa):

(10) Continente. Ningún episodio de incontinencia. Capaz de usar cualquier dispositivo por sí solo.
(5) Accidente ocasional. Máximo un episodio de incontinencia en 24 horas. Incluye necesitar ayuda en la manipulación de sondas y otros dispositivos.
(0) Incontinente.

7. USAR EL RETRETE:

(10) Independiente. Entra y sale solo y no necesita ningún tipo de ayuda por parte de otra persona.
(5) Necesita ayuda. Capaz de manejarse con pequeña ayuda: es capaz de usar el cuarto de baño. Puede limpiarse solo.
(0) Dependiente. Incapaz de manejarse sin ayuda mayor.

8. TRASLADO AL SILLON/CAMA:

(15) Independiente. No precisa ayuda.
(10) Minima ayuda. Incluye supervisión verbal o pequeña ayuda física.
(5) Gran ayuda. Precisa la ayuda de una persona fuerte o entrenada.
(0) Dependiente. Necesita grúa o alzamiento por dos personas. Incapaz de permanecer sentado.

9. DEAMBULACION:

(15) Independiente. Puede andar 50 m, o su equivalente en casa, sin ayuda o supervisión de otra persona. Puede usar ayudas instrumentales (bastón, muleta), excepto andador. Si utiliza prótesis, debe ser capaz de ponérsela y quitársela solo.
(10) Necesita ayuda. Necesita supervisión o una pequeña ayuda física por parte de otra persona. Precisa utilizar andador.
(5) Independiente. (En silla de ruedas) en 50 m. No requiere ayuda o supervisión.
(0) Dependiente.

10. SUBIR / BAJAR ESCALERAS:

(10) Independiente. Capaz de subir y bajar un piso sin la ayuda ni supervisión de otra persona.
(5) Necesita ayuda. Precisa ayuda o supervisión.
(0) Dependiente. Incapaz de salvar escalones

Valores personales

(Vara-García et al., 2021).

Elija los **2 valores** (de entre los que se señalan a continuación) más importantes en tu vida **y** el valor del **cuidado** de su familiar, y para cada uno de ellos, conteste a la siguiente pregunta:

Familia:

1. Ser un/a buen/ esposo/a: mantener y mejorar cada vez más mi relación con mi marido/esposa

2. Ser un/a buen/a padre/madre: mantener y mejorar cada vez más mi relación con mis hijos

Cuidado:

3. Ser un buen cuidador/a: mantener y mejorar mi relación con mi familiar enfermo y la forma en que le cuido

Desarrollo personal:

4. Desarrollarme y crecer como ser humano, aprendiendo y viviendo cosas que me permitan a ser cada vez mejor persona

Vida laboral:

5. Ser un buen/a profesional: ser cada vez mejor más eficaz y competente en mi trabajo

Cuidado de mí mismo/a:

6. Mantener mi salud física y mi bienestar psicológico: cuidar de mi salud física y mental

Ocio y disfrute:

1. Realizar actividades de disfrute.

Salud y autocuidado:

2. Realizar actividades para mantener un buen estado físico o psicológico, por ejemplo: andar, dietas, no fumar…

Ética y ciudadanía:

3. Participar en la vida comunitaria, por ejemplo: voluntariado, ONG, sindicatos.

Espiritualidad

4. Religión o lo que se entienda por espiritualidad (por ejem., conexión con naturaleza)

Valor 1: Cuidado de mi familiar

En los últimos **2 meses**:

¿Hasta qué punto estás **satisfecha/o** contigo mismo/a **por lo que haces** por el cuidado de tu familiar?

1 En absoluto	2 Un poco	3 Moderadamente	4 Bastante	5 Mucho

Valor 2 (elegido): ____

En los últimos **2 meses**:

¿Hasta qué punto estás **satisfecha/o** contigo mismo/a **por lo que haces** por____________________?

1 En absoluto	2 Un poco	3 Moderadamente	4 Bastante	5 Mucho

Valor 3 (elegido): ____

En los últimos **2 meses**:

¿Hasta qué punto estás **satisfecha/o** contigo mismo/a **por lo que haces** por ____________________?

1 En absoluto	2 Un poco	3 Moderadamente	4 Bastante	5 Mucho

Fusión cognitiva

(Cognitive Fusion Questionnarie CFQ; Romero-Moreno et al., 2014; Gillanders et al., 2014)

Conteste hasta qué punto se identifica con los siguientes enunciados:

	Nunca	**Muy rara vez**	**Rara vez**	**Alguna vez**	**Frecuentemente**	**Casi siempre**	**Siempre**
1.Mis pensamientos me provocan malestar o dolor emocional	1	2	3	4	5	6	7
2.Me siento tan atrapado/a en mis pensamientos que soy incapaz de hacer las cosas que realmente quiero hacer	1	2	3	4	5	6	7
3.Tiendo a analizar demasiado las situaciones , hasta un punto que me perjudica	1	2	3	4	5	6	7
4.Lucho con mis pensamientos	1	2	3	4	5	6	7
5.Me enfado conmigo mismo/a por tener determinados pensamientos	1	2	3	4	5	6	7
6.Tiendo a enredarme mucho en mis propios pensamientos	1	2	3	4	5	6	7
7.Es una gran lucha intentar deshacerme de los pensamientos molestos, incluso sabiendo que sería muy útil para mí librarme de ellos	1	2	3	4	5	6	7

Síntomas de ambivalencia

(Losada et al., 2017)

Conteste hasta qué punto se identifica con los siguientes enunciados:

	Nunca	**A veces**	**Frecuentemente**	**Siempre**
1. Tengo sentimientos mixtos hacia mi familiar (ternura-rabia, amor-odio, etc…)	0	1	2	3
2.Me siento dividido o en conflicto con respecto a cuestiones relativas a mi familiar	0	1	2	3
3.Siento tanto satisfacción como resentimiento (rabia) por ser cuidador	0	1	2	3
4.Aunque tengo buenas relaciones con otros familiares, a veces me siento enfadado porque no me ayudan más o no me ofrecen más ayuda	0	1	2	3
5.Tengo a la vez sentimientos positivos y negativos hacia mi familiar	0	1	2	3
6.Aunque por lo general siento que cuido bien, a veces me siento muy mal cuidador	0	1	2	3

Síntomas depresivos

(CES-D; Radloff, 1977)

A continuación se le presentan unas frases que describen como usted podría haberse sentido durante la **semana pasada**.

	Raramente o nunca (menos de 1 día)	**Alguna vez o pocas veces (1 o 2 días)**	**Ocasionalmente o varias veces (3 o 4 días)**	**Todo el tiempo (5-7 días)**
1- Me molestaron cosas que habitualmente no me molestan	0	1	2	3
2- No tuve hambre; tenía poco apetito.	0	1	2	3
3- Sentía que no podía librarme de la tristeza incluso con la ayuda de mi familia o amigos.	0	1	2	3
4- Sentí que era, al menos, tan bueno como otras personas.	0	1	2	3
5- Tuve problemas para concentrarme en lo que hacía.	0	1	2	3
6- Me sentí deprimido.	0	1	2	3
7- Sentí que todo lo que hacía era un esfuerzo.	0	1	2	3
8- Me sentí optimista sobre el futuro.	0	1	2	3
9- Pensé que mi vida había sido un fracaso.	0	1	2	3
10- Me sentí temeroso.	0	1	2	3
11- Mi sueño era inquieto, no descansaba.	0	1	2	3
12- Estaba contento.	0	1	2	3
13- Hablaba menos de lo habitual.	0	1	2	3
14- Me sentí solo/a.	0	1	2	3
15- La gente me resultaba antipática.	0	1	2	3
16- Disfruté la vida.	0	1	2	3
17- Lloré en ocasiones.	0	1	2	3
18- Me sentí triste.	0	1	2	3
19- Sentí que no le gustaba a la gente.	0	1	2	3
20- No tenía ganas de nada.	0	1	2	3

Síntomas de ansiedad

Subescala de Tensión de la Escala de Perfil de Estados de Ánimo (POMS, McNair et al., 1971)

A continuación le voy a leer una lista de palabras que describen cómo se pueden sentir las personas. Por favor, indique **con qué frecuencia se ha sentido así últimamente**

	Nada	**Un poco**	**Moderadamente**	**Bastante**	**Muchísimo**
1.Tenso/a	0	1	2	3	4
2.Agitado/a	0	1	2	3	4
3.A punto de estallar	0	1	2	3	4
4.Descontrolado/a	0	1	2	3	4
5.Relajado/a	0	1	2	3	4
6.Intranquilo/a	0	1	2	3	4
7.Inquieto/a	0	1	2	3	4
8.Nervioso/a	0	1	2	3	4
9.Con ansiedad	0	1	2	3	4

Anexo II. Versión Impresa del Estudio Uno

Behavioral Psychology / Psicología Conductual, Vol. 27, Nº 3, 2019, pp. 499-510

CARE-RECIPIENTS' DISRUPTIVE BEHAVIORS AND CAREGIVERS' COGNITIVE FUSION: RELEVANT VARIABLES FOR UNDERSTANDING CAREGIVERS' AMBIVALENT FEELINGS

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Abstract

The goal of this study was to analyze the relationship between stressors (frequency of and reaction to disruptive behaviors), cognitive fusion and ambivalence among caregivers, and more specifically to study whether cognitive fusion acts as a mediator in the relationship between stressors and ambivalence. To assess these variables, individual interviews were conducted with a total of 364 caregivers of a relative with dementia. Significant and positive correlations were found among stressors, cognitive fusion and ambivalence (*p*< .05). The model suggests that there is a significant and positive relationship between reaction to disruptive behaviors and ambivalent feelings among caregivers, although it seems to be mediated by cognitive fusion. The final model explains 37% of the variance of ambivalence, and it shows an excellent fit to the data. The results suggest that the relationship between frequency of disruptive behaviors and ambivalence seems to be mediated by reaction to disruptive behaviors and cognitive fusion; consequently this last variable seems to be relevant for understanding emotional ambivalence among caregivers.

KEY WORDS: *caregivers, dementia, cognitive fusion, emotional ambivalence, problematic behaviors.*

Resumen

El objetivo de este estudio fue analizar la relación entre factores estresantes (frecuencia y reacción a comportamientos problemáticos), fusión cognitiva y ambivalencia en cuidadores. Específicamente, estudiar si la fusión cognitiva actúa como variable mediadora en la relación entre factores estresantes y ambivalencia. Se realizaron entrevistas individuales a un total de 364 cuidadores familiares de

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The preparation of this paper was supported in part by grants from the Spanish Ministry of Economy and Competitiveness (PSI2012-31239 and PSI2015-65152-C2-1-R). Samara Barrera was supported by a FPU grant from the Spanish Ministry of Education, Culture and Sport. We thank all the caregivers for their participation in the study and also the following centers for collaborating with us in the project: Fundación Cien, Fundación María Wolff, Centro de Salud General Ricardos, Centro de Salud García Noblejas, Centro de Salud Benita de Ávila, Centro de Salud Vicente Muzas, Centro Reina Sofía de Cruz Roja, Centro de Psicología Aplicada de la Universidad Autónoma de Madrid, Hospital Gregorio Marañón.

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personas con demencia. Se encontraron correlaciones significativas y positivas entre los factores estresantes, fusión cognitiva y ambivalencia ($p < 0{,}05$). El modelo sugiere que existe una relación significativa y positiva entre la reacción a los comportamientos problemáticos del familiar y los sentimientos de ambivalencia, aunque parece estar mediada por la fusión cognitiva. El modelo final explica el 37% de la varianza de la ambivalencia y muestra un ajuste excelente a los datos. Los resultados sugieren que la relación entre frecuencia de comportamientos problemáticos y ambivalencia parece estar mediada por la reacción a dichos comportamientos y la fusión cognitiva. Esta última variable parece ser relevante para comprender la ambivalencia emocional en los cuidadores.

PALABRAS CLAVE: *cuidadores, demencia, fusión cognitiva, comportamientos problemáticos*.

Introduction

Providing care for a relative with Alzheimer's disease or related disorders has been associated with negative consequences for the caregiver’s mental and physical health (e.g., depression and stress) (Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013; Otero, Vázquez, Blanco, & Torres, 2017; Pinquart & Sörensen, 2003). Caregivers are subject to highly demanding tasks while devoting several hours per day over long periods of time. For these reasons, caring for a relative with dementia has been considered a prototypical example of a chronic stressful situation, and the theoretical framework that has received the most empirical support has been the stress and coping model adapted to caregiving (Knight & Sayegh, 2010). According to this approach, the impact of difficult situations and demands (stressors) in caregiver's distress depends on caregivers´ personal and contextual resources that can buffer or accentuate this impact (Knight & Sayegh, 2010).

Among the most significant and important stressors faced by caregivers are the behavioral and psychological symptoms of dementia (BPSD), which consist of a wide variety of patient behaviors, including repetition of questions, depression, physical aggression, and delusions (Ornstein et al., 2013). These symptoms are considered to be among the most difficult stressors that caregivers can face. Within BPSD (e.g., disruptive behaviors, memory problems or depressive symptoms), disruptive behaviors such as aggressiveness turn out to be the stressors that cause the greatest reaction (distress) in caregivers, although they are not the most frequent (Fauth & Gibbons, 2014).

To date, much of the research in the dementia caregiving field has focused on psychological outcome variables such as depression or anxiety. However, a variable that has scarcely been explored in the literature is emotional ambivalence. In the caregiving context, ambivalence has been defined as the simultaneous experience of positive and negative feelings toward the care recipient (Fingerman, Pitzer, Lefkowitz, Birditt, & Mroczek, 2008; Willson, Shuey, & Elder, 2003). It is a complex experience that resembles the feeling of being “divided in two directions” (Pillemer et al., 2007). Although this type of ambivalent attitude or emotion has been studied to a greater extent in other areas (e.g., intergenerational relationships; Birditt, Fingerman, & Zarit, 2010; Pillemer, Munsch, Fuller-Rowell, Riffin, & Suitor, 2012; Pillemer et al., 2007), it is not uncommon for caregivers to report simultaneously experiencing negative and positive emotions associated with care (Shim, Barroso, & Davis, 2012), an internal conflict that is typically perceived as aversive by the individual (Pillemer et al., 2007). Recently, Losada, Pillemer, Márquez González, Romero Moreno, and Gallego Alberto (2017) developed and tested the Caregiving Ambivalence Scale, finding that ambivalent feelings (e.g., feeling both satisfaction and resentment due to caregiving) contributed significantly and positively to the explanation of depressive and anxious symptomatology in caregivers. Apart from this, there are also studies that have found data in favor of ambivalence being especially likely to arise when disruptive behaviors by the person with dementia are frequent and stressful for the caregiver (Pillemer & Suitor, 2005). The association of disruptive behaviors and ambivalence is not surprising because such behaviors often act as triggers of negative emotions in caregivers, mingling with the positive feelings that are frequently associated with the care of a loved relative (Losada et al., 2018). However, although disruptive behaviors of the care recipient seem to be associated with experiencing ambivalent feelings, the process through which this occurs and which variables intervene is unclear.

One of the variables that could be contributing to the effect of disruptive behaviors in the development of ambivalent feelings is cognitive fusion. Cognitive fusion has been defined as the tendency for behavior to be overly regulated and influenced by cognition. When 'fused,' a person acts on thoughts as though they are literally true, cognitive events come to dominate behavior and experience over other sources of behavioral regulation (Gillanders et al., 2014). In recent years there has been a significant increase in interest in the study of cognitive fusion, which has been indicated as a highly relevant variable, significantly and positively related to psychopathological problems such as anxiety (Herzberg et al., 2012) and depression (Dinis, Carvalho, Pinto-Gouveia, & Estanqueiro, 2015). Specifically, recent studies suggest that cognitive fusion may play an important mediating role in the explanation of the relationship between the experience of chronic stressful life events (e.g., cancer) and anxiety (Gillanders, Sinclair, MacLean, & Jardine, 2015). Although cognitive fusion has scarcely been studied among the caregiver population, recent studies have found that caregivers of people with dementia who report a higher frequency of disruptive family behaviors as well as high levels of cognitive fusion also report higher levels of depressive and anxious symptomatology (Romero-Moreno, Márquez-González, Losada, Fernández-Fernández, & Nogales-González, 2015). However, to our knowledge, there are no studies that examine the relationship between cognitive fusion and other outcome variables such as emotional ambivalence.

Taking into consideration the aforementioned issues and following the stress and coping model adapted to caregiving (Knight & Sayeh, 2010), the aim of the present study was to explore the role played by cognitive fusion in the association between care-recipients' disruptive behaviors and caregivers' ambivalent feelings. In particular, our aim was to analyze the degree to which cognitive fusion exerts a mediating role in the explanation of the relationship between the disruptive behaviors of people with dementia (frequency of disruptive behaviors and reaction to these behaviors) and the experience of ambivalence in caregivers.

Our hypothesis is that a higher frequency of and reaction to disruptive behaviors of the care-recipient is associated with a higher level of cognitive fusion of the caregivers, that is, the tendency to assume the literality of thought. In turn, high levels of cognitive fusion may be linked to a higher frequency of negative emotions towards the care-recipient, which add to the positive feelings that are usually associated with caring for a loved one, thus increasing emotional ambivalence. In other words, we hypothesized that the variable cognitive fusion could act as a mediator in the relationship between frequency of and reaction to disruptive behaviors and feelings of ambivalence in caregivers.

Method

Participants

Participants in this study were 364 family caregivers of people with dementia. Inclusion criteria were: a) considering oneself to be the principal caregiver of a relative with dementia, b) devoting at least one hour per day to caring for the family member, c) having been a caregiver for at least three consecutive months, and d) being at least 18 years old. Five extreme cases were obtained in the frequency of and reaction to disruptive behaviors variables. In addition, three multivariate outliers (Mahalanobis distance of $p< .001$) were obtained. Therefore, the sample was reduced to 356 participants. The sociodemographic characteristics of the sample are shown in Table 1. The sample consisted mainly of women (76.10%) and had a mean age of 61.53 years (*SD*= 13.70). Participants reported having provided care for a mean of 46.44 months (*SD*= 42.72) and devoting approximately half a day caring for their relative 13.62 (*SD*= 8.06).

Table 1
Characteristics of the sample (*N*=356)

Variables	Total	Male (*n*= 85)	Female (*n*= 271)
Caregiver age			
M	61.50	64.82	60.46
SD	13.70	15.48	12.95
Range	21-87	29-87	21-86
Time since becoming a caregiver (months)			
M	46.44	47.41	46.13
SD	42.72	55.70	37.87
Range	3 - 444	3-444	3-300
Daily hours caring			
M	13.62	14.04	13.49
SD	8.06	8.05	8.07
Range	1-24	1-24	1-24

Instruments

Apart from sociodemographic information (gender, caregivers' age, time being a caregiver, and number of daily hours devoted to caregiving), the following variables were measured:

a) *Revised Memory and Behavior Problems Checklist* (Teri et al., 1992), Spanish version by Nogales, Losada, & Romero-Moreno (2015). This checklist measured how often the person with dementia displayed disruptive behaviors and how the caregiver reacted to them using the subscales of frequency of disruptive behaviors and reaction to disruptive behaviors. Both subscales comprise eight Likert-type scale items. In the frequency subscale, each item (e.g., "aggressive to others verbally") is rated on a scale ranging from 0 ("never occurs") to 4 ("occurs daily or more often"). In the reaction to disruptive behavior subscale, each item (e.g., "how much has this bothered or upset you?") is rated from 0 ("not at all") to 4 ("extremely"). A total score is obtained by summing the eight individual frequency and reaction scores, with higher scores reflecting greater severity of disruptive problems. The internal consistency (Cronbach's α) for the frequency of disruptive behaviors and reaction subscales in this sample was .60 and .68 respectively, similar findings to those originally obtained by Teri et al. (1992) and by Nogales et al. (2015).

b) *Cognitive Fusion Questionnaire* (CFQ; Gillanders et al., 2014), Spanish version by Romero-Moreno, Márquez-González, Losada, Gillanders, & Fernández-Fernández (2014). This scale measures the tendency to believe in the literal content of thoughts and feelings. Seven items (e.g., "I feel so trapped in my thoughts that I am unable to do the things I really want to do") are rated on a Likert-type scale ranging from 1 (Never) to 7 (Always). The scores of the items are summed in order to get a total score of the measure, with higher scores reflecting higher cognitive fusion. The internal consistency (Cronbach's alpha) for this scale in the present study was .88.

c) *Caregiving Ambivalence Scale* (CAS, Losada et al., 2017). The CAS measures ambivalent feelings in dementia family caregivers. This is a 5-item scale (e.g., "I have mixed feelings towards my relative [tenderness-rage, love-hate, etc.]") that assesses the degree to which caregivers' feelings toward their relative are mixed or conflicted. Participants are asked to select the option that best describes their feelings during the last month. Each item is rated on a Likert-type scale that ranges from 0 ("Never") to 3 ("Always"). The scores in the five items are summed in order to obtain a total score, with higher scores reflecting more ambivalent feelings. Cronbach's alpha coefficient for this scale was .87 in this study.

Procedure

Participants were recruited through different social services and health care centers of the Community of Madrid (Spain) and through media outreach such as Internet. The first contact was established by telephone to verify if the participants met the inclusion criteria of the study. Once this was established, face-to-face interviews were conducted in the participating centers. Caregivers gave their informed consent to participate in the study, which was approved by the Spanish Ministry of Economy and Competitiveness as well as by The Ethics Committee of Rey Juan Carlos University (Madrid).

Data analysis

Following Tabachnick and Fidell (2001) criteria, analyses for sample normality and outliers (univariate and multivariate) were conducted. Descriptive data (means, standard deviations, ranges, and frequencies) were calculated for the assessed variables. In order to investigate the relationship between variables, correlation analyses were run. The IBM SPSS Statistics program, version 22.0 (IBM, 2013) was used for all analyses.

In order to analyze the association between the variables, a theoretical model was developed, drawing on the stress and coping model adapted to caregiving (e.g., Knight & Sayegh, 2010). The following variables were included: sociodemographic variables (gender, caregivers' age, time since becoming a caregiver, and number of daily hours devoted to caregiving), demands or stressors (frequency of disruptive behaviors and reaction to disruptive behaviors), potential mediator (cognitive fusion) and, as the outcome variable, ambivalent feelings. First, all the associations between variables that had been shown to be significant in the correlation analyses were included as paths in the model. Next, following the model-generation strategy (Joreskog & Sörbom, 1993), only those associations between the variables that were observed as significant once the first path analysis was run were included in the final model. In addition to the chi square (χ^2) statistic, the chi square value divided by the degrees of freedom (χ^2/df) was considered, with values under or near 3 indicating good model fit (Bollen, 1989). The root mean square error of approximation (RMSEA), the normed fit index (NFI) and the Tucker-Lewis index (TLI) were also evaluated as additional indicators of model fit, considering Hu and Bentler's (1998) indications of values under .06 (RMSEA) and over .95 (NFI and TLI) as indicating excellent fit of the data to the model. Finally, mediation was analyzed following the bootstrapping approach recommended by Preacher and Hayes (2004) using 1000 bootstrap samples. IBM SPSS Amos version 21.0.0 was used for these analyses.

Results

Correlational analyses

The results of the correlational analyses are show in Table 2. Significant and positive associations between the variables frequency of disruptive behaviors, reaction to disruptive behaviors, cognitive fusion and ambivalence were obtained (in all cases $p< .01$). Caregivers' age was significantly and negatively correlated with cognitive fusion and ambivalence. The results also showed a positive and significant association between gender (being female), frequency and reaction to disruptive behaviors, cognitive fusion and ambivalence. Time since becoming a caregiver was significantly and negatively correlated with cognitive fusion, but showed no relation to any of the other variables in the model. Finally, the number of daily hours devoted to caregiving showed a significant and negative association with ambivalence.

Table 2
Pearson correlations between the assessed variables

Variables	1	2	3	4	5	6	7
1. Gender (0= female)	-						
2. Caregiver age	.14*	-					
3. Time since becoming a caregiver	.01	.17*	-				
4. Daily hours caring	.03	.33**	.01	-			
5. Frequency of disruptive behaviors	-.21**	-.13*	.04	.03	-		
6. Reaction to disruptive behaviors	-.20**	-.13*	.03	-.06	.79**	-	
7. Cognitive fusion	-.26**	-.18**	-.12*	-.04	.21**	.28**	-
8. Ambivalent feelings	-.28**	-.23**	-.04	-.12*	.38**	.48**	.47**

Note: *p< .05; **p< .01.

Path model for explaining relationship between stressors and ambivalent feelings

Figure 1 shows the associations obtained through the path analysis for ambivalent feelings, including all the significant associations between variables. Time since becoming a caregiver and number of daily hours devoted to caregiving were initially introduced in the model, but were discarded in the final model because no significant associations with the rest of the variables included in the model were obtained.

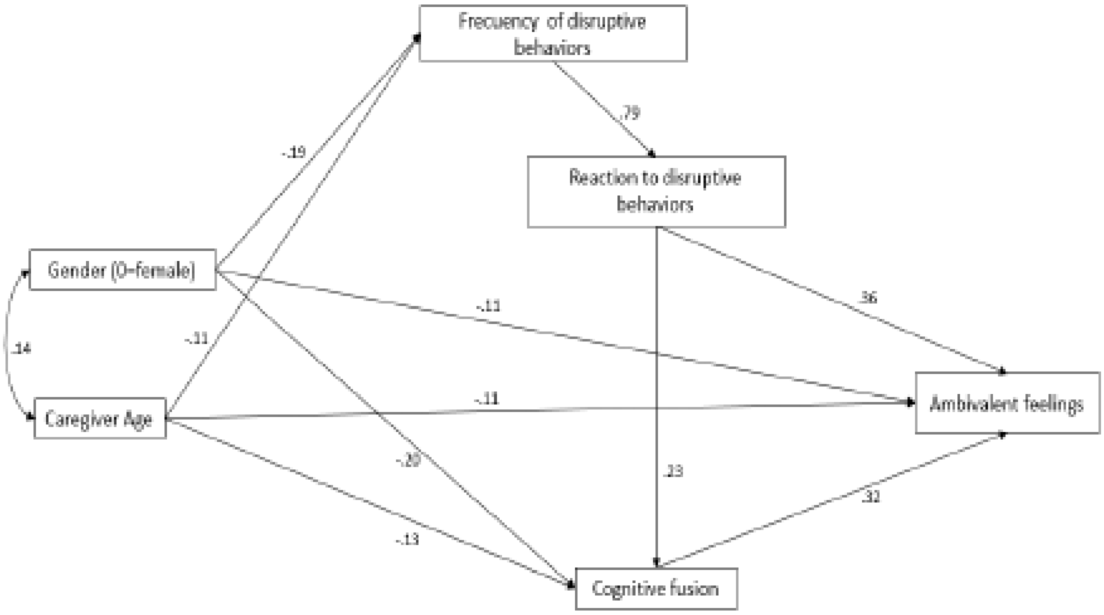
As can be seen, all the variables (except frequency of disruptive behaviors) have a direct association with ambivalence. Female and younger caregivers, with higher stress reactions to disruptive behaviors and with higher scores in cognitive fusion report more ambivalence.

In addition to the direct associations, additional indirect influences on ambivalence were found. Even though a significant positive association between frequency of disruptive behaviors and ambivalence was observed in the correlation analyses, this association is no longer significant when all the variables are considered together in the model. The results suggest that frequency of disruptive behaviors have an indirect association with ambivalence through its influence on reaction to disruptive behaviors. The results of the bootstrap analysis for testing mediation suggest that this indirect association is significant (standardized indirect effect: .34, p< .01, SE= .04, CI= .27-.41). In addition, even though a significant and positive correlation was observed between frequency of disruptive behaviors and cognitive fusion, this association was not significant in the model. The influence of frequency of disruptive behaviors on cognitive fusion is indirect, through its influence on reaction to disruptive behaviors, as was found through the analysis for testing mediation (standardized indirect effect: .18, p< .01, SE= .04, CI= .12-.25). These findings suggest that caregivers who experience a higher frequency of disruptive behaviors also have a more stressful reaction to these behaviors and get more cognitively fused. Finally, there is also an indirect influence of reaction to disruptive behaviors on ambivalence through the influence of reaction on cognitive fusion. Again, the results of the bootstrap analysis for testing mediation suggest that this association is significant (standardized indirect effect: .07, $p< .01$, SE= .02, CI= .05-.11). Caregivers who report being more stressed due to their care-recipients' disruptive behaviors are more cognitively fused, and this association seems to increase their ambivalence.

The final model explained 37% of the variance of caregiver's ambivalent feelings. The obtained fit indices suggest an excellent fit of the path model to the data (χ^2= 2.674, p= .614, χ^2/df= .669, RMSEA= .000, NFI= .996, TLI= 1.009).

Figure 1

Path analysis testing the role of frequency of and reaction to disruptive behaviors and cognitive fusion in caregiver's ambivalent feelings



Note: All associations are significant ($p< .05$). The errors have been omitted for ease of presentation.

Discussion

The objective of this study was to analyze the role of cognitive fusion in the model of caregiver stress and to explore the role of this variable as a contributor to caregivers' ambivalent feelings. Concretely, our goal was to analyze if cognitive fusion acts as mediator in the relationship between frequency of and reaction to disruptive behaviors and ambivalence in caregivers. To our knowledge, this is the first study that simultaneously analyzes the relationship between the variables frequency of disruptive behaviors, reaction of the caregivers to relative's disruptive behaviors, cognitive fusion and ambivalent feelings.

The results obtained coincide with previous studies in that the frequency of and reaction to disruptive behaviors of the care recipient are significantly and positively associated with caregiver's ambivalent feelings (Losada et al., 2017, 2018). In addition, the results also confirm the relationship observed in previous studies between the frequency of care-recipients' disruptive behaviors and caregivers' cognitive fusion (Romero-Moreno et al., 2014). However, as far as we know, this is the first study that analyses the association between the variable cognitive fusion and ambivalent feelings, variables which, as observed in the results of this study, show a significant and positive relationship. The results also suggest that the frequency of disruptive behaviors is not associated with ambivalence in a direct way, but in an indirect one, with this association being explained through two paths: 1) caregivers´ reaction to disruptive behaviors acts as a mediator in the relationship between the frequency of disruptive behaviors and ambivalence; and 2) the impact of caregiver's reaction to disruptive behaviors on ambivalent feelings is mediated by through cognitive fusion.

In conclusion, it can be said that our initial hypotheses are confirmed. Intense stress reactions to care recipients´ disruptive behaviors are associated with an inadequate cognitive functioning of the caregivers (increased levels of cognitive fusion), thus facilitating the emergence and/or maintenance of negative emotions towards their relative. These negative emotions add to the positive feelings that are usually associated with caring for a loved relative, thus increasing the emotional ambivalence. These findings provide support for the stress and coping model (Knight & Sayegh, 2010), which postulates that the influence of stressors (e.g., disruptive behaviors) on caregiving consequences (in this study, ambivalence) is modulated by other variables (in this study, reaction to disruptive behaviors and cognitive fusion). Although the cross-sectional nature of this study prevents us from reaching causal conclusions, the results obtained suggest an interesting path through which disruptive behaviors can contribute to increasing caregivers´ distress (emotional ambivalence), because more intense reactions to disruptive behaviors seem to be associated with higher levels of cognitive fusion among caregivers.

These results have several implications for practice. In the clinical setting, it can be hypothesized that caregivers' distress may be reduced by intervening in two areas. First, behavioral interventions for decreasing the frequency of care-recipients' disruptive behaviors or the reaction of caregivers to these behaviors (e.g., Bravo-Benítez & Navarro-González, 2018; Logsdon, McCurry, & Teri, 2007) may reduce not only the sources of distress but may also minimize the chances of caregivers getting fused with their thoughts, and the likelihood of the emergence of negative emotions towards the care-recipient. In addition, the use of acceptance-based strategies (e.g., acceptance and commitment therapy, ACT; Hayes, Strosahl, & Wilson, 1999) that include cognitive fusion as a main target of the interventions as well as a mediator of the impact of these interventions (Zettle, Rains, & Hayes, 2011) may be also helpful. According to this idea, ACT-based interventions could be useful in caregivers by promoting the opposite mechanism to cognitive fusion, that is, cognitive defusion; this implies teaching caregivers skills to help them distance themselves from their own thoughts through acceptance, thus diminishing the power their thoughts have over behavior, without directly attempting to modify their content (Losada et al., 2015).

This study presents several limitations that should be mentioned. First, as already noted, the cross-sectional design of the study prevents causal inferences. The direction of the associations that are shown in the model may be different. For example, cognitive fusion may increase the reaction to disruptive behaviors. Therefore, it is necessary to treat the results with caution, and future experimental and longitudinal studies to confirm the data obtained here are recommended. Second, the sample was composed of caregivers who participated voluntarily in this study, which limits the generalization of the results to the rest of the caregiver population. Despite these limitations, the results of this study suggest that the frequency of disruptive behaviors of the care recipient may have not only a direct effect on caregivers' ambivalent feelings. The results suggest that the influence of these behaviors on ambivalence can be mediated by cognitive fusion, as well as by the discomfort associated with the disruptive behaviors of the relatives (reaction to disruptive behaviors). High levels of reaction to disruptive behaviors could place caregivers in a situation of vulnerability to ambivalent feelings, making it difficult for them to distance themselves from their thoughts and develop a more adaptive coping with the stressors and demands associated with caregiving.

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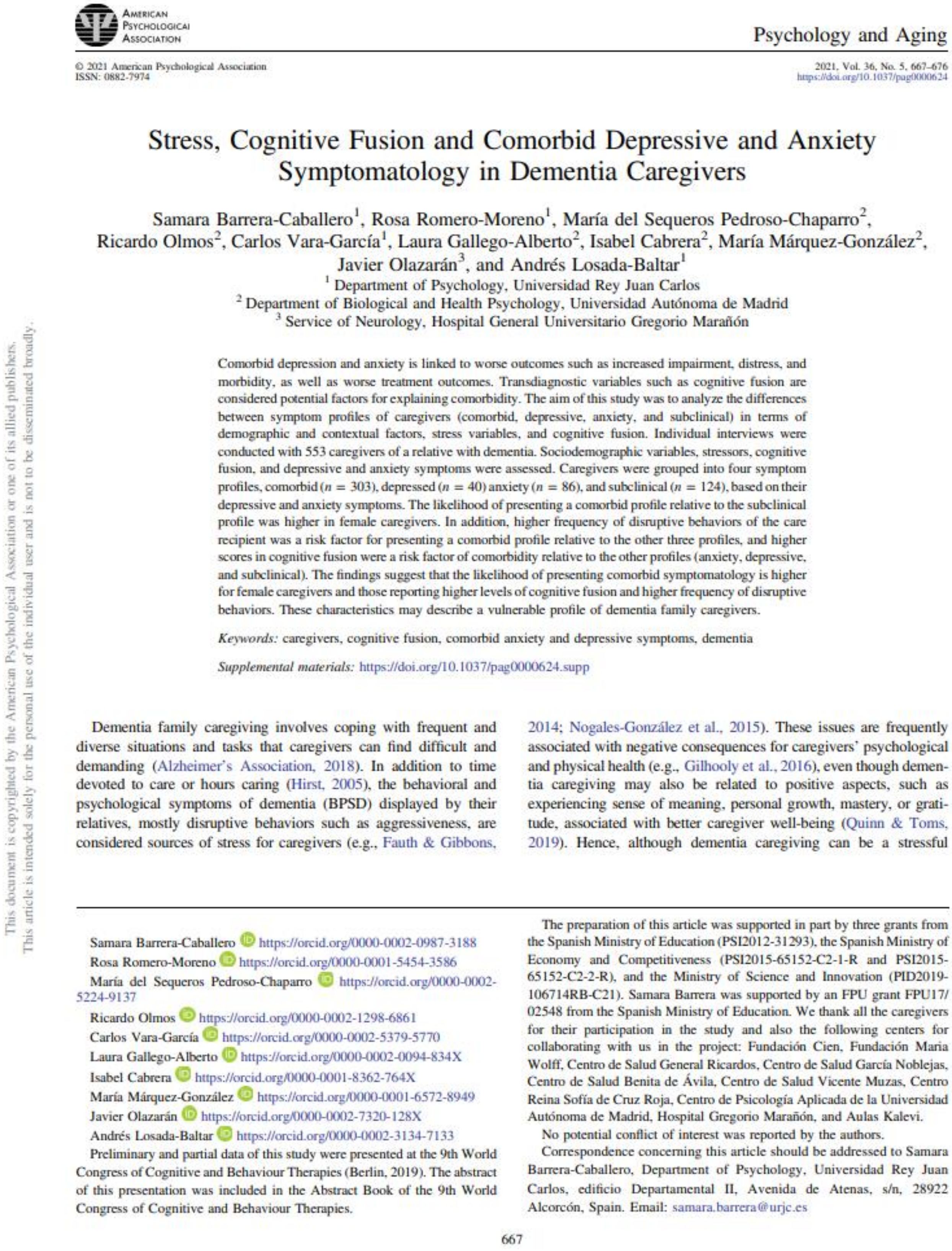
RECEIVED: June 12, 2018
ACCEPTED: September 25, 2018

Anexo III: Versión Impresa del Estudio Dos



AMERICAN PSYCHOLOGICAL ASSOCIATION

Psychology and Aging

© 2021 American Psychological Association
ISSN: 0882-7974

2021, Vol. 36, No. 5, 667–676
https://doi.org/10.1037/pag0000624

Stress, Cognitive Fusion and Comorbid Depressive and Anxiety Symptomatology in Dementia Caregivers

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Comorbid depression and anxiety is linked to worse outcomes such as increased impairment, distress, and morbidity, as well as worse treatment outcomes. Transdiagnostic variables such as cognitive fusion are considered potential factors for explaining comorbidity. The aim of this study was to analyze the differences between symptom profiles of caregivers (comorbid, depressive, anxiety, and subclinical) in terms of demographic and contextual factors, stress variables, and cognitive fusion. Individual interviews were conducted with 553 caregivers of a relative with dementia. Sociodemographic variables, stressors, cognitive fusion, and depressive and anxiety symptoms were assessed. Caregivers were grouped into four symptom profiles, comorbid (n = 303), depressed (n = 40) anxiety (n = 86), and subclinical (n = 124), based on their depressive and anxiety symptoms. The likelihood of presenting a comorbid profile relative to the subclinical profile was higher in female caregivers. In addition, higher frequency of disruptive behaviors of the care recipient was a risk factor for presenting a comorbid profile relative to the other three profiles, and higher scores in cognitive fusion were a risk factor of comorbidity relative to the other profiles (anxiety, depressive, and subclinical). The findings suggest that the likelihood of presenting comorbid symptomatology is higher for female caregivers and those reporting higher levels of cognitive fusion and higher frequency of disruptive behaviors. These characteristics may describe a vulnerable profile of dementia family caregivers.

Keywords: caregivers, cognitive fusion, comorbid anxiety and depressive symptoms, dementia

Supplemental materials: https://doi.org/10.1037/pag0000624.supp

Dementia family caregiving involves coping with frequent and diverse situations and tasks that caregivers can find difficult and demanding (Alzheimer's Association, 2018). In addition to time devoted to care or hours caring (Hirst, 2005), the behavioral and psychological symptoms of dementia (BPSD) displayed by their relatives, mostly disruptive behaviors such as aggressiveness, are considered sources of stress for caregivers (e.g., Fauth & Gibbons, 2014; Nogales-González et al., 2015). These issues are frequently associated with negative consequences for caregivers' psychological and physical health (e.g., Gilhooly et al., 2016), even though dementia caregiving may also be related to positive aspects, such as experiencing sense of meaning, personal growth, mastery, or gratitude, associated with better caregiver well-being (Quinn & Toms, 2019). Hence, although dementia caregiving can be a stressful

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Preliminary and partial data of this study were presented at the 9th World Congress of Cognitive and Behaviour Therapies (Berlin, 2019). The abstract of this presentation was included in the Abstract Book of the 9th World Congress of Cognitive and Behaviour Therapies.

The preparation of this article was supported in part by three grants from the Spanish Ministry of Education (PSI2012-31293), the Spanish Ministry of Economy and Competitiveness (PSI2015-65152-C2-1-R and PSI2015-65152-C2-2-R), and the Ministry of Science and Innovation (PID2019-106714RB-C21). Samara Barrera was supported by an FPU grant FPU17/02548 from the Spanish Ministry of Education. We thank all the caregivers for their participation in the study and also the following centers for collaborating with us in the project: Fundación Cien, Fundación Maria Wolff, Centro de Salud General Ricardos, Centro de Salud García Noblejas, Centro de Salud Benita de Ávila, Centro de Salud Vicente Muzas, Centro Reina Sofía de Cruz Roja, Centro de Psicología Aplicada de la Universidad Autónoma de Madrid, Hospital Gregorio Marañón, and Aulas Kalevi.

No potential conflict of interest was reported by the authors.

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the last three consecutive months to caring tasks, and (c) being at least 18 years old. All participants were recruited in the context of different studies that shared the same design for obtaining baseline data (Losada et al., 2015, 2017; Márquez-González et al., 2020). A total of 673 potential participants were contacted and 120 (17.89%) declined to participate. Caregivers agreed to participate voluntarily in the studies and signed the informed consent. The studies were approved by the Spanish Ministry of Science and Innovation and the Ethics Committee of the Universidad Rey Juan Carlos (Madrid, Spain).

Variables and Measures

Caregivers' data on gender, kinship, and age were obtained, as well as care-recipients' gender and type of dementia diagnosed. Data on care-recipients' gender were not available for 29 subjects. Considering previous studies showing differences between spousal and other caregivers (e.g., adult children and children-in-law; Pinquart & Sörensen, 2011), the kinship variable was recoded in two categories: spouses (wives/husbands) (42.3%) versus others (adult children and other relatives such as sisters, uncles, fathers- and mothers-in-law) (57.7%). Daily hours devoted to caregiving, and time since being a caregiver were assessed as potential stressor variables. The stage of the disease of the care recipient was measured through the Global Deterioration Scale (GDS; Reisberg et al., 1982), although data were not available for 41 subjects. In addition, the following variables were assessed.

Frequency and Reaction to Disruptive Behaviors

We used the Spanish version (Nogales-González et al., 2015) of the frequency and reaction subscales of the disruptive behaviors dimension of the Revised Memory and Behavior Problems Checklist (Teri et al., 1992). The frequency subscale consists of eight items measuring how often the person who has dementia behaves disturbingly (e.g., "Destroying property" "Arguing, irritability, and/or complaining"), ranging from 0 (*never occurred*) to 4 (*occurs daily or more often*). The reaction subscale measures caregivers' reaction to those eight behaviors (e.g., "How much has this behavior upset you?") with responses ranging from 0 (*not at all*) to 4 (*extremely*). In this study, internal consistency (Cronbach's α) for the frequency of disruptive behaviors subscale was 0.66, and 0.73 for the reaction to these behaviors subscale, similar to those reported in the original study (Teri et al., 1992). Average reaction rating score was calculated following suggestions by Teri et al. (1992) and Roth et al. (2003). For disruptive behavior problems that were not reported, reaction was coded as missing. It is thus possible for caregivers to have high average reaction ratings even when the number of reported disruptive behaviors is small (Roth et al., 2003).

Cognitive Fusion

The Spanish version (Romero-Moreno et al., 2014) of the Cognitive Fusion Questionnaire (Gillanders et al., 2014) was used. The scale is composed of seven items that measure different facets of cognitive fusion such as reacting emotionally to thoughts (e.g., "My thoughts cause me distress or emotional pain"), behavior being highly regulated by cognitive events (e.g., "I get so caught up in my thoughts that I am unable to do the things that I most want to do") and attempts to control thinking (e.g., "I struggle with my thoughts"). Answers range from 1 (*never*) to 7 (*always*). The internal consistency (Cronbach's α) for this study was 0.89.

Depressive Symptomatology

The level of depressive symptomatology was assessed using the Spanish version of the Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977) validated in dementia family caregivers in Spain (Losada et al., 2012). This is a 20-item scale (e.g., "I felt sad"; "I cried sometimes") that assesses how often people felt depressive symptoms during the previous week. Scores for each item range from 0 (*rarely or none of the time—less than 1 day*) to 3 (*most or all of the time—5–7 days*) on a Likert-type scale. Scores equal to or over 16 on this scale are associated with clinically significant depressive symptomatology (Radloff, 1977). The internal consistency (Cronbach's α) in this study was 0.89.

Anxiety Symptomatology

The Tension subscale of the Profile of Mood States Scale (POMS; McNair et al., 1971) was used to assess the level of anxiety. This subscale consists of nine items (e.g., "How often have you felt irritable?"), each ranging from 1 (*not at all*) to 4 (*extremely*) on a Likert-type scale. Scores equal to or over 13 on this scale are associated with a clinically significant level of anxiety (Losada et al., 2015). The internal consistency (Cronbach's α) in this study was 0.90.

Data Analysis

Following Tabachnick and Fidell (2001) criteria, the sample was checked for normality and presence of univariate and multivariate outliers. Five extreme cases were detected in the scores for *frequency of* and *reaction to disruptive behaviors* variables and *time since being a caregiver*. In addition, five multivariate outliers (Mahalanobis distance of $p < .001$) were detected. We then performed the analysis with and without the inclusion of extreme cases and results were the same. Therefore, we decided to keep the full sample (to gain power and to avoid the arbitrary decision to remove some cases).

Univariate descriptive statistics (means, standard deviations, ranges, and frequencies) and Pearson correlation analyses were analyzed.

The sample was grouped into four symptom profiles of caregivers according to the cut-off point of CES-D (≥16) (Radloff, 1977) and POMS (≥13) (McNair et al., 1971) scales. The following groups or symptoms profiles were created: (a) *Comorbid* profile: high levels of both depressive and anxiety symptomatology, (b) *Depressive* profile: high depressive symptoms and low anxiety symptoms, (c) *Anxiety* profile: low depressive symptoms and high anxiety symptoms, and (d) *Subclinical* profile: low levels of depressive and anxiety symptomatology. We analyzed potential differences between the four profiles in contextual and sociodemographic factors (caregivers and care-recipients' characteristics), stressors, and cognitive fusion using ANOVAs (using Tukey's pairwise comparisons procedure to control Type-I error rate) and chi-square tests for quantitative and categorical variables, respectively.

context, not all caregivers experience negative and/or positive consequences in the same way.

Most of the research studying the effects of caregiving on caregivers' psychological health has focused on depressive symptomatology. This may in part be due to the high prevalence of this particular outcome variable in the caregiver population, mostly in female and spousal caregivers (Pinquart & Sörensen, 2003).

Regarding prevalence data of mental health disorders, a recent meta-analysis conducted by Collins and Kishita (2019) showed that the adjusted prevalence estimate of depression among caregivers of people with dementia was 31.24%; thus, around 1 in 3 such caregivers suffer from depression. Even though most of the research on psychological consequences of caregiving has focused on depression or depressive symptoms, anxiety symptoms are also reported as frequent in the caregiver population, although this variable has been less studied than depressive symptoms (Cooper et al., 2008; Kaddour & Kishita, 2020). The recent meta-analysis carried out by Kaddour and Kishita (2020) reported that clinically relevant levels of anxiety symptoms are present in 42.6% of the caregivers.

Depressive and anxiety symptoms have been very extensively studied as outcome variables in the caregiver population but have mostly been analyzed separately. However, depressive and anxiety symptomatology can also appear simultaneously in caregivers. Mahoney et al. (2005) found that an 8.5% of their sample presented clinically significant levels for both anxiety and depression levels, as assessed through the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and Joling et al. (2015), using a clinical diagnostic interview, found that 32% of spousal caregivers or relatives with dementia presented a comorbid presentation of anxiety and depression. Results in caregiver populations from areas other than dementia have also shown high prevalence of concurrent anxiety and depressive symptoms. For example, similar comorbidity rates have been reported for caregivers of children with cystic fibrosis (Driscoll et al., 2009; Quittner et al., 2014).

Comorbidity is a frequent psychopathological phenomenon, suggesting that clinical mental health symptomatology may share common or transdiagnostic core pathological processes (Hayes & Hofmann, 2018; Newby et al., 2015). For this reason, researchers have developed transdiagnostic (Norton, 2012) or unified (Barlow et al., 2010) approaches, aimed at identifying "cognitive and behavioral processes that are common across a range of depressive and anxiety conditions" (Andersen et al., 2016, p. 674). Psychological inflexibility is considered to be a transdiagnostic process that refers to the rigid attachment to internal experiences (Hayes et al., 2011). The opposite process, that is, psychological flexibility, is defined as "the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends" (Hayes et al., 2006, p. 7). Levin et al. (2014) found in the general population that psychological inflexibility is related more to comorbid depression, anxiety, and substance use disorders than to only having one of these disorders. Therefore, the authors suggest that psychological inflexibility may be a transdiagnostic pathological core process and an important target for interventions.

Psychological inflexibility is a higher order construct, one of its core and transdiagnostic subprocess being cognitive fusion (Hayes et al., 2011). Cognitive fusion is a tendency for behavior that is overly regulated and influenced by cognition, in contrast to distancing from thoughts. "When 'fused,' a person acts on thoughts as though they are literally true, cognitive events come to dominate behavior and experience over other sources of behavioral regulation, and he or she becomes less sensitive to direct consequences" (Gillanders et al., 2014, p. 84). The attention and behavior of people with high levels of cognitive fusion are dominated by the verbal content of their thoughts, without being aware of the thought process itself, moving the person away from the relevant personal goals and values of his or her life (Gillanders et al., 2014). Several studies have found a strong and positive association of cognitive fusion with depressive and anxiety symptoms in clinical and subclinical general populations (Carvalho et al., 2019; Gillanders et al., 2014; Herzberg et al., 2012). Gillanders et al. (2015) also highlighted in a cross-sectional study that cognitive fusion shows a potential indirect effect in the relationship between the experience of chronic stressful life events (e.g., cancer) and anxiety. In the field of caregiving, cognitive fusion also seems to have a potential indirect effect in the relationship between frequency of disruptive behaviors and caregivers' ambivalent feelings (Barrera-Caballero et al., 2019). Despite the paucity of studies, caregivers with higher levels of cognitive fusion have been found to show more severe depressive and anxiety symptoms (Romero-Moreno et al., 2014). These findings seem to support the potential relevance of cognitive fusion in explaining both depressive and anxiety symptoms. However, to our knowledge, there are no studies analyzing this transdiagnostic dimension as an explanation of caregivers' comorbid depressive and anxiety symptomatology.

Taking into account the prevalence of comorbidity between depression and anxiety that has been reported in family caregivers of people with dementia (Joling et al., 2015), identifying aspects of the central process of distress in caregivers outlined above could be important for explaining this comorbid manifestation of symptoms, and for helping to make decisions about clinical evaluation and interventions.

The aims of this study were: (a) to analyze the differences between caregivers' symptom profiles (comorbid, depressive, anxiety, and subclinical) in contextual and demographic variables, as well as in stressors (time devoted to care, frequency and reaction to disruptive behaviors, BPSD) and the characteristics of care recipients and caregivers, such as gender, age or kinship, and (b) to analyze the role of cognitive fusion as a central transdiagnostic process in the comorbid presentation of depressive and anxiety symptoms in dementia family caregivers, as compared with depressive, anxiety and subclinical symptoms, but also controlling for the effects of the other assessed variables, which may be related to comorbid depressive and anxiety symptoms.

We hypothesize that caregivers presenting higher levels of cognitive fusion would be at greater risk of suffering comorbid depressive and anxiety symptoms than the other profiles. Also, those reporting higher stress levels would be at greater risk of presenting comorbid symptomatology.

Method

Participants and Procedure

A total of 553 face-to-face interviews were conducted with caregivers of relatives suffering from dementia or related disorders. Participants were recruited through social and health centers from the Autonomous Community of Madrid. They were informed about the study by telephone, and an appointment for an interview was arranged if they met the following inclusion criteria: a) considering themselves the main caregiver, (b) devoting at least 1 hr per day for

Two multinomial logistic regression analyses were carried out to identify predictors of distress in the four groups. Caregivers' age and gender, care-recipients' gender, kinship (spouses vs. adult child and others), care hours, duration providing care, frequency of disruptive behaviors, and cognitive fusion were included in both regressions as predictor variables. The first regression was tested without including reaction to disruptive behaviors as a predictor and the second one was tested including it. For the first regression, there was a reduction in the sample size to 524 due to missing data on care-recipients' gender (29 participants, 5.2% of the total sample). For the second regression (including reaction to disruptive behaviors as a predictor), the sample size was reduced to 481, due to missing data on care-recipients' gender and participants not reporting any disruptive behavior. The comorbid profile was fixed as the reference category in the nominal dependent variable to be compared with the three other categories, that is, depressive, anxiety, and subclinical symptoms profiles. A significance level of 5% was used throughout all analyses. The IBM SPSS Statistics program (Version 22.0) was used for all analyses.

Results

Participant Characteristics

The sample was composed of 553 dementia family caregivers, mostly female (72.30%). Participants had been caregivers for a long period (average of 45.96 months, *SD*: 35.04; range: 3–192), reporting an average of 13.34 daily hours (*SD*: 8.05; range: 1–24) caring of their relative. The average age of the participants was 61.76 years (*SD*: 13.74 range: 21–88). Regarding kinship, 42.30% of caregivers provided care for their spouses, 51.90% for their parents, and the rest of the participants (5.8%) took care of other relatives (e.g., sisters, uncles, fathers-in-law, and mothers-in-law). Regarding the care-recipient characteristics, the majority of them were female (59.5%) and the majority were diagnosed with Alzheimer's disease (66.7%). The remaining care recipients were diagnosed with other dementias (29.3%) and mild cognitive impairment (4%). Finally, most of the care recipients had moderate or severe cognitive impairment (85.8%).

Most of the caregivers reported comorbid depressive and anxiety symptomatology (comorbid profile; $n = 303$, 54.8%). The remaining participants were grouped into depressive profile ($n = 40$, 7.2%), anxiety profile ($n = 86$, 15.6%), and subclinical profile ($n = 124$, 22.4%).

Descriptive Information and Correlational Analysis of the Assessed Variables

Univariate descriptive statistics and Pearson correlations for the study variables are shown in Table 1. According to the hypotheses of the study, cognitive fusion was positively associated with both depressive ($r = .55$; $p < .001$) and anxiety symptoms ($r = .56$; $p < .001$). In addition, cognitive fusion was also associated with frequency of disruptive behaviors ($r = .18$; $p < .001$) and reaction to these behaviors ($r = .28$; $p < .001$). Frequency of disruptive behaviors and reaction to these behaviors were positively associated with depressive symptoms ($r = .25$; $p < .001$; $r = .30$; $p < .001$, respectively) and anxiety symptoms ($r = .29$; $p < .001$; $r = .31$; $p < .001$, respectively). Depressive and anxiety symptoms were themselves highly positively correlated ($r = .71$; $p < .001$). Male caregivers reported less frequency and reaction to disruptive behaviors ($r = -.15$; $p < .001$; $r = -.17$; $p < .001$), cognitive fusion ($r = -.21$; $p < .001$), and depressive ($r = -.28$; $p < .001$) and anxiety symptomatology ($r = -.26$; $p < .001$). Caregivers' age was negatively associated with frequency of disruptive behaviors ($r = -.12$; $p = .005$), cognitive fusion ($r = -.20$; $p < .001$), and anxiety symptoms ($r = -.15$; $p = .001$), but positively associated with daily hours caring ($r = .36$; $p < .001$) and time since being a caregiver ($r = .12$; $p < .001$). Also, when the cared person was a male, it was positively associated with caregivers' age ($r = .29$; $p < .001$), daily hours caring ($r = .18$; $p < .001$), and depressive symptoms ($r = .13$; $p = .002$). Regarding kinship, being a spousal caregiver was associated with being older ($r = -.74$; $p < .001$), more daily hours caring ($r = -.42$; $p < .001$), lower anxiety levels ($r = .14$; $p < .001$), and lower cognitive fusion levels ($r = .19$; $p < .001$).

Differences Between Symptom Profiles in the Assessed Variables

Differences between symptom profiles in the sociodemographic and assessed variables are reported in Table 2. There were significant differences between symptom profiles in demographic factors. The comorbid profile was significantly associated with being a

Table 1

Descriptive Statistics (Range, Mean, and Standard Deviation) and Pearson Correlations (N = 553)

Measure	1	2	3	4	5	6	7	8	9	10	Range	*M*	*SD*
1. Caregiver gender (0 = female)	—										—	—	—
2. Care-recipient gender (0 = female)$^{\#}$	−34**	—									—	—	—
3. Kinship (0 = spouse)	−.17**	−.51**	—								—	—	—
4. Caregivers' age	.15**	.29**	−.74**	—							21–88	61.76	13.74
5. Daily hours caring	.03	.18**	−.42**	.36**	—						1–24	13.34	8.05
6. Time since being a caregiver	−.02	−.03	−.02	.12**	−.03	—					3–192	45.96	35.04
7. Frequency of disruptive behaviors	−.15**	.04	.09*	−.12**	−.01	.01	—				0–28	7.07	5.54
8. Reaction to disruptive behaviors†	−.17**	.08§	.09	−.06	−.05	−.06	.30**	—			0–32	14.58	9.45
9. Cognitive fusion	−.21**	−.04	.19**	−.20**	−.06	−.07	.18**	.28**	—		7–49	24.81	10.31
10. Depressive symptoms	−.28**	.13**	−.00	−.03	.07	−.03	.25**	.30**	.55**	—	0–51	20.67	11.57
11. Anxiety symptoms	−.26**	.04	.14**	−.15**	.00	.01	.29**	.31**	.56**	.71**	0–36	17.78	8.33

Note. $^{\#}N = 524$; $^{\dagger}N = 508$; $^{\S}N = 481$.
$^{*}\ p < .05$. $^{**}\ p <. 01$.

Table 2
Differences Between Symptom Profiles in the Assessed Variables (N = 553)

Variables	Comorbid profile ($N = 303$, 54.8%)	Depressive profile ($N = 40$, 7.2%)	Anxiety profile ($N = 86$, 15.6%)	Subclinical profile ($N = 124$, 22.4%)	F, χ^2	p	Post hoc pairwise comparisons (Tukey $\alpha = .05$)
Caregiver gender, *n* (row %)					62.66	.000**	—
Male caregivers	55 (35.9%)	6 (3.9%)	24 (15.7%)	68 (44.4%)			
Female caregivers	248 (62.0%)	34 (8.5%)	62 (15.5%)	56 (14.0%)			
Kinship, *n* (row %)					8.43	.038*	—
Spouse	122 (52.1%)	18 (7.7%)	29 (12.4%)	65 (27.8%)			
Son/daughter and others	181 (56.7%)	22 (6.9%)	57 (17.9%)	59 (18.5%)			
Age of caregivers, *M* (*SD*)	60.66 (13.79)	65.8 (11.08)	60.6 (12.27)	64.0 (14.92)	3.23	.022*	Comorbid < depressive Comorbid < subclinical Depressive > anxiety
Stage of the disease of the care recipient, *M* (*SD*)	4.75 (1.18)	4.89 (1.18)	4.55 (1.21)	4.71 (1.17)	0.95	.415	—
Daily hours caring, *M* (*SD*)	13.6 (8.02)	13.57 (8.19)	12.30 (8.52)	13.1 (7.77)	.69	.555	—
Time since being a caregiver, *M* (*SD*)	46.11 (35.97)	41.52 (26.55)	44.51 (36.61)	48.00 (34.29)	.40	.750	—
Care-recipient gender, *n* (row %)#					7.16	.067	—
Male care recipient	169 (51.4%)	22 (6.7%)	55 (16.7%)	83 (25.2%)			
Female care recipient	121 (62.1%)	15 (7.7%)	24 (12.3%)	35 (17.9%)			
Frequency of disruptive behaviors, *M* (*SD*)	8.32 (5.98)	4.32 (4.25)	5.90 (4.37)	5.67 (4.70)	15.78	.000**	Comorbid > depressive Comorbid > anxiety Comorbid > subclinical
Reaction to disruptive behaviors, *M* (*SD*)†	16.90 (8.97)	12.69 (9.77)	12.46 (9.14)	10.46 (9.06)	17.81	.000**	Comorbid > depressive Comorbid > anxiety Comorbid > subclinical
Cognitive fusion, *M* (*SD*)	29.42 (9.19)	21.22 (9.09)	21.64 (8.38)	16.93 (8.29)	65.66	.000**	Comorbid > depressive Comorbid > anxiety Comorbid > subclinical Anxiety > subclinical Depressive > subclinical

Note. #$N = 524$; †$N = 508$: comorbid profile ($N = 290$, 57.1%); depressive profile ($N = 30$, 5.9%); anxiety profile ($N = 78$, 15.3%); subclinical profile ($N = 110$, 21.7%).
* $p < .05$. ** $p <. 01$.

female caregiver (62.0% vs. 35.9%; Z = 5.5), while the subclinical profile was associated with being a male caregiver (44.4% vs. 14.0%; Z = 7.7). In addition, it was found that subclinical profile was associated with a spousal relationship between caregiver and care recipient compared to parent or other kinship situations (27.8% vs. 18.5%; Z = 2.6). We found significant differences between the profiles and age: the caregiver comorbid profile was younger than the depressive (p = .025), and subclinical (p = .019) profiles, and the caregiver depressive profile was significantly older than the anxiety profile (p = .046).

In addition, there were significant differences between symptom profiles in frequency and reaction to disruptive behaviors, and in cognitive fusion. Specifically, caregivers in the comorbid profile reported higher frequency of disruptive behaviors of the care recipient than depressive, anxiety, and subclinical profiles (p < .001). Also, caregivers in the comorbid profile showed higher reaction to these behaviors than depressive (p =.016), anxiety, and subclinical profiles (p < .001). Differences between symptom profiles in daily hours caring and time since being a caregiver were nonsignificant. Caregivers in the comorbid profile presented higher levels of cognitive fusion than depressive, anxiety, and subclinical profile (p < .001).

Determinants of Comorbid Depressive and Anxiety Symptomatology Profile Versus Depressive, Anxiety, or Subclinical Profile

As it has been described in the data analysis section, we conducted two multinomial regressions: a first one including as predictors all the assessed variables except reaction to disruptive behaviors, and a second one adding as a predictor reaction to disruptive behaviors. The sample size for the first regression was larger (N = 524) than the model which includes reaction to disruptive behaviors (N = 481) because the latter model shows the coefficient for reaction for those reporting problem behaviors. The likelihood ratio chi-square test (LR) for reaction to disruptive behaviors (LR(3) = 6.765, p = .080) did not reach statistical significance. As the effect of reaction to disruptive behaviors did not contribute beyond and above the predictors included in the previous regression model, we only show the regression model without this predictor (Table 3). Table 3 shows the coefficients (adjusted *odds ratio*) and their 95% confidence intervals predicting the subclinical, anxiety, and depressive profiles versus the reference comorbid profile. *OR*s significantly higher than 1 indicate a higher likelihood of being in the subclinical, anxiety or depressive profile, relative to the comorbid profile, and vice versa for *OR* below 1. The examined predictors were demographic factors, frequency of disruptive behaviors of care recipient, and cognitive fusion.

Significant results were found for caregivers gender (LR(3) = 26.163; p < .001) and caregivers' age (LR(3) = 8.663; p = .034). With regard to stressors, frequency of disruptive behaviors had a significant relationship with the symptom profile (LR(3) = 23.064; p < .001). Cognitive fusion (LR(3) = 136.315; p < .001) also made a significant contribution.

Men were more likely than women caregivers to be included in the subclinical profile, relative to the comorbid profile, *OR* = 3.765; 95% CI [1.949—7.274]. Being older was associated with a higher likelihood of being in the depressive profile relative to the comorbid profile, *OR* = 1.079; 95% CI [1.023—1.138]. In addition, frequency of disruptive behavior is a risk factor to be in the comorbid profile relative to subclinical profile, *OR* = .925; 95% CI [.877—.976], anxiety profile, *OR* = .923; 95% CI [.874—.974], and depressive profile, *OR* = .852; 95% CI [.778—.933]. Finally, cognitive fusion was also a risk factor in each comparison. Higher cognitive fusion was associated with a higher likelihood of being in the comorbid profile relative to the other three profiles. In particular, the likelihood of being in the subclinical profile (relative to the comorbid profile) decreased by 14.8% per unit increase in cognitive fusion, *OR* = .852; 95% CI [.824—.881]. The likelihood of being in the anxiety profile decreased by 9% per unit increase in cognitive fusion, *OR* = .910; 95% CI [.882—.939]. Finally, the likelihood of being in the depressive profile decreased by 9.1% per unit increase in cognitive fusion, *OR* = .909; 95% CI [.872—.948].

Discussion

The main objectives of this study were to analyze the possible differences between caregivers' symptom profiles in terms of demographic factors, potential stress variables, and cognitive fusion and to examine which caregivers were more vulnerable to comorbid depressive and anxiety symptomatology, compared to those with depressive, anxiety, or subclinical symptoms. The effects of other important contextual and demographic variables were controlled for. To our knowledge, this is the first study to analyze the differences between caregivers with comorbid depressive and

Table 3

Multinomial Logistic Regression Analyses of Determinants of Symptom Profile (N = 524) in Caregivers of People With Dementia

Factors	Subclinical vs. comorbid profile *OR* [95% CI]	Anxiety vs. comorbid profile *OR* [95% CI]	Depressive vs. comorbid profile *OR* [95% CI]
Caregiver gender (0 = female)	**3.765 [1.949, 7.274]**	1.141 [0.560, 2.329]	0.279[0.069, 1.130]
Care-recipient gender (0 = female)	0.724 [0.345, 1.521]	0.597 [0.271, 1.313]	0.436 [0.114, 1.668]
Kinship (0 = spouse)	1.154 [0.403, 3.308]	1.509 [0.507, 4.493]	2.174 [0.389, 12.135]
Caregivers' age	1.011 [0.978, 1.045]	1.012 [0.979, 1.047]	**1.079 [1.023, 1.138]**
Daily hours caring	0.970 [0.934, 1.007]	0.975 [0.940, 1.012]	0.981 [0.934, 1.030]
Time since being a caregiver	0.999 [0.991, 1.006]	0.997 [0.990, 1.005]	0.991 [0.979, 1.003]
Cognitive fusion	**0.852 [0.824, 0.881]**	**0.910 [0.882, 0.939]**	**0.909 [0.872, 0.948]**
Frequency of disruptive behaviors	**0.925 [0.877, 0.976]**	**0.923 [0.874, 0.974]**	**0.852 [0.778, 0.933]**
−2LL	942.34 (24)		

Note. Statistically significant coefficients (p < .05) are highlighted in bold.

anxiety symptoms and other symptom profiles and to identify possible correlates of these differences.

The results show a high prevalence of comorbid symptoms in family caregivers of people with dementia, with more than half of the participants showing simultaneously significant levels of depressive and anxiety symptomatology (54.8%). It is worth mentioning that the cutoffs for the measures used in this study undoubtedly influence the number of caregivers being classified as depressed or anxious. However, as reported in Footnote[1] and supplemental materials, the obtained rate of comorbid symptoms was also high (29.1%) using different cut-off points for the CES-D (Vázquez et al., 2007) and for the POMS (McNair et al., 2003). The obtained comorbidity rate, although large, was not unexpected, considering the findings reported by Joling et al. (2015), who found that during a 2-year follow-up period, 60% family caregivers of people with dementia developed a depressive and/or anxiety disorder (32% comorbid). The present study also reveals that clinically relevant anxiety symptoms were very prevalent among caregivers, with almost 70.4% of the caregivers of our sample suffering from this problem (alone or comorbid with clinically relevant depressive symptoms). Joling et al. (2015) also reported a larger proportion of anxiety problems compared to depressive problems. Despite this prevalence for clinically relevant symptoms of anxiety, it is surprising that anxiety has received far less attention than depressive symptomatology in the scientific literature (Kaddour & Kishita, 2020).

In noncaregiving populations, the comorbid presentation of mood and anxiety disorders is associated with worse outcomes, such as a higher severity and chronicity of the specific psychopathology, lower psychosocial functioning, higher likelihood of suicidal behavior, and lower treatment efficacy and greater relapse (e.g., Bronisch & Wittchen, 1994; Brown et al., 1995, 1996; Sareen et al., 2005). Our findings suggest that a high proportion of family caregivers of people with dementia has a comorbid presentation of clinically relevant levels of depressive and anxiety symptomatology, and so caregivers may be especially vulnerable to the described outcomes.

In relation to sociodemographic factors, the findings of this study show that female caregivers would report more comorbid symptoms than male caregivers, a finding coherent with other studies that report higher levels of distress for female caregivers (Collins & Kishita, 2019; Joling et al., 2015; Kaddour & Kishita, 2020). These findings may be related to their more vulnerable situation in terms of exposure to stressors (Pinquart & Sörensen, 2006), and to having higher cognitive fusion than men. With respect to age, the findings suggest that caregivers in the comorbid group are younger than caregivers in the depressive and subclinal profiles.

With respect to potential caregiving stressor variables, the results of the present study suggest that both frequency and reaction to care-recipients' disruptive behaviors are associated with distress (depressive and anxiety symptoms) in caregivers, in line with other studies (Feast et al., 2016; Nogales-González et al., 2015). Regarding our hypothesis on comorbidity and stressors, it is partially supported. First, caregivers who reported a comorbid symptomatology presented higher frequency of behavior problems and reaction associated with these behaviors than those caregivers who reported depressive symptoms, anxiety symptoms, and subclinical symptomatology. However, only frequency of disruptive behaviors, differentiated between the comorbid profile and the other symptom profiles.

The findings of this study suggest that care-recipients' disruptive behaviors may be especially relevant in terms of understanding the comorbid presence of depressive and anxiety symptoms in caregivers. It is worth mentioning that dementia per se (the illness) is not the only factor contributing to the development and maintenance of BPSD. These difficulties occur in the context of a relationship. Consequently, caregiver factors, environmental triggers, and interactions between the caregiver and the care recipient are also relevant (Kales et al., 2015), and so future studies should analyze the potential role of these factors in the development of BPSD and the comorbid presentation of depressive and anxiety symptoms in caregivers.

One variable that also seems to be relevant for understanding the comorbid presentation of depressive and anxiety symptoms in family caregivers of people with dementia is cognitive fusion. While the association between cognitive fusion and depressive or anxiety symptoms has already been described in previous studies (Romero-Moreno et al., 2014, 2015), this study offers the first evidence that cognitive fusion seems to be an important correlate of comorbidity in caregivers. Our hypothesis is supported by the results showing that caregivers in the comorbid profile had higher levels of cognitive fusion or a greater tendency to be regulated by the meaning of their thoughts than those caregivers with depressive, anxiety, and subclinical symptoms profiles, after controlling for the remaining distress predictors (demographic and stressors variables). Moreover, there was no difference in cognitive fusion between the depressive and anxiety profiles, which provides additional empirical support to the consideration of cognitive fusion as a transdiagnostic process. In this line, the obtained results are consistent with previous studies showing that psychological inflexibility, which includes cognitive fusion, is related to a range of comorbid psychological problems such as depressive, anxiety, eating, or substance use disorders (e.g., Levin et al., 2012, 2014; Rawal et al., 2010; Venta et al., 2012). This variable may be a common process across emotional problems.

The results suggest a high rate of comorbidity between depressive and anxiety symptoms in family caregivers, most of them female caregivers. This fact may be relevant considering the high increase in the prevalence of dementias worldwide, as well as the high number of family caregivers who continue to be the main source of care for community-dwelling older adults suffering from dementing conditions (e.g., Alzheimer's Association, 2018; Stokes et al., 2015). The identification of correlates of comorbidity such as

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[1] In order to provide additional support for the obtained findings, additional analyses were done. The analyses were repeated using different cut-off points: 26 for the CES-D (Vázquez et al., 2007), and 17 for the POMS (McNair et al., 2003). Although, as expected, different percentages of symptom profiles were obtained (comorbid profile; n = 161, 29.1%; depressive profile; n = 19, 3.4%, anxiety profile; n = 142, 25.7%, and subclinical profile; n = 231, 41.8%), the main findings of the study, those related to the tested model, are maintained, indicating that the model is consistent. The results of these analyses are shown in online Supplemental Materials (see Supplemental A).Apart from the multinomial regression presented in the main text, two other multinomial regressions can be found in the online supplemental materials. The first regression (see Supplemental B) includes interaction between caregiver gender and the care-recipient's gender. As no interaction effect was found (LR(3) = 4.894, p = .180), we decided to omit this predictor in Table 3. The results of the regression comparing the depressive, anxiety, and subclinical profiles in terms of what predictors differentiated among them are shown in Supplemental C.

cognitive fusion and care-recipient's disruptive behaviors may be useful for identifying potential relevant assessment and intervention targets.

Several limitations of the present study should be considered. First, the correlational and cross-sectional nature of the study prevents causal inferences. It would be necessary to carry out experimental and longitudinal studies to confirm that disruptive behaviors, cognitive fusion, and caregivers' gender contribute to explain comorbid depressive and anxiety symptomatology in family caregivers of people with dementia. Longitudinal studies may also help to elucidate the core process of comorbid anxiety and depression across time, and also, whether anxiety precedes the onset of depression in family caregivers of people with dementia, as previous studies have suggested in noncaregiver clinical samples (Brown et al., 2001). The sociodemographic characteristics of our sample are similar to those described in other studies done with caregivers (e.g., in terms of gender or age distribution); however, since the sample was composed of caregivers who volunteered to participate, the results cannot be generalized to the general population of caregivers. Also, participants in this study reported many hours devoted to caregiving tasks and a high degree of cognitive impairment of the care recipient. Studies done with other caregiver samples are needed to replicate the obtained results.

Furthermore, the subclinical profile group comprised caregivers whose scores were not severe enough to cross the threshold. However, some of them may have had symptoms warranting clinical attention or intervention. It is also worth mentioning that the high level of depressive and anxiety symptoms in the sample could be explained by other reasons. In this study, cut-off scores were the only criteria used to define the symptom profiles and it is possible that levels of clinically significant symptoms were overestimated for this reason. Future studies could consider not only cut-off scores but also diagnostic criteria (e.g., Joling et al., 2015). In addition, even though the selected measures for depressive and anxiety symptoms have good psychometric properties, they may not capture differences in the way these conditions are manifested differently in older people, compared with younger adults (i.e., Brenes, 2006; Hybels et al., 2012). Furthermore, the high levels of symptomatology in our sample could be associated with low availability of resources for caregivers, such as government financial or social support (Schulz, 2020).

Despite these limitations, the findings of this study suggest that comorbid depressive and anxiety symptomatology is an important issue that deserves further research given its high prevalence in family caregivers of people with dementia. Cognitive fusion as well as care-recipient's disruptive behaviors are important factors to be considered for a deeper understanding and more rational treatment of the comorbidity in dementia family caregivers.

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