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TESIS DOCTORAL

Sociocultural and psychological factors and family caregivers' mental health. Importance of kinship

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1. Resumen General

La población mundial está envejeciendo rápidamente debido fundamentalmente a avances sociosanitarios y a una disminución de las tasas de natalidad. Concretamente, en España, la población mayor está en aumento, algo especialmente observable en el grupo de personas mayores de 80 años (Conde-Ruiz y González, 2021). A pesar de que la mayoría de las personas mayores viven sin problemas de salud importantes, lo anterior se asocia con un incremento en la prevalencia de enfermedades degenerativas, como las demencias, y a un aumento significativo de las necesidades de cuidados, que se proporcionan fundamentalmente en los hogares por familiares. El cuidado familiar de personas con demencia, principalmente realizado por mujeres de la familia, puede tener consecuencias negativas para la salud física y mental de las personas cuidadoras, incluyendo depresión, ansiedad, culpa y soledad (Schulz et al., 2020).

La depresión y la ansiedad son algunas de las principales consecuencias psicológicas del cuidado familiar, con tasas de prevalencia que oscilan entre el 30% y el 80% en cuidadores de personas con demencia (Huang, 2022; Kaddour y Kishita, 2020). Además, los sentimientos de culpa y soledad, si bien han sido estudiadas en menor medida por la literatura, parecen también afectar significativamente al malestar emocional de los familiares cuidadores (Kovaleva et al., 2018; Losada et al., 2018). De acuerdo con la literatura científica, las mujeres cuidadoras experimentan mayores niveles de estas consecuencias en comparación con los hombres cuidadores, debido entre otros factores a la tradicional atribución del cuidado al rol femenino (Bartlett et al., 2018). Los estudios también parecen indicar que el parentesco con la persona cuidada juega un papel importante, siendo las hijas cuidadoras las más vulnerables a experimentar problemas de salud mental, seguidas por las esposas (Watson et al., 2019).

La presente tesis doctoral, basada en lo planteado por el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010) y teniendo en cuenta la limitada literatura disponible en esta área, busca profundizar en el análisis de cómo variables culturales y psicológicas se relacionan con las consecuencias emocionales de las personas cuidadoras, con especial atención a variables como el familismo y los pensamientos disfuncionales. El familismo, valor predominante en culturas mediterráneas como la española, enfatiza la lealtad y solidaridad familiar y puede conllevar que el cuidado se perciba como una obligación moral, especialmente en el caso de las mujeres (Van der Lippe, y Lippényi, 2020). Estudios previos han encontrado una asociación significativa entre la percepción de obligaciones familiares y la presencia de pensamientos disfuncionales asociados al cuidado. Estos pensamientos pueden llevar a estrategias de afrontamiento desadaptativas, como descuidar el autocuidado y restringir actividades de ocio, contribuyendo al malestar emocional de las personas cuidadoras (Losada et al., 2010). Esto va en consonancia con lo planteado por el modelo cognitivo asociado al cuidado, que sugiere que la cultura influye en la percepción y manejo del cuidado, destacando la importancia de comprender y abordar estas dinámicas culturales en la salud mental de los cuidadores (Losada et al., 2006)

Por lo tanto, la presente investigación se compone de cuatro estudios independientes que tienen como objetivo fundamental una mayor comprensión del papel de dichas variables en la salud mental de los familiares cuidadores. Todos ellos presentan una estructura similar compuesta por diferentes secciones, a saber: Introducción, Método, Resultados, Discusión y Referencias. Se emplearán diferentes metodologías en los estudios, incluyéndose en todos los estudios el análisis de la relación de parentesco con la persona cuidada para comprender mejor las necesidades y vulnerabilidades específicas de cada grupo de cuidadores (esposas, esposos, hijas e hijos).

Previo a la presentación de los cuatro estudios, la presente tesis doctoral cuenta con una introducción general donde se detalla de manera exhaustiva el modelo teórico en el que se enmarca y la literatura previa disponible con relación a dicha línea de investigación. Posteriormente, se describen los objetivos generales de la tesis doctoral y los objetivos e hipótesis específicas de cada uno de los estudios que la componen. Después, se encontrará una sección dedicada a la metodología general de la tesis, en la que se detallan el procedimiento, los participantes y las variables seleccionadas en los distintos estudios. Además, en esta sección se resumen de manera concisa los distintos análisis de datos llevados a cabo. Por último, tras la presentación de los cuatro estudios, se dedicará una sección a la discusión general de los resultados encontrados y a las posibles implicaciones prácticas, además de ofrecer una serie de conclusiones derivadas de la realización de la tesis doctoral.

El primer estudio tuvo como objetivo principal analizar la posible influencia del familismo, los pensamientos disfuncionales y las variables de afrontamiento en la explicación de los sentimientos de soledad percibida en las personas cuidadoras. Un total de 273 familiares de personas con demencia participaron en el estudio. Se evaluaron variables sociodemográficas, familismo, pensamientos disfuncionales, estrategias de afrontamiento de solicitud y recepción de ayuda, apoyo social percibido y actividades de ocio. Se realizaron análisis del ajuste de un modelo teórico propuesto para explicar el efecto de variables culturales y psicológicas en los sentimientos de soledad en cada grupo de parentesco. Los resultados mostraron que, si bien no se encontraron diferencias significativas en la distribución de la soledad por parentesco, existe una alta presencia de soledad percibida entre los cuidadores. Además, los datos reflejaron que niveles más altos de familismo se relacionan con mayores niveles de pensamientos disfuncionales, y estos se asociaron con estrategias de afrontamiento menos adaptativas para lidiar con el cuidado (menos apoyo social y menos actividades de ocio). Esto, a su vez, se asocia con puntuaciones más altas en el sentimiento de soledad, siendo particularmente relevante este modelo en el grupo de hijas. Por lo tanto, los factores socioculturales asociados con el proceso de cuidado parecen desempeñar un papel importante en la explicación de los sentimientos de soledad en los familiares cuidadores.

El segundo estudio tuvo como objetivo fundamental estudiar del impacto de las obligaciones familiares y la deseabilidad social en la manifestación de malestar emocional de personas cuidadoras, considerando la relación de parentesco con la persona cuidada. Participaron 284 cuidadores divididos en esposos, esposas, hijas e hijos. Se evaluaron las variables familismo, pensamientos disfuncionales, deseabilidad social, frecuencia y reacción de comportamientos problemáticos y sintomatología depresiva y de culpa. Los resultados mostraron una relación significativa entre la deseabilidad social y los pensamientos disfuncionales en las esposas e hijas de los cuidadores. Además, los datos mostraron que la deseabilidad social está relacionada con una menor expresión de reacciones a comportamientos problemáticos, específicamente en esposas e hijas. También se encontró que la deseabilidad social, al influir en cómo se informan las reacciones a comportamientos problemáticos, parece tener un efecto indirecto en los sentimientos de culpa de los cuidadores de hijas. Esto es relevante considerando la asociación entre los sentimientos de culpa y la sintomatología depresiva. Por lo tanto, los resultados sugieren que factores psicosociales como la deseabilidad social pueden influir en cómo los cuidadores, especialmente las mujeres, informan su angustia emocional relacionada con el cuidado. En consecuencia, es posible que los niveles de angustia expresados por los cuidadores sean más altos de lo que realmente informan cuando tienen altos niveles de deseabilidad social, ya que pueden ajustar sus respuestas para cumplir con las expectativas sociales. Estos hallazgos destacan la importancia de considerar factores socioculturales en las intervenciones para cuidadores, especialmente para hijas.

El tercer estudio buscó identificar perfiles de cuidadores familiares de personas con demencia según variables psicosociales y de recursos, analizando el papel del parentesco en la relación entre tales perfiles y el malestar emocional. Participaron 288 cuidadores familiares divididos en cuatro grupos de parentesco. Se recabó información sobre variables psicosociales tales como el familismo, los pensamientos disfuncionales y la evitación experiencial, variables de recursos como las actividades de ocio y el apoyo social y la presencia de síntomas depresivos, ansiosos y de culpa. Se realizó un análisis de conglomerados jerárquico utilizando el método Ward y tablas de contingencia entre los conglomerados y la variable de parentesco para determinar la distribución de los participantes según la relación de parentesco. Se identificaron cinco conglomerados o perfiles: *Baja vulnerabilidad psicosocial-Altos recursos, Baja vulnerabilidad psicosocial-Bajos recursos, Mixto, Alta vulnerabilidad psicosocial-Altos recursos y Alta vulnerabilidad psicosocial-Bajos recursos.* Los resultados sugirieron que los grupos asociados con menor malestar emocional fueron el perfil 1 (Baja vulnerabilidad psicosocial-Altos recursos) y el perfil 4 (Alta vulnerabilidad psicosocial-Altos recursos). Por el contrario, los perfiles asociados con mayor malestar emocional fueron el perfil 2 (Baja vulnerabilidad psicosocial-Bajos recursos) y el perfil 3 (Mixto). Por tanto, los datos indican que niveles altos de pensamientos disfuncionales, familismo y evitación experiencial no siempre tienen una función desadaptativa, sino que esto podría depender de variables socioculturales y de recursos como el parentesco con el cuidador o el apoyo social percibido.

Por último, el cuarto estudio tuvo como objetivo fundamental analizar el impacto de los pensamientos disfuncionales en la explicación de los síntomas depresivos y de ansiedad de los cuidadores, centrándose en el efecto moderador de la función familiar en tal relación y en el papel del parentesco. Un total de 278 cuidadores de personas con demencia participaron en el estudio, dividiéndose en cuatro grupos de parentesco. Se evaluaron variables sociodemográficas, obligaciones familiares, pensamientos disfuncionales, frecuencia y reacción de comportamientos problemáticos, función familiar y sintomatología depresiva y ansiosa. Se realizaron análisis de regresión jerárquica con el objetivo de analizar si existe una relación directa de los pensamientos disfuncionales y la función familiar con ambas sintomatologías y si el funcionamiento familiar modera la relación entre los pensamientos disfuncionales y la presencia de sintomatología depresiva y ansiosa en los distintos grupos de parentesco. Los resultados reflejaron que el efecto moderador de la función familiar fue significativo solo para las hijas. Por tanto, los datos sugieren que una familia funcional puede tener un papel protector del malestar emocional incluso cuando los cuidadores, especialmente las hijas, tienen creencias rígidas sobre el cuidado. De esta manera, se destaca la relevancia del papel de la familia en el proceso del cuidado, pues puede contribuir de manera significativa a comprender el malestar psicológico de los cuidadores familiares de personas con demencia.

1. General Abstract

The global population is rapidly aging primarily due to socio-sanitary advances and declining birth rates. Specifically, in Spain, the older population is increasing, particularly noticeable among individuals over 80 years old (Conde-Ruiz & González, 2021). Although most older adults live without significant health issues, this trend is associated with an increase in the prevalence of degenerative diseases, such as dementia, and a significant rise in care needs, primarily provided at home by family members. Family caregiving for individuals with dementia, mainly performed by female family members, can have negative consequences for caregivers' physical and mental health, including depression, anxiety, guilt, and loneliness (Schulz et al., 2020).

Depression and anxiety are among the main psychological consequences of family caregiving, with prevalence rates ranging from 30% to 80% among caregivers of individuals with dementia (Huang, 2022; Kaddour & Kishita, 2020). Furthermore, feelings of guilt and loneliness, although studied to a lesser extent in the literature, also seem to significantly impact the emotional distress of family caregivers (Kovaleva et al., 2018; Losada et al., 2018). According to scientific literature, female caregivers experience higher levels of these consequences compared to male caregivers, due in part to the traditional attribution of caregiving to the female role (Bartlett et al., 2018). Studies also indicate that the kinship with the care recipient plays a significant role, with daughters being the most vulnerable caregivers to experience mental health issues, followed by spouses (Watson et al., 2019).

This doctoral thesis, based on the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010) and considering the limited literature available in this area, seeks to delve into the analysis of how cultural and psychological variables are related to caregivers' emotional consequences, with special attention to variables such as familism and

dysfunctional thoughts. Familism, a predominant value in Mediterranean cultures like the Spanish culture, emphasizes family loyalty and solidarity and may lead caregiving to be perceived as a moral obligation, especially among women (Van der Lippe & Lippényi, 2020). Previous studies have found a significant association between the perception of family obligations and the presence of dysfunctional thoughts associated with caregiving. These thoughts can lead to maladaptive coping strategies, such as neglecting self-care and restricting leisure activities, contributing to caregivers' emotional distress (Losada et al., 2010). This is consistent with the cognitive caregiving model, which suggests that culture influences caregiving perception and management, highlighting the importance of understanding and addressing these cultural dynamics in caregivers' mental health (Losada et al., 2006).

Therefore, this research consists of four independent studies that aim to gain a deeper understanding of the role of these variables in family caregivers' mental health. They all follow a similar structure composed of different sections: Introduction, Method, Results, Discussion, and References. Different methodologies will be employed in the studies, all of which include the analysis of the kinship relationship with the care recipient to better understand the specific needs and vulnerabilities of each group of caregivers (spouses, daughters, and sons).

Prior to the presentation of the four studies, this doctoral thesis includes a general introduction detailing the theoretical framework and the available previous literature related to this line of research. Subsequently, the general objectives of the doctoral thesis and the specific objectives and hypotheses of each of the studies comprising it are described. Then, there is a section dedicated to the general methodology of the thesis, detailing the procedure, participants, and selected variables in the different studies. Additionally, this section concisely summarizes the different data analyses conducted. Finally, after the presentation of the four studies, a section will be dedicated to the general discussion of the findings and their potential practical implications, as well as offering a series of conclusions derived from the completion of the doctoral thesis.

The first study aimed to analyze the possible influence of familism, dysfunctional thoughts, and coping variables on perceived loneliness in caregivers. A total of 273 family caregivers of individuals with dementia participated in the study. Sociodemographic variables, familism, dysfunctional thoughts, coping strategies of seeking and receiving help, perceived social support, and leisure activities were evaluated. Analyses of the fit of a proposed theoretical model to explain the effect of cultural and psychological variables on feelings of loneliness in each kinship group were conducted. The results showed that, although no significant differences were found in the distribution of loneliness by kinship, there is a high presence of perceived loneliness among caregivers. Furthermore, the data reflected that higher levels of familism are related to higher levels of dysfunctional thoughts, which are associated with less adaptive coping strategies for dealing with caregiving (less social support and fewer leisure activities). This, in turn, is associated with higher loneliness scores, with this model being particularly relevant in the daughters' group. Therefore, sociocultural factors associated with the caregiving process seem to play an important role in explaining caregivers' feelings of loneliness.

The second study aimed to study the impact of family obligations and social desirability on caregivers' emotional distress, considering the kinship relationship with the care recipient. A total of 284 caregivers were divided into spouses, daughters, and sons. The variables familism, dysfunctional thoughts, social desirability, frequency and reaction to problematic behaviors, and depressive and guilt symptomatology were assessed. The results showed a significant relationship between social desirability and dysfunctional thoughts in caregivers' wives and daughters. Moreover, the data showed that social desirability is related to a lower expression of reactions to problematic behaviors, specifically in wives and daughters. It was also found that social desirability, by influencing how reactions to problematic behaviors are reported, seems to have an indirect effect on guilt feelings of daughter caregivers. This is relevant considering the association between guilt feelings and depressive symptomatology. Therefore, the results suggest that psychosocial factors such as social desirability can influence how caregivers, especially women, report their emotional distress related to caregiving. Consequently, it is possible that the levels of distress expressed by caregivers are higher than what they actually report when they have high levels of social desirability, as they may be adjusting their responses to meet social expectations. These findings highlight the importance of considering sociocultural factors in interventions for caregivers, especially for daughters.

The third study aimed to identify profiles of family caregivers of people with dementia based on psychosocial and resource variables, analyzing the role of kinship in the relationship between these profiles and emotional distress. A total of 288 family caregivers were divided into four kinship groups. Information was gathered on psychosocial variables such as familism, dysfunctional thoughts, and experiential avoidance, as well as resource variables such as leisure activities and social support, and the presence of depressive, anxious, and guilt symptoms. A hierarchical cluster analysis using the Ward method and contingency tables between clusters and kinship variables were conducted to determine the distribution of participants according to kinship. Five clusters or profiles were identified: Low psychosocial vulnerability-High resources, Low psychosocial vulnerability-Low resources, Mixed, High psychosocial vulnerability-High resources, and High psychosocial vulnerability-Low resources. The results suggested that groups associated with lower emotional distress were profile 1 (Low psychosocial vulnerability-High resources) and profile 4 (High psychosocial vulnerability-High resources). Conversely, profiles associated with higher emotional distress were profile 2 (Low psychosocial vulnerability-Low resources) and profile 3 (Mixed). Therefore, the data indicate that high levels of dysfunctional thoughts, familism, and experiential avoidance do not always have a maladaptive function, but this may depend on sociocultural and resource variables such as kinship with the caregiver or perceived social support.

Finally, the fourth study aimed to analyze the impact of dysfunctional thoughts on explaining depressive and anxiety symptoms among caregivers, focusing on the moderating effect of family function in this relationship and the role of kinship. A total of 278 caregivers of people with dementia participated in the study, divided into four kinship groups. Sociodemographic variables, family obligations, dysfunctional thoughts, frequency and reaction to problematic behaviors, family function, and depressive and anxiety symptoms were evaluated. Hierarchical regression analyses were conducted to examine whether there is a direct relationship between dysfunctional thoughts and family function with both symptomologies, and whether family function moderates the relationship between dysfunctional thoughts and the presence of depressive and anxiety symptoms in the different kinship groups. The results reflected that the moderating effect of family function was significant only for daughters. Therefore, the data suggest that a functional family can play a protective role in emotional distress even when caregivers, especially daughters, have rigid beliefs about caregiving. Thus, the relevance of the family's role in the caregiving process is highlighted, as it can significantly contribute to understanding the psychological distress of family caregivers of people with dementia.

2. Introducción General

2.1. Envejecimiento poblacional y demencias

La población mundial está experimentando una significativa transición demográfica en las últimas décadas, dejando de ser la población predominantemente joven, convirtiéndose en una sociedad con una presencia significativa de la población de mayor edad (United Nations, 2022). En el año 2017 tuvo lugar un hito mundial fundamental pues, por primera vez en la historia, el número de individuos con edades superiores a 64 años superó al de los niños menores de 5 años (Ritchie y Roser, 2023). Además, se espera que el porcentaje de la población a partir de los 60 años aumente un 34% en las siguientes décadas y que la tendencia del envejecimiento poblacional sea más acelerada que en el pasado (Conde-Ruiz y González, 2021). Más concretamente, se prevé así que el número de población mayor en los próximos 40 años se multiplique por 3.25, alcanzando para el año 2060 un total aproximado de 3.038,77 millones de personas mayores, lo que correspondería a un 29.7% de la población mundial (Mattiuzzi y Lippi, 2020; World Health Organization, 2018). Este aumento en el envejecimiento de la población viene dado, entre otras razones, por las mejoras sociosanitarias que han tenido lugar durante el último siglo y el aumento de la esperanza de vida que esto conlleva (Crimmins, 2015), sumado al descenso de la tasa de natalidad (Vollset et al., 2020; Gallagher, 2020).

En España se observa una marcada tendencia hacia el envejecimiento de la población, situándose como uno de los países de la Unión Europea con una mayor proporción de habitantes mayores de 80 años. En el año 2020 el porcentaje de ciudadanos españoles mayores de 65 años ya había alcanzado el 22.9% (Conde-Ruiz y González, 2021) y la esperanza de vida al nacer llegó a los 82.3 años, 9.5 años por encima de la esperanza de vida media a escala mundial (Instituto Nacional de Estadística, INE, 2022).

El incremento de la población mayor y el aumento de la esperanza de vida se asocian con una mayor aparición de diversas afecciones médicas que pueden contribuir a la pérdida de autonomía funcional, como las enfermedades degenerativas (Beard et al., 2016). Estas enfermedades requieren atención y cuidados continuos durante un prologado periodo de tiempo, para que los afectados puedan enfrentar las actividades diarias (Meinow et al., 2020). Este escenario es más común en la población de mayor edad (80 años o más). De entre las diferentes afecciones de la salud ligadas al envejecimiento, la presente tesis doctoral se centra en el estudio del cuidado de las personas con demencia.

2.2. Prevalencia de las demencias

Las demencias, definidas como un conjunto de afecciones neurológicas que afectan de manera negativa a la función cognitiva, funcional y afectiva de las personas que la sufren y a la capacidad de llevar a cabo actividades de la vida diaria, es considerada actualmente la séptima causa de muerte a nivel mundial y una de las principales causas de dependencia y discapacidad de la población (Alzheimer's Association, 2023). Dentro de las demencias, la enfermedad de Alzheimer es la más común (entre el 50% y 70% de los casos de demencia). Se trata de una enfermedad crónica neurodegenerativa de la que no se conoce cura y que suele presentarse en personas con edades de 60 años o más. A medida que progresa la enfermedad, al igual que ocurre con otras demencias, el deterioro cognitivo aumenta, generándose dificultades en diferentes áreas cognitivas como la memoria, la resolución de problemas y el lenguaje, entre otras, lo que conlleva un profundo impacto a nivel personal, social y económico (Alzheimer's Association, 2023). La esperanza de vida media en Europa tras el diagnostico de

Alzheimer oscila entre los 6 y 7 años, pudiendo llegar a alcanzar los 10 años o más cuando la persona diagnosticada tiene unos 70 años (Alzheimer's Association, 2022). En España, las tasas de prevalencia de las demencias oscilan entre 4.3% y el 17.2%, encontrándose las cifras más altas en población mayor de 70 años. La enfermedad de Alzheimer representa entre el 60% y el 80% de las demencias diagnosticadas en nuestro país (Galende et al., 2021).

Es común que las personas con demencia experimenten cambios en el estado de ánimo, la personalidad y el comportamiento, afectando tanto a su calidad de vida como a la de sus familias. Además, las demencias suponen una carga económica importante que va aumentando a medida que la enfermedad avanza. Según los datos recogidos por el Institute Health Metrics and Evaluation (IHME), en el año 2017, alrededor de 50 millones de personas vivían con demencia en el mundo, y se estima que para el 2050 esta cifra se triplique (Gong et al., 2023). El coste económico que esto supone a nivel mundial ha alcanzado los 818 mil millones de dólares en los últimos años (Wimo et al., 2023). En España, en particular, superó los 16.000 millones de euros, representando aproximadamente el 15% del gasto sanitario total (Galende et al., 2021).

2.3. Características del cuidado familiar

Con respecto al cuidado de las personas con demencia, un alto porcentaje es llevado a cabo por las familias en el hogar, siendo en España alrededor del 80% de los casos. Este tipo de cuidado es ofrecido por familiares o amigos de forma no remunerada (Durante et al., 2022). Concretamente, el cuidado de las personas con demencia tiende a recaer en una única persona, generalmente un miembro de la familia nuclear (cónyuge o hijos), que desempeña el role de cuidador principal. Suele ser asumido por las mujeres, especialmente por las hijas y esposas (Collins & Kishita, 2020; Rexhaj et al., 2023).

Los cuidadores familiares se encargan de atender las necesidades de la persona enferma y de hacer frente a la mayoría de los gastos que esto conlleva. A lo largo de la enfermedad, las personas con demencia van experimentando un incremento en sus niveles de dependencia, manifestando cada vez mayores dificultades en la realización de diferentes actividades de la vida diaria, entre las que se incluyen: el manejo de las finanzas, las tareas de la casa, la medicación, el aseo personal y la alimentación (Grant y Graven, 2018). Además, los cuidadores familiares deben lidiar con la aparición de los síntomas conductuales y psicológicos de la demencia (BPSD), como agitación, agresión, trastorno del sueño y desinhibición, entre otros. Si bien estos síntomas pueden ocurrir con menos frecuencia que los problemas relacionados con la cognición, son considerados como una de las principales causas de sobrecarga y malestar emocional asociadas al cuidado (Chunga et al., 2021; Kim et al., 2021).

Por ello, los familiares cuidadores deben afrontar diferentes retos relacionados con el mantenimiento de la salud física, psicología, social y financiera de la persona cuidada, recibiendo insuficiente apoyo para ello y contando con escaso conocimiento con relación al cuidado de personas con demencia (Holt Clemmensen et al., 2021). De esta manera, el número de horas dedicadas al cuidado también se incrementa a medida que la enfermedad avanza, siendo la media 2,4 horas diarias en los niveles de deterioro iniciales o leves, 8 horas para los niveles medios o moderados y llegando a las 24 horas diarias para los niveles altos o severos de deterioro (Reina et al., 2019). Por tanto, se estima que los cuidadores dedican una media de 30h semanales a las tareas del cuidado a lo largo de la enfermedad (Alzheimer´s Association, 2023).

Actualmente, en España, a diferencia de la tendencia a una distribución más igualitaria en relación con las responsabilidades del cuidado entre hombres y mujeres en los países del norte de Europa (Hajek & König, 2018), el cuidado de un familiar con demencia sigue recayendo principalmente en las mujeres. España es un país mediterráneo en el que la atribución del cuidado de manera tradicional al rol de género femenino sigue estando muy presente (Herlofson & Brandt, 2020). Por ello, el cuidado familiar de familiares de personas con demencia en nuestro país es llevado a cabo principalmente por esposas y, en mayor medida, por hijas con edades comprendidas entre 50 y 60 años que toman el rol de cuidadora principal (López-Cerdá et al., 2019).

Además, la literatura sugiere que las mujeres cuidadoras se involucran en mayor medida, en comparación con los hombres, en la realización de tareas relacionadas con la higiene del familiar cuidado y la administración de la medicación durante la noche (Martínez-Santos et al., 2021). De esta manera, se enfrentan a un mayor número de demandas del cuidado, invirtiendo una mayor cantidad de tiempo (Sharma et al., 2016).

2.4. Consecuencias del cuidado familiar

El aumento de la esperanza de vida, junto con el creciente nivel de dependencia funcional en personas con demencia y el significativo porcentaje de cuidado familiar en el hogar, lleva a que los cuidadores familiares perciban que ofrecen cuidados las 24 horas del día (Goodhart & Pradhan, 2020). El cuidado de un familiar con demencia es una tarea compleja, altamente exigente e impredecible, que se lleva a cabo durante un periodo de tiempo prolongado (Alzheimer´s Association, 2023), que puede conllevar la aparición de consecuencias negativas tanto en la salud física (hipertensión, enfermedades cardiovasculares, deterioro del sistema inmune, etc.; Vara-García et al., 2022) como mental (estrés, depresión, ansiedad, etc.; Frías et al., 2020) de la persona cuidadora, especialmente en las mujeres cuidadoras (Erol et al., 2016; Walter & Pinquart, 2020). Además, la literatura sugiere un mayor número de consecuencias negativas en los cuidadores de familiares con demencia en comparación con la población general (D'Aoust et al., 2015) y con la población cuidadora de otros tipos de enfermedad (Collins & Kishita, 2020; Pinquart & Sörensen, 2003).

El cuidado de un familiar con demencia también puede estar asociado, según la literatura previa, con consecuencias positivas para las personas cuidadoras, pudiendo percibirse así el rol de cuidador como inspirador, enriquecedor o gratificante y actuando como factores protectores de la satisfacción vital y la calidad de vida de los cuidadores (Johansson et al., 2022). Wang et al., (2022) realizaron una revisión de diferentes investigaciones acerca de los aspectos positivos del cuidado e identificaron cuatro dimensiones que englobaban los principales aspectos positivos manifestados por los cuidadores. Dichas dimensiones hacen referencia al aumento de la sensación de logro y la gratificación, de la cohesión y funcionamiento familiar, del crecimiento personal otorgando un propósito en la vida y de los sentimientos de reciprocidad en la relación cuidador-persona cuidada.

No obstante, dado el efecto en la salud que el malestar emocional del cuidador puede tener tanto en la persona que cuida como en el propio cuidador, esta tesis doctoral se enfoca en investigar las implicaciones adversas del cuidado para la salud mental de los cuidadores.

2.4.1. Consecuencias psicológicas del cuidado familiar

Si bien las consecuencias psicológicas del cuidado en los familiares de personas con demencia son numerosas, la presente tesis doctoral centra su atención en algunas de las que se observan con mayor frecuencia en las personas que cuidan.

En primer lugar, la depresión, ampliamente estudiada por la literatura debido a su impacto severo en el bienestar personal, familiar y laboral, constituye una de las principales causas de discapacidad a nivel mundial según la Organización Mundial de la Salud (GBD 2017; Disease and Injury Incidence and Prevalence Collaborators, 2018). Su prevalencia entre los cuidadores de personas con demencia supera a la de la población general (Chamberlain et al., 2023), afectando al menos a uno de cada tres cuidadores, con tasas de prevalencia que varían entre el 30% y el 83% (Huang, 2022; Kaddour y Kishita, 2020).

La sintomatología depresiva, que hace referencia a un conjunto de síntomas asociados con la presencia de afecto negativo (tristeza y anhedonia), baja activación conductual y pensamientos desadaptativos, parece afectar a más del 50% de los cuidadores (Liu et al., 2017). Esta sintomatología se asocia con la reducción de la calidad de vida, el incremento de consecuencias negativas en la salud física y el aumento del riesgo de suicidio, entre otras, observándose en los sistemas de atención médica una asociación notable entre la depresión de las personas cuidadoras y un mayor uso de los servicios de urgencias (Huang, 2022). Además, la presencia de depresión en la persona cuidadora se ha relacionado con un deterioro cognitivo más acelerado en el familiar enfermo (Norton et al., 2013).

La ansiedad, otra consecuencia psicológica destacada entre las personas cuidadoras, se caracteriza por la presencia de síntomas emocionales y somáticos, como la preocupación, el miedo y la tensión muscular. A menudo, la presencia de sintomatología ansiosa ha sido pasada por alto en la literatura sobre personas cuidadoras (Collins y Kishita, 2020). Sin embargo, se estima que la prevalencia de la ansiedad en esta población es similar a la de la depresión, alrededor del 32.1% (Kaddour y Kishita, 2020), considerablemente mayor que en los cuidadores familiares de otras enfermedades como los accidentes cerebrovasculares (Loh et al., 2017) y que en la población general que no desempeña labores de cuidado (Charlson et al., 2019). Además, según el metaanálisis realizado por Kaddour y Kishita (2020), aproximadamente el 42.6% de la población cuidadora presenta una sintomatología ansiosa clínicamente significativa.

Por último, los sentimientos de culpa y de soledad, si bien no han recibido tanta atención en la literatura previa, presentan una alta prevalencia en los familiares cuidadores (Kovaleva et al., 2018). Ambos sentimientos generan también un impacto negativo la salud mental de los familiares cuidadores de personas con demencia, estando asociados con mayores niveles de sufrimiento (Losada et al., 2018). La culpa ha sido definida como la sensación negativa experimentada tras la transgresión de un valor o una norma social importante (Gonyea et al., 2008; Gallego-Alberto et al., 2022). Se trata de una emoción incapacitante que se presenta de manera frecuente en la población cuidadora y que contribuye significativamente a la explicación del malestar emocional de los cuidadores (Losada et al., 2018). Recientemente, Prunty y Foli (2019) han identificado tres factores clave que contribuyen en la aparición del sentimiento de culpa: (a) creencias sobre el grado de responsabilidad u obligación para con su familiar cuidado; (b) una percepción negativa respecto a las acciones propias como cuidador asociado a la creencia de que se está actuando en detrimento del familiar cuidado y (c) percepciones de descuido hacia uno mismo u otras áreas debido al esfuerzo dedicado al cuidado.

Por otro lado, el sentimiento de soledad, definido como una experiencia negativa que ocurre cuando la red de apoyo social de una persona es insuficiente en términos de cantidad o calidad (Perlman y Peplau, 1981), puede afectar de manera negativa a procesos cognitivos como la memoria, la atención o el razonamiento lógico de la persona que la sufre. A nivel emocional, se manifiesta en forma de desesperación, sintomatología depresiva, aburrimiento y autodesprecio (Vasileiou et al., 2017) y, a nivel social, reduciendo la efectividad en la interacción interpersonal en comparación con la población que no presenta niveles de soledad significativos (Heinrich y Gullone, 2006). Los cuidadores familiares tienden a experimentar una disminución gradual del apoyo social a medida que progresa la enfermedad, ya que tienden a dedicarse completamente al cuidado del familiar enfermo a medida que aumenta la dependencia funcional (Nemcikova et al., 2023). Por consiguiente, varios estudios han identificado el sentimiento de soledad como un componente fundamental en la experiencia del cuidado, con niveles más altos que los observados en la población que no desempeña roles de cuidado (Beeson, 2003; Kovaleva et al., 2018).

2.4.2. Consecuencias psicológicas del cuidado familiar en función del género y el parentesco

Según la literatura previa, las mujeres cuidadoras son más vulnerables a sufrir consecuencias emocionales negativas derivadas del cuidado de un familiar con demencia (Erol et al., 2016; Losada et al., 2023). Estudios previos ponen de manifiesto una mayor prevalencia de sintomatología depresiva (Collins y Kishita, 2020, de estrés y ansiedad (Xiong et al., 2020), de culpa (Losada et al., 2010) y de soledad (Ekwall et al., 2005). Una de las principales razones que explican un mayor riesgo a experimentar mayores consecuencias psicológicas por parte de las mujeres es la anteriormente mencionada atribución tradicional de la tarea del cuidado al rol de género femenino. Esta atribución del cuidado lleva a las mujeres a involucrarse en mayor medida en el cuidado, dedicando más tiempo y enfrentando mayores demandas, lo que aumenta sus probabilidades de presentar consecuencias psicológicas negativas (Bartlett et al., 2018; Sharma et al., 2016). Además, el género de la persona cuidadora se ha relacionado con el funcionamiento familiar, ya que las expectativas sociales tienden a situar a las mujeres en el rol de cuidadoras principales, por lo que se les brinda una menor asistencia y apoyo social en comparación con los hombres cuidadores (Akpınar et al., 2011; Sharma et al., 2016)

La relación de parentesco con la persona cuidada también juega un papel relevante en el malestar emocional de los familiares cuidadores, siendo las hijas cuidadoras quienes presentan una especial vulnerabilidad a presentar problemas de salud mental (Martín-María et al., 2022; Watson et al., 2019). Según los resultados obtenidos por estudios como el de Tavero et al. (2018), las hijas cuidadoras manifiestan autoevaluaciones más negativas con relación a la salud física, psicológica y social, lo que genera un gran impacto en su calidad de vida. La atribución del cuidado a las mujeres, sumada a la multiplicidad de roles que desempeñan las hijas cuidadoras (trabajadoras, madres, esposas, hijas, etc.), puede generar en las hijas un mayor riesgo de sufrir problemas de salud mental que los cónyuges o hijos cuidadores (Losada et al., 2010; Romero-Moreno et al., 2014). En concreto, la literatura señala mayores niveles de malestar emocional en las hijas, incluyendo síntomas depresivos y ansiosos, así como sentimientos de culpa y de soledad (Erol et al., 2016; Losada et al., 2010; Stefani et al., 2003). Asimismo, los cónyuges tienden a manifestar niveles más altos de satisfacción vital y a percibir una mejor calidad de vida del familiar cuidado en comparación con los cuidadores hijos/as adultos (Anderson et al., 2013). Sin embargo, los cónyuges informan niveles superiores de impacto emocional cuando el familiar cuidado es trasladado a una residencia de mayores (Rigby et al., 2019).

2.5. Marco teórico: el cuidado como un proceso de estrés

2.5.1. Modelo de estrés y afrontamiento de Lazarus y Folkman (1984)

Debido a que las demencias conllevan un deterioro progresivo de las capacidades cognitivas, funcionales y conductuales de la persona que la sufre, las personas cuidadoras deben ir adaptándose a medida que avanza la enfermedad a diferentes niveles de asistencia y cuidado a la persona enferma. Es por ello que el cuidado de un familiar con demencia es considerado un estresor crónico, pues implica una serie de demandas cambiantes y de manera constante durante un largo periodo de tiempo, muchas horas al día (Knight y Sayegh, 2010; Schulz et al., 2020).

Diferentes modelos teóricos han tratado de ofrecer una explicación a la presencia de malestar emocional en las personas cuidadoras, siendo quizá el que más respaldo empírico ha recibido el modelo de estrés y afrontamiento propuesto por Lazarus y Folkman (1984), adaptado al cuidado. Según este modelo, las consecuencias del estrés asociado al cuidado no dependen únicamente de las fuentes del estrés a las que debe enfrentarse un individuo, sino que también dependen de la interacción de este con la situación estresante, específicamente, de cómo evalúe la situación y de qué recursos (externos e internos) disponga. Es decir, las consecuencias del estrés asociado al cuidado se verán también influidas por la evaluación que la persona hace sobre la situación estresante y de los recursos personales y sociales de los que dispone, tratándose así de un enfoque transaccional del estrés y afrontamiento. Esto es, las personas realizan evaluaciones constantes de los estímulos de su entorno y, cuando estos son percibidos como amenazantes o perjudiciales, se inician diferentes estrategias de afrontamiento en función de los recursos disponibles, con el objetivo de abordar directamente el estresor (afrontamiento centrado en el problema) o de gestionar el malestar emocional generado (afrontamiento centrado en la emoción), u otros (por ej., evitación del problema). El resultado de los procesos de afrontamiento es reevaluado por la persona como favorable, desfavorable o no resuelto, conllevando las dos últimas la presencia de emociones negativas. Por último, la adaptación fallida del individuo al desequilibrio experimentado supone la realización de estrategias de afrontamiento adicionales que, en numerosas ocasiones, van asociadas a un fracaso continuo que provoca la presencia de afecto negativo y puede acarrear la aparición de alteraciones fisiológicas (Biggs et al., 2017).

2.5.2. Modelo sociocultural de estrés y afrontamiento de Aranda y Knight (1997)

Diversos modelos se han sido propuestos específicamente para comprender las consecuencias del cuidado en la salud mental y física de las personas cuidadoras, basándose en el modelo de Lazarus y Folkman (1984). Entre ellos, destaca el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Aranda y Knight ,1997). Este modelo pretende ofrecer un marco conceptual para comprender el proceso de estrés y afrontamiento de las personas cuidadoras de distintas culturas o etnias, haciendo hincapié en la importancia de la cultura en la explicación de las consecuencias del estrés asociado al cuidado. De esta manera, añade un enfoque cultural, considerando la influencia de valores culturales específicos en el proceso de afrontamiento y estrés de las personas cuidadoras y en los resultados en la salud derivados de este.

Generalmente, los modelos de estrés y afrontamiento comparten una serie de categorías de las variables. Por un lado, las *variables contextuales,* entre las que se encuentran la edad, el género, el estatus socioeconómico y la relación de la persona cuidadora y el familiar enfermo, entre otras. Por otro lado, se encuentran las variables denominadas est*resores primarios y secundarias en el cuidador,* que resultan tanto del efecto directo del cuidado de la persona enferma como del impacto que dicha tarea genera en otras áreas de la vida del cuidador, como el trabajo y la familia. También se consideran aquellas *variables relacionadas con la valoración estresante o satisfactoria* de las demandas llevada a cabo persona cuidadora. Por último, se consideran l*as variables potencialmente mediadoras* de la carga del cuidado, como las actitudes, las estrategias de afrontamiento y el apoyo social, y las *variables consecuencias* de las demandas en la salud física y mental y en la calidad de vida de la persona cuidadora (Aranda y Knight, 1997). El modelo sociocultural de estrés y afrontamiento (1997) subraya la influencia de la de la cultura en las diferentes variables del proceso de estrés y afrontamiento mencionadas, conllevando riesgos diferenciales de trastornos de salud específicos en función de la etnia, variaciones en la percepción de los estímulos estresores por parte del cuidador, y diferencias en el carácter mediador del estrés de variables como el apoyo social o el tipo de afrontamiento. Por tanto, ese modelo pretende precisar en mayor medida la teoría existente con respecto a las personas cuidadoras y la metodología utilizada en la evaluación del cuidado en función de diferentes grupos culturales. Concretamente, Aranda y Knight (1997), en relación con las diferencias culturales en el cuidado, enmarcaron los valores culturales en la dimensión individualismo/familismo, resaltando el énfasis del individualismo en la cultura occidental mayoritaria. Este individualismo, según los autores, aumenta la percepción del cuidado como una carga en comparación con las culturas más familistas.

En la década posterior a la propuesta del modelo sociocultural de estrés y afrontamiento (Aranda y Knight, 1997), diferentes autores propusieron la existencia de un modelo central común *(The common core stress and coping model for caregivers*) en la explicación del malestar emocional de los cuidadores (Chun et al., 2007; Kim et al., 2007; Sörensen y Pinquart, 2005). Este modelo común propone un conjunto de variables relacionadas, considerando la presencia de comportamientos problemáticos por parte de la persona enferma como un estresor fundamental para los familiares cuidadores. Además, establece como variable mediadora entre los estresores y las consecuencias en la salud la evaluación de carga realizada por la persona cuidadora, manifestando una asociación significativa entre niveles superiores de la evaluación de carga y peores consecuencias en la salud en el familiar cuidador. Se ha encontrado evidencia a favor de este modelo en poblaciones de diferentes etnias, como afroamericanos, hispanoamericano y coreanomaericanos (Chun et al., 2007; Shurgot y Knight, 2004), así como en la población cuidadora en España (Losada et al., 2006), en Corea y en Canadá (Clyburn et al., 2000).

Por último, Knight y Sayegh (2010) realizaron una revisión del modelo sociocultural de estrés y afrontamiento, con el objetivo de aportar evidencia favorable al modelo central común mencionado y añadir una mayor comprensión de la influencia de las diferencias culturales. Esto es, cómo los valores de cada cultura pueden conllevar variaciones en los diferentes componentes del modelo y en el tipo de afrontamiento del cuidado. En su revisión, los autores cuestionan el carácter protector del familismo en las consecuencias del cuidado, afirmando que la naturaleza de dicho valor es más compleja de lo planteado (Knight y Sayegh, 2010).

El familismo se define como un valor cultural relacionado con la creencia de que los individuos deben ser solidarios y mantenerse leales a los miembros de su familia, mostrando una alta dedicación, reciprocidad y apego hacia los mismos (Heller, 1970; Sabogal et al., 1987) y sacrificando, en caso de ser necesario, el interés individual por el bienestar familiar (Martí & Cid, 2015; Mendez-Luck et al.,2016). En su revisión, Kinght y Sayegh (2010) no encontraron evidencia a favor de la asociación entre el familismo y niveles más bajos de carga del cuidado o menores consecuencias en la salud del cuidador, estudiada en diversos grupos culturales (Chun et al., 2007; Kim et al., 2007). De hecho, los resultados obtenidos por Losada et al. (2006) con población cuidadora en España sugieren una relación positiva entre el valor del familismo y el estado de ánimo deprimido. De esta manera, se trató de explorar la estructura de factores y las propiedades psicométricas de las medidas de evaluación del familismo. Losada et al. (2008) confirmaron la existencia de tres factores o dimensiones en la escala de Sabogal et al. (1987). En primer lugar, la dimensión de Obligaciones Familiares, que hace referencia a la obligación percibida por los individuos de ofrecer ayuda y apoyo, tanto emocional como material, a los miembros de la familia que lo requieran (Gaugler et al., 2009). En según lugar, la dimensión de Apoyo Percibido de la Familia, relacionada con las expectativas culturales presentes en los individuos acerca de la solidaridad de los miembros de la familia en caso de necesidad. Por último, la dimensión Familia como referente, evalúa el grado en que la familia actúa como fuente principal de reglas y orientación acerca de cómo deben los miembros comportarse. Con respecto a estos tres factores, resultados obtenidos en población cuidadora en España (Losada et al., 2010) mostraron un efecto negativo de las obligaciones familiares en el malestar emocional y un efecto positivo del apoyo percibido de la familia en la reducción de dicho malestar. La presencia de obligaciones familiares, además, puede conllevar a la percepción del cuidado como una obligación moral, especialmente en las mujeres (Van der Lippe, y Lippényi, 2020).

En relación con otras poblaciones, la investigación disponible sugiere que el familismo se considera un factor protector contra varios resultados negativos, como el comportamiento de riesgo en jóvenes, problemas emocionales en individuos con enfermedad coronaria y abuso psicológico en adultos mayores (Fang et al., 2019; Wheeler et al., 2017). Sin embargo, investigaciones recientes, como el metaanálisis realizado por Tian et al. (2022), han proporcionado evidencia consistente al cuestionamiento de la función protectora del familismo en la salud mental de los cuidadores familiares de personas con demencia, especialmente al considerar la dimensión de las obligaciones familiares. Estos estudios sugieren que niveles más altos de familismo están relacionados con un mayor malestar emocional en los familiares cuidadores (Parveen et al., 2013; Losada et al., 2010). Este fenómeno se atribuye principalmente a los sentimientos de obligación derivados del valor del familismo en el cumplimiento de los deberes del cuidado. En otras palabras, cuando los cuidadores familiares se sienten incapaces de cumplir con las obligaciones familiares, pueden desencadenar consecuencias emocionales como la depresión y la ansiedad (Falzarano et al., 2022). Además, los valores culturales, como es el caso del familismo, pueden influir en los sistemas de creencias de los cuidadores, lo que potencialmente contribuye al desarrollo de modelos cognitivos desadaptativos y diversas consecuencias emocionales (Tian et al., 2022).

Los hallazgos obtenidos de la revisión del modelo sociocultural de estrés y afrontamiento resaltan la importancia de examinar diversas dimensiones del familismo, en especial las obligaciones familiares, para obtener una mayor comprensión de las disparidades culturales en los efectos de salud relacionados con el cuidado (Knight y Sayegh, 2010). Por lo tanto, la presente tesis doctoral tendrá como una de las variables principales de estudio las obligaciones familiares, enmarcadas dentro del modelo sociocultural de estrés y afrontamiento.

2.5.3 Dimensiones del modelo sociocultural de estrés y afrontamiento

A continuación, se describirán diferentes variables enmarcadas dentro de las dimensiones que componen el modelo sociocultural de estrés y afrontamiento mencionadas anteriormente, con el objetivo de permitir una mejor comprensión del enfoque y el estudio de las variables seleccionadas en la presente tesis doctoral.

a) Variables contextuales

Dentro de esta categoría se engloban aquellas variables psicosociales que pueden considerarse predisponentes en el proceso de estrés asociado al cuidado. Por un lado, en relación con el contexto cultural en el que se enmarca el cuidado se encontrarían las variables del familismo, y el sesgo de deseabilidad social. Por otro lado, se encontrarían variables psicológicas como la presencia de pensamientos disfuncionales y variables sociodemográficas como la edad y el género del cuidador, la relación de parentesco entre la persona cuidadora y el familiar enfermo, tener un trabajo remunerado fuera de casa, vivir con los hijos y vivir con la persona cuidada.

En relación con el contexto cultural, *el familismo*, como se ha mencionado anteriormente, se refiere a la creencia de los individuos de mantense leales y solidarios a la familia. Este valor está más presente en unas culturas que en otras. Dentro del contexto europeo, el familismo es un valor predominante en las sociedades mediterráneas, como es el caso de España (Uccheddu et al., 2019). Una alta presencia de este valor, en concreto de la dimensión de obligaciones familiares, puede conllevar la combinación del cuidado con el sentimiento de obligación, dado que cuidar a un familiar enfermo no solo requiere de solidaridad o afecto familiar, sino que también del cumplimiento de una responsabilidad o deber (Tian et al., 2022). Si bien son escasos los estudios que han analizado diferencias en la percepción de obligaciones familiares, son las mujeres quienes parecen presentar mayores niveles de obligaciones familiares (Barigozzi et al., 2020. La atribución tradicional del cuidado al role de género femenino lleva a las mujeres a internalizar en mayor medida el cuidado de un familiar enfermo como una obligación moral, lo que parece tener un efecto impacto negativo significativo en el malestar emocional de la persona cuidadora, pues se asocia con la presencia *de pensamientos disfuncionales asociados al cuidado*. Esto es, de acuerdo con lo planteado por el modelo cognitivo asociado al cuidado, la cultura influye en como el cuidado es percibido y manejado (Losada et al., 2006).

La presencia de obligaciones familiares puede llevar a las personas cuidadoras a presentar pensamientos relacionados con la percepción del cuidado como un deber que debe ser desempeñado por la persona más cercana. De esta manera pueden aparecer pensamientos relacionados con la reticencia a recibir ayuda por parte del cuidador principal y con la dedicación plena al cuidado del familiar enfermo (ej: “Solo la persona más cercana sabe cómo cuidar bien a un familiar enfermo”; “un cuidador únicamente debe pedir ayuda a otras personas cuando la situación sea límite”; “cuando una persona cuida de un familiar enfermo, debe dejar sus intereses a un lado y dedicarse por completo a la persona enferma”). Estos pensamientos pueden derivar en el uso de estrategias de afrontamiento desadaptativas por parte de la persona cuidadora (disminución del autocuidado, de la petición de ayuda y de las actividades de ocio), asociándose con consecuencias negativas para su malestar emocional (Kwon et al., 2017; Márquez-González et al., 2007).

Otra variable cultural que podría estar relacionada con el familismo y que influye en la expresión emocional de las personas cuidadoras es el s*esgo de la deseabilidad social*. Este se define como la tendencia de los sujetos a negar comportamientos que no son socialmente aceptados y aceptar únicamente aquellos que si lo son (Dunn y Shome, 2009; Furnham, 1986; Tyson, 1992). De esta manera, los individuos manifiestan respuestas que creen ser socialmente esperadas en vez de informar de sus sentimientos reales (Holtgraves, 2004), lo que puede ocultar, moderar o generar relaciones entre variables (Randall et al., 1993). Sin embargo, la influencia del sesgo de deseabilidad en el ámbito del cuidado y su posible relación con las obligaciones familiares ha sido escasamente estudiado.

En relación con las variables contextuales relacionadas con la persona cuidadora, la edad es una variable de la que se han encontrado resultados contradictorios en la literatura previa. Si bien existen estudios que afirman que los familiares cuidadores con más edad informan de mayores niveles de carga asociada al cuidado (Tsai et al., 2021), otros autores informan de lo contrario, afirmando que son los cuidadores con menor edad los que presentan mayores niveles de consecuencias negativas del cuidado (Anderson et al., 2013; Schulz et al., 2020). Con respecto al género y la relación de parentesco de la persona cuidada, como se ha mencionado previamente, las mujeres cuidadoras informan de mayores consecuencias negativas asociadas al cuidado, especialmente las hijas cuidadoras (Losada et al., 2023; Watson et al., 2019). Por último, variables como, vivir con los hijos y vivir con la persona cuidada, pueden conllevar el aumento de la probabilidad de las personas cuidadoras de presentar consecuencias negativas asociadas al cuidado, debido a la multiplicidad de roles que deben desempeñar y la dificultad de encontrar el equilibrio entre las demandas del cuidado y las demandas derivadas de los distintos roles (Gilsenan et al., 2023; Zarit &

Whitlatch, 1992). Lo mismo sucede con la ocupación de un empleo remunerado fuera del hogar. Mientras que el trabajo ofrece un salario y una mayor interacción social, lo que puede proteger contra el aislamiento en los cuidadores (Segel-Karpas et al., 2018), también puede dificultar el equilibrio entre las demandas derivadas de este y las responsabilidades del cuidado, especialmente para las hijas cuidadoras que no reducen su tiempo dedicado al cuidado a pesar de trabajar fuera del hogar (Bédard et al., 2005).

b) Estresores y valoración de la situación

Los síntomas conductuales y psicológicos asociados a las demencias (BPDS) son considerados por la literatura previa uno de los principales estresores en la tarea del cuidado de un familiar enfermo (Kim et al., 2021). Se trata de una gran variedad de reacciones psicológicas, síntomas psiquiátricos y comportamentales que se producen en el contexto del cuidado por parte de las personas que sufren cualquier tipo de demencia, entre los que se encuentran: pérdidas de memoria, agresiones físicas y verbales por parte de la persona cuidada, agitación, hostilidad y deambulación, entre otras (Finkel y Burns, 2000). Este tipo de comportamientos tiene tasas de prevalencia en las personas con demencia de entre el 42% y el 86% (Nogales-González et al., 2015), y dificultan de manera considerable la tarea del cuidado, asociándose con mayores niveles de estrés y malestar psicológico y con la disminución del bienestar subjetivo los familiares cuidadores. Además, la presencia de comportamientos problemáticos afecta también a la calidad de vida del familiar enfermo, conllevando un mayor uso de recursos de atención médica, una disminución en la calidad del cuidado recibido, el ingreso en residencias más temprano y un aumento de la mortalidad (Gimeno et al., 2021; Lochhead et al., 2016).

Otras variables que se consideran estresores del cuidado incluyen la duración del tiempo que el cuidador ha estado proporcionando cuidados al familiar enfermo y la cantidad de horas diarias dedicadas al cuidado. Cuidar a un familiar con demencia se percibe como una fuente de estrés mayor en comparación con el cuidado de personas con otras enfermedades (Pinquart y Soresen, 2003), ya que implica una serie de demandas que requieren de la inversión de una gran cantidad de tiempo. Esto lleva a los cuidadores a reducir o incluso eliminar su tiempo libre, las interacciones con amigos y familiares, las actividades de ocio y su participación en la vida laboral para centrarse exclusivamente en el cuidado del familiar enfermo. Esta situación incrementa la probabilidad de aislamiento social y dificultades para mantener una vida personal, familiar, profesional y social equilibrada, lo que correlaciona con la presencia de problemas de salud mental, entre los que destaca la presencia de sintomatología depresiva (Lindeza et al., 2020), que tienden a empeorar a medida que aumenta el tiempo dedicado al cuidado (Brodaty y Donkin, 2009). Además, llevar más tiempo cuidando de un familiar enfermo implica mayor probabilidad de que la enfermedad este más avanzada y de que el deterioro del familiar sea mayor, lo que hace más probable que el cuidador tenga que lidiar, entre otras cosas, con el hecho de que el familiar cuidado ya no le reconozca, algo que resulta difícil de afrontar y que se asocia con tristeza, frustración y estrés (McCabe et al., 2018).

Por último, el deterioro cognitivo del familiar con demencia hace referencia a los niveles de alteración producidos en diferentes capacidades como la memoria, la función lingüística, la ejecución de la actividad motora, el pensamiento abstracto, el procesamiento de la información y la capacidad de juicio. Este deterioro, que afecta a la capacidad funcional del familiar enfermo, se asocia con una mayor presencia de malestar emocional tanto en la persona cuidadora como en el familiar cuidado. Estudios previos muestran una asociación entre mayores niveles de deterioro y mayor presencia de sintomatología depresiva tanto en la persona cuidadora como en el familiar cuidado (Lu et al., 2007).

c) Recursos

La literatura previa sugiere el carácter mediador o moderador de variables que hacen referencia a recursos internos o externos del cuidador, como el funcionamiento familiar, el apoyo social, el ocio y la evitación experiencial, que juegan un papel destacado en el proceso de estrés asociado al cuidado.

Una de las variables que más apoyo empírico ha recibido es el apoyo social, definido como los recursos sociales que los individuos perciben que otras personas no profesionales (familiares o allegados) del entorno les proporcionan (Dam et al., 2016). Parece desempeñar un papel protector en la carga, el estrés y las consecuencias negativas experimentadas por las personas cuidadoras (Fauth et al., 2012; Shiba et al., 2016). Por el contrario, la insuficiencia o inexistencia de recursos adaptativos internos y externos por parte de los cuidadores frente a las demandas derivadas del cuidado de un familiar con demencia aumentaría los niveles de carga experimentada (Adelman et al., 2014; Kim et al., 2012). Según la hipótesis de amortiguamiento de Cohen y Wills (1985), el apoyo social percibido reduce, o en su defecto, acelera, las consecuencias negativas del estrés en la salud. Por tanto, el nivel de las consecuencias negativas derivadas del cuidado puede diferir en función del apoyo social con el que cuente la persona cuidadora, ya que cuando existe un equilibrio entre los recursos del cuidador y las demandas, los cuidadores pueden experimentar experiencias positivas asociadas a este (Ruisoto et al., 2020).

Otro recurso relevante en el proceso del cuidado es la funcionalidad familiar. Puede entenderse como el tipo de dinámicas y la calidad de las relaciones dentro de una familia, actuando como un factor protector de la salud mental de los cuidadores, previniendo o mitigando su malestar emocional relacionado con el estrés del cuidado (Mitrani et al., 2006). Concretamente, según investigaciones previas, la calidad de las relaciones entre la persona cuidadora y el resto de miembros de la familia puede actuar como un factor de vulnerabilidad o como un factor de protección frente al malestar emocional de los cuidadores (Smith et al., 2022). Se han identificado diferentes factores que conforman dicha variable, entre los que se encuentran la cohesión marital, los patrones de comunicación, y la presencia de conflictos y límites poco difusos entre los miembros de la familia (Mitrani et al., 2006). Una baja cohesión familiar y mala comunicación entre los miembros, la presencia de límites muy rígidos o demasiado permeables y un alto nivel de conflictos familiares se han relacionado con una respuesta menos eficiente la presencia de enfermedades crónicas, como es el caso de las demencias, y con niveles más bajos de salud auto informada de los cuidadores (Strawbridge y Wallhagen, 1991).

Una tercera variable que ha mostrado un papel amortiguador del malestar en el proceso del cuidado son las actividades de ocio, que pueden mitigar el deterioro de la salud mental de las personas cuidadoras (Losada et al., 2010). Según investigaciones previas, el cuidado familiar de personas con demencia se relaciona una menor participación en las actividades de ocio comparada con la participación de personas no cuidadoras (Ho et al., 2014) debido a la priorización del cuidado, lo que aumenta la probabilidad de experimentar consecuencias emocionales negativas (Cuijpers, 2005). Además, patrones de pensamiento disfuncionales relativos a la responsabilidad del cuidado sumado al sentimiento de culpa que pueden experimentar si no atienden lo suficiente al familiar enfermo provoca una menor satisfacción de las actividades de ocio (Romero-Moreno et al., 2014). Esto se ha vinculado con mayores niveles de depresión (Mausbach et al., 2012), ansiedad (Anthony-Bergstone et al.,1988) y menor bienestar subjetivo (Arango-Lasprilla et al., 2010). Las actividades de ocio realizadas junto a otras personas favorecen la provisión de compañía y sentimientos de autodeterminación, lo que las hace especialmente relevantes por su relación con el apoyo social y su efecto protector de los efectos perjudiciales del estrés derivado del cuidado (Schüz et al., 2015). Por tanto, las actividades de ocio son un recurso fundamental en el afrontamiento del estrés de las personas cuidadoras y la reducción o la falta de satisfacción con éstas puede convertirse en un estresor adicional en el proceso del cuidado.

Por último, estudios recientes ponen de manifiesto el papel mediador de estrategias de afrontamiento desadaptativas como la evitación experiencial en la relación entre los estresores del cuidado de personas con demencia y un mayor riesgo de consecuencias negativas en la salud mental de los familiares cuidadores. La evitación experiencial es la tendencia por parte de un individuo a evitar el contacto con pensamientos, emociones e imágenes negativas y los contextos o eventos que provocan su aparición (Hayes et al., 1996), tratando así de controlar de una forma rígida las experiencias internas no deseadas. Elevados niveles de evitación experiencial en las personas cuidadoras se asocian con la aparición de sintomatología depresiva y mayores problemas de salud física (Spira et al., 2007; Márquez-González et al., 2018; Whitebird et al., 2013).

d) Consecuencias del cuidado

En apartados anteriores se ha reflejado que el cuidado familiar de personas con demencia se asocia con numerosas consecuencias negativas tanto físicas como emocionales en las personas cuidadoras. Existe consenso a la hora de asociar el cuidado familiar de personas con demencia con consecuencias negativas para la salud mental (por ej., depresión, ansiedad, culpa y soledad; Losada et al., 2010; Schulz et al., 2020) y física (Mausbach et al., 2007; Roth et al., 2019).

2.6. Líneas futuras de investigación acerca del efecto de las variables socioculturales en la salud mental de los cuidadores de personas con demencia

Si bien en los últimos años ha ido cobrando más relevancia, la investigación acerca de la influencia de las variables socioculturales en la salud mental de los cuidadores continúa siendo escasa y limitada. Actualmente, sigue existiendo discrepancia en relación con el papel de las variables culturales en la carga y el malestar emocional asociado al cuidado (Mora-Castañeda et al., 2020). Si bien el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010) sugiere un impacto indirecto de las variables culturales en la salud física y emocional del cuidador a través de la influencia en los recursos y las estrategias de afrontamiento, existen estudios que defienden la existencia de diferencias significativas en la salud emocional de los cuidadores cuando se compraran diferentes orígenes étnicos y culturales (Arévalo-Flechas et al., 2014; Sousa et al., 2016). Menos estudiado aún ha sido el efecto de dichas variables culturales en función de la relación de parentesco con el familiar cuidado. Por tanto, se proponen diferentes desafíos y necesidades dentro del estudio de la influencia de las variables culturales en el proceso de estrés del cuidado, teniendo en consideración la relación de parentesco. En este contexto, esta tesis doctoral busca arrojar luz sobre estos aspectos, los cuales se describirán a continuación:

En primer lugar, es bien sabido por la literatura previa que el cuidado de un familiar con demencia se asocia con consecuencias negativas tanto físicas como psicológicas en los familiares cuidadores. Con respecto a la salud mental, variables emocionales como el sentimiento de soledad han sido escasamente estudiadas, a pesar de que la literatura disponible sugiere una alta prevalencia entre las personas cuidadoras. Concretamente, los resultados obtenidos por Stefani et al. (2003) mostraron mayores niveles de sentimiento de soledad en las hijas cuidadoras en comparación con los cónyuges cuidadores. Sin embargo, el papel de las variables culturales en la percepción de soledad en las personas cuidadoras en función de la relación de parentesco con el familiar enfermo no ha sido aún estudiada. Esto podría proporcionar información de utilidad para una mayor comprensión de este sentimiento asociado al proceso del cuidado y para que futuras intervenciones tengan en consideración la influencia de aspectos culturales en diferentes grupos de cuidadores.

En segundo lugar, al igual que ocurre con el sentimiento de soledad, la culpa es otra variable de salud mental que apenas ha recibido atención en investigaciones previas, si bien parece generar también altos niveles de sufrimiento en las personas cuidadoras (Losada et al., 2018). Son escasos los estudios que han tratado de analizar las diferencias en el sentimiento de culpa en función del género o la relación de parentesco. Además, la posible asociación entre el familismo y el sesgo de deseabilidad social, debido a la posible necesidad de las personas cuidadoras de ajustarse de manera fiel a lo que se espera socialmente de ellos y a las normas familiares, y su influencia en la manifestación de variables emocionales, no ha sido aún estudiada por las investigaciones previas. Si bien existen estudios que afirman que existe una mayor internalización del valor cultural del familismo en las mujeres (Goodman et al., 1994; Van der Lippe & Lippényi, 2020), no existe literatura disponible acerca de la posible influencia de dichas variables culturales en la manifestación de malestar emocional por parte de las personas cuidadoras en función de la relación de parentesco. Por tanto, analizar la influencia conjunta de las variables culturales del familismo y la deseabilidad social en el proceso de estrés asociado al cuidado, considerando la relación de parentesco con la persona cuidada, podría favorecer una evaluación más precisa y eficaz de los cuidadores y contribuir al diseño de intervenciones psicológicas dirigidas a la población cuidadora.

En tercer lugar, el estudio del malestar emocional asociado al cuidado en función de diferentes perfiles creados a partir de los niveles manifestados tanto en variables psicosociales (por ej., familismo) como en variables de recursos (por ej., apoyo social), considerando la relación de parentesco en las posibles diferencias en la vulnerabilidad de los perfiles obtenidos, podría aportar información relevante acerca de perfiles de vulnerabilidad al malestar emocional asociado al cuidado. Esto podría mejorar la identificación de dichos perfiles y aumentar la eficacia de recursos empleados en las intervenciones en función de la relación de parentesco. De esta manera, se podría recabar información relevante para mejorar la efectividad de las intervenciones dirigidas a la población cuidadora ya que, actualmente, su eficacia es en el mejor de los casos, moderada (Cheng et al., 2020).

Por último, el funcionamiento familiar parece ser un factor relevante en la explicación de la salud mental de las personas cuidadoras (Sutter et al., 2014). Sin embargo, ha sido escasamente estudiado por la literatura científica (Cheng et al., 2019). Existen estudios que defienden el papel fundamental del funcionamiento de la familia en la salud emocional de los cuidadores (Smith et al., 2022) pero su posible carácter protector en función de la relación de parentesco entre la persona cuidada y el familiar enfermo no ha sido analizado aún. Esto podría ofrecer información relevante para la comprensión del malestar emocional de las personas cuidadoras y para la identificación de factores protectores de su salud mental en función de la relación de parentesco, lo que podrá contribuir a aumentar la eficacia de las intervenciones dirigidas a esta población al permitir un mayor enfoque en las dinámicas familiares adaptativas.

2.7. Resumen final

El número de personas mayores dependientes está aumentando debido al envejecimiento de la población, asociado fundamentalmente al incremento de la esperanza de vida y a la reducción de la tasa de natalidad (Ritchie, & Roser, 2023). En el mundo, actualmente, más de 50 millones de personas viven con demencia, y se estima que esta cifra se triplique para el año 2050 (Gong et al., 2023). El cuidado desempeñado por familiares o amigos de manera no remunerada en el hogar es la fuente principal del cuidado de personas con demencia, siendo en España alrededor del 80% de los casos (Durante et al., 2022). El cuidado familiar suele recaer en una única persona que forma parte de la familia más próxima y que suele ser mujer (Collins & Kishita, 2020).

El cuidado de una persona con demencia, debido a la complejidad y exigencia que conlleva, se asocia con la aparición de consecuencias negativas físicas y psicológicas significativas en las personas cuidadoras. Según la literatura previa, los cuidadores familiares de personas con demencia parecen manifestar un mayor número de consecuencias negativas en comparación con población cuidadora de personas que padecen otros tipos de enfermedades (Collins & Kishita, 2020; Pinquart & Sörensen, 2003) y con la población general (D'Aoust et al., 2015). En relación con las consecuencias psicológicas del cuidado, las investigaciones previas han centrado su atención principalmente en la depresión y la ansiedad (Kaddour y Kishita, 2020). Sin embargo, otras variables emocionales menos estudiadas, como el sentimiento de soledad y culpa, parecen ser también relevantes en el sufrimiento emocional de las personas cuidadoras (Losada et al., 2018).

Según lo planteado por el modelo sociocultural de estrés y afrontamiento, las variables culturales cobran especial relevancia en el proceso de estrés asociado al cuidado (Knight y Sayegh, 2010). En concreto, el valor del familismo, altamente presente en sociedades mediterráneas como España (Herlofson & Brandt, 2020), parece ser muy relevante para la comprensión del impacto del cuidado en la salud de los familiares cuidadores. De hecho, los resultados obtenidos por Losada et al. (2006, 2010) con población cuidadora en España sugieren una relación positiva entre el valor del familismo y el estado de ánimo deprimido. Mayores niveles de familismo se asocian con una mayor presencia de pensamientos disfuncionales o desadaptativos, que pueden interferir negativamente en el afrontamiento del cuidado y aumentar los niveles de malestar emocional (Losada et al., 2010). Es decir, estos pensamientos o creencias disfuncionales median entre el estrés y las consecuencias en la salud de la persona cuidadora.

Con respecto al papel de las familias de las personas cuidadoras, existen estudios que sugieren mayores niveles de malestar emocional en cuidadores de familias con niveles más bajos de funcionalidad familiar (Peñaranda et al., 2009). Además, la variable parentesco con la persona cuidada parece influir también significativamente en el impacto del estrés asociado al cuidado, existiendo trabajos que sugieren que especialmente las hijas cuidadoras pueden ser más vulnerables a los efectos del cuidado (Pinquart y Sörensen, 2006). Por tanto, y en consonancia con el modelo cognitivo adaptado al cuidado (Losada et al., 2006), la cultura de pertenencia y los valores socioculturales parecen influir de forma relevante en la forma de pensar, afrontar y sentir el cuidado por parte de las personas cuidadoras.

Son escasos los estudios enfocados al análisis conjunto de los efectos de variables culturales y psicológicas en el estudio de las consecuencias emocionales de las personas cuidadoras. La presente tesis doctoral pretende profundizar en la comprensión de los efectos de variables socioculturales y psicológicas, y la relación de parentesco con la persona cuidada en el malestar emocional de los cuidadores familiares de personas con demencia. Para ello, se realizarán cuatro estudios que emplean diferentes diseños y metodologías.

3. Objetivos e Hipótesis

La presente tesis doctoral tiene como objetivo principal avanzar en el estudio del impacto de aspectos socioculturales y psicológicos en el malestar emocional de los cuidadores familiares de personas con demencia. En concreto, el análisis de variables psicosociales como el valor del familismo y la presencia de pensamientos disfuncionales será fundamental en el estudio y explicación de consecuencias psicológicas negativas asociadas al cuidado (soledad, depresión, ansiedad y culpa). Además, la presente tesis analizará lo anterior centrándose en la relación de parentesco con la persona cuidada con el objetivo de analizar el posible impacto diferencial de variables psicosociales sobre el malestar en función del parentesco, y comprender en mayor medida las necesidades y vulnerabilidades de cada grupo de parentesco. Para ello, siguiendo un diseño transversal, se han realizado cuatro estudios independientes entre sí que siguen una misma línea de investigación, cuyos objetivos específicos e hipótesis planteadas serán descritas a continuación.

3.1. Objetivos e hipótesis específicos

A continuación, se describirán los objetivos específicos de cada uno de los estudios que componen la presente tesis doctoral:

3.1.1. Estudio uno: Sociocultural Influences on the Feeling of Loneliness of Family Caregivers of People with Dementia: The Role of Kinship

Este primer estudio está publicado en la revista *International Journal of Environmental Research and Public Health* **(**IJERPH) como parte del número especial Salud mental, envejecimiento y género (JCR- Q1: Factor de impacto 2.849) en el año 2021.

a) Objetivo general

Analizar el grado en el que el valor del familismo, la presencia de pensamientos disfuncionales y variables de afrontamiento contribuyen en la explicación del sentimiento de soledad en las personas cuidadoras, en función de la relación de parentesco con el familiar cuidado.

b) Objetivos específicos

1) Evaluar el grado en el que la soledad percibida está presente en las personas cuidadoras y analizar posibles diferencias en la percepción de dicho sentimiento en función de la relación de parentesco con la persona cuidada.
2) Evaluar el ajuste y adecuación de un modelo teórico propuesto en función del parentesco, analizando el grado en el que el valor cultural del familismo (dimensión obligaciones familiares) se asocia con los pensamientos disfuncionales asociados al cuidado y con diferentes estrategias de afrontamiento como la solicitud y recepción de ayuda, la percepción de apoyo social y la participación en actividades de ocio.
3) Analizar el grado en el que dichas asociaciones contribuyen en la explicación del sentimiento de soledad percibido en las personas cuidadoras en función del parentesco.

c) Hipótesis

H1: Se esperaba encontrar que un porcentaje significativo de familiares cuidadores informase de sentimientos de soledad, especialmente en las mujeres cuidadoras. Más concretamente, se esperaba que las hijas cuidadoras manifestasen mayores niveles de sentimiento de soledad en comparación con los otros grupos de parentesco (esposas, esposos e hijos).

H2: Se anticipaba una asociación positiva entre la presencia del valor cultural del familismo y los pensamientos disfuncionales asociados al cuidado, lo que conllevarían la realización de estrategias de afrontamiento perjudiciales para la persona cuidadora, como solicitar y recibir menos ayuda. Esto, a su vez, se relacionaría con una menor percepción de apoyo social y con una menor participación en actividades de ocio.

H3: Se preveía que una mayor realización de dichas estrategias de afrontamiento perjudiciales conllevaría mayores niveles de sentimiento de soledad percibido en las personas cuidadoras. Además, debido a la atribución tradicional del cuidado al rol de género femenino, se esperaba que las consecuencias en los niveles de solead percibidos por las hijas cuidadoras fueran especialmente significativos, ya que están expuestas a un mayor conflicto de roles.

3.1.2. Estudio dos: Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences

Este segundo estudio se ha publicado en la revista *Aging & Mental Health* (JCR-Q2: Factor de impacto 3.658) en el año 2022.

a) Objetivo general

El objetivo principal del estudio fue analizar el papel de variables socioculturales como el familismo (dimensión obligaciones familiares) y el sesgo de deseabilidad social en la explicación de la sintomatología de culpa y depresiva de los cuidadores familiares de personas con demencia. Además, se trató de estudiar el efecto de dichas variables socioculturales en función de la relación de parentesco con la persona cuidada.

b) Objetivos específicos

1) Analizar el ajuste de un modelo teórico propuesto acerca de la asociación entre las obligaciones familiares y el sesgo de deseabilidad social en la presencia de pensamientos

disfuncionales y en el informe de la reacción a comportamientos problemáticos realizados por el familiar con demencia.

2) Estudiar el grado en que dichas asociaciones contribuyen en la explicación de la sintomatología de culpa y depresión en las personas cuidadoras.
3) Identificar posibles diferencias en las asociaciones planteadas en función de la relación de parentesco con la persona cuidada.

c) Hipótesis

H1: se esperaba que puntuaciones más altas en obligaciones familiares y en deseabilidad social se asociarían con una mayor presencia de pensamientos disfuncionales asociados al cuidado, lo que conllevaría mayores niveles de sintomatología depresiva

H2: Se anticipaba, además, que mayores niveles de deseabilidad social implicarían un menor informe de malestar emocional asociado al cuidado, es decir, menores niveles manifestados de reacción a comportamientos problemáticos mostrados por el familiar enfermo, de sentimientos de culpa y de sintomatología depresiva.

H3: Se esperaban diferencias basadas en la relación de parentesco con la persona cuidada en las asociaciones propuestas en el modelo. Es decir, se preveía que las esposas e hijas cuidadoras presentarían una mayor influencia de las variables socioculturales mencionadas (obligaciones familiares y sesgo de deseabilidad social) en la explicación de la sintomatología de culpa y depresión en comparación con los esposos y los hijos. Además, teniendo en cuenta la existencia de efectos indirectos señalados en la literatura científica del familismo sobre variables emocionales como la depresión, se esperaba encontrar efectos indirectos significativos entre las variables socioculturales del modelo y los niveles de culpa y/o sintomatología depresiva.

3.1.3. Estudio tres: Profiles of dementia caregivers according to psychosocial and resource variables. Importance of kinship.

El tercer estudio ha sido aceptado para publicar en la revista *Spanish Journal of Psychology* (JCR-Q3: Factor de impacto 2.30) en el año 2024.

a) Objetivo general

El objetivo general del estudio fue identificar diferentes perfiles de cuidadores familiares de personas con demencia en función de los niveles manifestados en distintas variables psicosociales (familismo (dimensión obligaciones familiares), pensamientos disfuncionales asociados al cuidado y evitación experiencial) y de recursos (apoyo social percibido y realización de actividades de ocio). Además, se pretendía estudiar si cada perfil identificado contaba con una mayor representación de cada grupo de parentesco y analizar posibles diferencias entre los perfiles en los niveles de malestar emocional manifestado por las personas cuidadoras.

b) Objetivos específicos

1) Estudiar la existencia de diferentes perfiles de familiares cuidadores de personas con demencia en función de los niveles manifestados en variables psicosociales y de recursos.
2) Analizar si existen diferencias entre los perfiles en los niveles manifestados de sintomatología depresiva, ansiosa y de culpa en función de los niveles obtenidos en las distintas variables.
3) Evaluar si los grupos de parentesco se distribuyen de forma diferencial en función de los perfiles encontrados.

c) Hipótesis

H1: Se esperaba encontrar diferentes perfiles según la combinación de niveles altos o bajos en las variables psicosociales y de niveles altos o bajos de las variables de recursos.

H2: Se planteaba que aquellos perfiles caracterizados por niveles altos de familismo (obligaciones familiares), pensamientos disfuncionales y evitación experiencial (lo que se consideró como vulnerabilidad psicosocial), y por niveles bajos de apoyo social y actividades de ocio (considerados como niveles bajos de recursos), informarían de mayores niveles de sintomatología depresiva, ansiosa y de culpa.

H3: Por el contrario, se esperaba que aquellos perfiles caracterizados por niveles bajos de familismo (obligaciones familiares), pensamientos disfuncionales y evitación experiencial (lo que se consideró como baja vulnerabilidad psicosocial) y por altos niveles de apoyo social y actividades de ocio, manifestarían niveles más bajos en de sintomatología depresiva, ansiosa y de culpa.

H4: Se esperaba que aquellos perfiles con niveles más altos de malestar emocional informado (mayores niveles de sintomatología depresiva, ansiosa y de culpa) estarían representados mayoritariamente por los grupos de parentesco de esposas e hijas. Concretamente, se plantaba que el perfil identificado con mayores niveles de las sintomatologías mencionadas contará con una mayor presencia de hijas cuidadoras.

3.1.4. Estudio cuatro: Moderating effect of family function on the relationship between dysfunctional thoughts associated with caregiving and anxious and depressive symptoms. Importance of kinship

El cuarto estudio está en proceso de revisión para su potencial publicación en una revista científica con impacto JCR.

a) Objetivo general

El presente estudio tuvo como objetivo principal examinar el papel de los pensamientos disfuncionales en la comprensión de la sintomatología depresiva y ansiosa y explorar el posible efecto moderador de la función familiar en la relación entre los pensamientos disfuncionales y dichas sintomatologías. Además, se pretendió estudiar la existencia de posibles diferencias en las asociaciones obtenida en función de la relación de parentesco con la persona cuidada.

b) Objetivos específicos

1) Estudiar la influencia de los pensamientos disfuncionales y el funcionamiento familiar en la explicación de la sintomatología depresiva y ansiosa de las personas cuidadoras.
2) Analizar el posible efecto moderador de la función familiar en la relación entre los pensamientos disfuncionales y los niveles manifestados por las personas cuidadoras en ambas sintomatologías.
3) Evaluar posibles diferencias en las asociaciones obtenidas considerando la relación de parentesco entre la persona cuidadora y el familiar enfermo.

c) Hipótesis

H1: Se esperaba que la inclusión de las variables propuestas contribuiría significativamente al modelo probado en la explicación del malestar emocional de los familiares cuidadores (sintomatología depresiva y ansiosa).

H2: Se anticipó que la presencia de pensamientos disfuncionales se relacionaría con mayores niveles de sintomatología depresiva y ansiosa únicamente para aquellos cuidadores que manifestases niveles bajos de función familiar, debido al conflicto ocasionado entre la manera de pensar de la persona cuidadora y el apoyo recibido por la familia.

H3: Estos resultados serán particularmente relevantes para los grupos de parentesco de esposas e hijas en comparación con los grupos de esposos e hijos, debido a que las mujeres están expuestas en mayor medida a las expectativas culturales en relación a su responsabilidad en el cuidado.

4. Metodología General

La presente tesis doctoral se compone de cuatro estudios independientes que abordan una misma temática de investigación, referida a la importancia de los aspectos socioculturales y los pensamientos disfuncionales asociados al cuidado en la explicación del malestar emocional de las personas cuidadoras de familiares con demencia. Los tres primeros estudios ya han sido publicados en revistas internacionales indexadas en Journal Citation Reports (JCR), como la *International Journal of Environmental Research and Public Health* **(**IJERPH), que se ubicaba en el cuartil Q1 en el año 2021, Aging *& Mental Health,* que se encontraba en el cuartil Q2 en el año 2022, y *Spanish Journal of Psychology*, que se encuentra en el cuartil Q3 en el año 2024. El cuarto artículo está en proceso de revisión para ser publicado en una revista con impacto JCR.

Todos los estudios siguen una estructura similar compuesta por las secciones: Introducción, Método, Resultados, Discusión y Referencias. A lo largo de este capítulo se detallan las características metodológicas compartidas por los estudios, proporcionándose información acerca de los participantes, los procedimientos de muestreo y los instrumentos utilizados para la medición de las distintas variables seleccionadas. Además, se describen los diferentes métodos de análisis de datos llevados a cabo en cada uno de los estudios.

4.1 Participantes y procedimiento

Los cuatro estudios que componen la presente tesis doctoral tienen como objetivo general el estudio del papel de variables psicosociales y la presencia de pensamientos disfuncionales en la comprensión del malestar emocional de familiares cuidadores de personas con demencia. Por tanto, la muestra utilizada en todos los estudios consiste en familiares cuidadores que cumplen una serie de criterios específicos de inclusión, a saber: (1) ser mayor de edad, (2) identificarse como el cuidador principal de un familiar con diagnóstico de demencia o deterioro cognitivo leve, (3) dedicar al menos una hora diaria o siete horas semanales a tareas relacionadas con el cuidado, y (4) llevar al menos tres meses a cargo del cuidado del familiar. El número total de participantes varía entre 273 y 288, en función del estudio específico.

Para el reclutamiento y la selección de los participantes en los cuatro estudios fue fundamental la colaboración de distintos centros de la Comunidad de Madrid, que desempeñaron un papel activo en el contacto con las personas interesadas en la participación en la investigación y en la facilitación de recursos esenciales para poder llevar a cabo los diferentes estudios que componen la tesis doctoral. Se contactó con centros como la Asociación de Familiares de Enfermos de Alzheimer de Madrid Suroeste (AFAMSO), el Ayuntamiento de Madrid (Dirección General de Mayores), Aulas Kalevi, el Servicio de Atención Primaria de Centro Miguel Servet de la Comunidad de Madrid, la Unidad de Memoria de Cantoblanco, la Fundación Cien, el Centro de Salud General Ricardos, el Centro de Salud García Noblejas, el Centro de Salud Benita de Ávila, el Centro de Salud Vicente Muzas, el Centro Reina Sofía de Cruz Roja, el Centro de Psicología Aplicada de la Universidad Autónoma de Madrid y los Servicios Sociales de Getafe. Estos centros, en un primer contacto con las personas interesadas, ofrecían información detallada acerca de los objetivos del estudio y realizaron un contacto inicial de cribado que permitía la confirmación del cumplimiento de los criterios de inclusión mencionados.

Una vez seleccionados los participantes que cumplían los criterios de inclusión, estos fueron invitados a realizar entrevistas individuales de manera presencial por psicólogos entrenados para dicha tarea. De forma previa al inicio de las entrevistas se llevó a cabo la lectura detallada de un consentimiento informado a cada participante, asegurando la plena comprensión de los objetivos y procedimientos involucrados de la investigación. La firma de dicho consentimiento informado aseguró la participación voluntaria de los familiares cuidadores. Las entrevistas abordaron la evaluación de aspectos sobre la salud y bienestar de los cuidadores, en el contexto de su rol de cuidadores de un familiar con demencia. Tuvieron una duración aproximada de 1,5 horas y se realizaron en el centro colaborador correspondiente,

Los cuatro estudios realizados se enmarcan en los proyectos "*Sentimientos de culpa, familismo, motivos para el cuidado y riesgo cardiovascular y mental en cuidadores de personas con demencia: un estudio longitudinal y de intervención*" (PSI2015-65152-C2-1-R) y "*Predictores longitudinales psicosociales de vulnerabilidad y fortaleza psicológica y física en cuidadores familiares de personas con demencia. El papel de la ambivalencia*" (PID2019-106714RB-C21), financiados por el Ministerio de Economía y Competitividad,y el Ministerio de Ciencia e Innovación, respectivamente. Además, todos los estudios cuentan con la aprobación del comité de ética de la Universidad Rey Juan Carlos.

4.2. Variables e instrumentos de evaluación

En esta sección se proporciona una breve descripción de las variables estudiadas y los instrumentos utilizados para su medición en los distintos estudios que componen la Tesis Doctoral. En cada estudio se proporciona información más exhaustiva sobre cada variable evaluada y sobre los datos psicométricos correspondientes a cada escala, y en el Anexo 1 se incluye una copia de los instrumentos utilizados con el objetivo de ofrecer información más detallada. Se presentan las variables organizadas según el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), lo que permite una mayor comprensión de las diferentes dimensiones del proceso de estrés en el contexto del cuidado que se han abordado a lo largo de los distintos estudios que componen la tesis.

4.2.1. Variables sociodemográficas y contextuales

Se recopilaron datos en relación con las características sociodemográficas identificadas como relevantes según el modelo de estrés y afrontamiento adaptado al cuidado propuesto por Knight y Sayegh (2010), tanto de los familiares cuidadores como de las personas cuidadas. Con respecto a las variables sociodemográficas del cuidador, se obtuvieron datos sobre la edad, género, la relación de parentesco con la persona cuidada, tener un trabajo remunerado fuera de casa, vivir con los hijos y vivir con la persona cuidada. Respecto a las variables sociodemográficas de la persona cuidada, se recopiló información acerca de su edad, género y el tipo de diagnóstico de demencia. En relación con las variables contextuales, se recogió información de diferentes variables psicosociales: familismo, deseabilidad social y pensamientos disfuncionales asociados al cuidado.

En primer lugar, el familismo se evaluó mediante el empleo de la subescala correspondiente a la dimensión “obligaciones familiares” de la Escala Revisada de Familismo (RFS por sus siglas en inglés *Revised Familism Scale*; versión en español por Losada et al., 2020). Dicha subescala se compone de 6 ítems (por ej., "la mayoría de lo que hace un hijo o una hija debería hacerse para complacer a sus padres") con un rango de respuesta tipo Likert entre 0 (“totalmente en desacuerdo”) y 4 (“totalmente de acuerdo”).

En segundo lugar, para la evaluación de la presencia de pensamientos disfuncionales se administró el Cuestionario de Pensamientos Disfuncionales sobre el Cuidado (DTCQ por sus siglas en inglés, *Dysfunctional Thoughts about Caregiving Questionnarie*; Losada, 2005), desarrollado en español. Este cuestionario está compuesto por 16 ítems tipo Likert (por ej., "Solo la persona más cercana sabe cómo cuidar realmente bien a su familiar enfermo"), cuyo rango de respuesta oscila entre 0 (totalmente en desacuerdo) y 4 (totalmente de acuerdo).

Por último, el sesgo de deseabilidad social se midió mediante el empleo de la versión breve en español (Ávila y Tomé, 1989) de la Escala de Deseabilidad Social de Marlowe-Crowne (MCSDS por sus siglas en inglés *Marlowe-Crowne Social Desirability Scale*; Crowne y Marlowe, 1960). Esta escala consta de 10 ítems con un rango de respuesta de entre 1 (ítems que la persona considera ciertos) y 0 (ítems que la persona considera falsos). Algunos ejemplos de los ítems serían “Nunca he sentido antipatía por nadie" o "Siempre soy educado”.

4.2.2. Estresores

Se recabó información referida al tiempo que la persona lleva cuidando al familiar enfermo (medido en meses) y el número de horas diarias dedicadas a la tarea del cuidado. Además, se evaluó la capacidad funcional de la persona con demencia mediante el empleo de la escala Barthel (Mahoney y Barthel, 1965), que analiza el nivel de independencia de la persona en diferentes actividades básicas de la vida diaria (ej. Comer, asearse y subir escaleras). La puntuación total oscila de 0 a 100, reflejando puntuaciones más altas una mayor independencia del individuo. También se evaluó el estado cognitivo de la persona cuidada utilizando la Escala De Deterioro Global (GDS; por sus siglas Global Deterioration Scale en inglés; Reisberg et al., 1982). Esta escala consiste en la descripción clínica de 7 fases de progresión de la demencia, siendo la fase (1) normalidad y la (7) demencia grave.

La frecuencia y reacción a los síntomas conductuales y psicológicos de las demencias (BPSD) se evaluaron mediante la administración del Listado Revisado de problemas de Memoria y Conducta (RMBPC por sus siglas en inglés *Revised Memory and Behavior Problems Checklist*; Teri et al., 1992; versión en español por Nogales-González et al., 2015). Este cuestionario se compone de 24 ítems (por ej., “su familiar destruye la propiedad” o “su familiar pierde o cambia cosas de lugar”) que miden, por un lado, la frecuencia durante la semana anterior de los síntomas del familiar enfermo, con un rango de respuesta oscila de 0 ('nunca ocurre') a 4 ('ocurre a diario'), y, por otro lado, evalúan en qué medida dichos comportamientos han generado malestar a la persona cuidadora, desde 0 ('no me estresó en absoluto') hasta 4 ('me estresó extremadamente').

4.2.3. Recursos del cuidador

La solicitud y recepción de la ayuda fueron evaluados mediante la administración de dos ítems diseñados ad hoc para este estudio. En primer lugar, para la petición de ayuda, se utilizó el ítem "¿Solicita ayuda a sus familiares para cuidar a tu familiar enfermo?”, mientras que para evaluar la recepción de esta se utilizó el ítem ¿Recibió ayuda?”. Ambos ítems cuentan con un rango de respuesta tipo Likert que va desde 1 (“Nunca”) hasta 4 (“Siempre”).

El apoyo social percibido se evaluó mediante la administración del Cuestionario de Apoyo social (PSQ por sus siglas en inglés *Psychosocial Support Questionnaire*; Reig et al., 1991), desarrollado en español. Este cuestionario se compone de 6 ítems (por ej., “mis amigos y/o familiares me visitan en casa”) con un formato de respuesta tipo Likert entre 0 (“Nunca”) y 3 (“Muy a menudo”).

Para la evaluación de la frecuencia de actividades de ocio se administró la escala de Satisfacción con el Tiempo de Ocio (LTS por sus siglas en inglés *Leisure Time Satisfaction Scale*; Stevens et al., 2004;), adaptada al español (Romero-Moreno et al., 2014). Esta escala tipo Likert está compuesta por 6 ítems (por ej., "Durante el último mes, he tenido tiempo para pasar buenos momentos con otras personas") con un rango de respuesta que oscila entre 0 ("En absoluto") y 4 ("Mucho").

La función familiar se evaluó mediante el empleo del cuestionario Family APGAR (Smilkstein, 1978) en su versión española (Bellón et al., 1996). Este cuestionario evalúa cinco aspectos diferentes de la función familiar (adaptabilidad, compañerismo, crecimiento, afecto y resolución familiar) a través de 5 ítems (por ej., “las decisiones importantes se toman en la familia”). Presenta una escala de respuesta tipo Likert que va desde 0 ("Casi nunca") hasta 2 (“Siempre).

Por último, para la evaluación de la evitación experiencial se utilizó la escala Cuestionario de Evitación Experiencial en el Cuidado (EACQ por sus siglas en inglés *Experiential Avoidance in Caregiving Questionnaire*; Losada et al., 2014), desarrollado en español. Este cuestionario consta de 15 ítems (por ej., “Cada vez que vienen pensamientos malos sobre mi familiar o mi situación como cuidador, intento escapar de ellos y distraerme”) con un rango de respuesta entre 1 (“nada en absoluto”) y 5 (“Mucho”).

4.2.4 Variables resultado: consecuencias psicológicas del cuidado

La sintomatología depresiva se evaluó mediante la Escala de Depresión del Centro de Estudios Epidemiológicos (CES-D por sus silgas en inglés *Center for Epidemiologic Studies-Depression Scale*; Radloff et al., 1977) en su versión española (Losada et al., 2012). Esta escala se compone de 20 ítems (por ej., “Sentí que todo lo que hacía era un esfuerzo”) con un rango de respuesta tipo Likert del 0 (“raramente o nunca”) al 3 (“todo el tiempo”) para describir los diferentes síntomas depresivos que los individuos pudieron haber experimentado a lo largo de la última semana.

El sentimiento de soledad percibido se evaluó mediante el empleo de la versión española del ítem 14 (“Me sentí solo/a”) de la escala CESD (Radloff et al., 1977; versión española por Losada et al., 2012). Cuenta con una escala de respuesta tipo Likert que oscila entre 0 ("Raramente o nunca") y 3 ("Todo el tiempo"). Estudios previos han empleado este ítem como indicador de soledad (por ej., Hughes et al., 2004) siendo igual o similar al incluido en distintos instrumentos empleados para la evaluación del sentimiento de solead, como, por ejemplo, la escala OARS (Losada et al., 2012).

La evaluación de la sintomatología ansiosa se realizó mediante el empleo de la subescala de Tensión del Perfil de Estados de Ánimo (POMS por sus siglas en inglés *Profile of Mood States;* McNair et al., 1971) en su versión en española (Balaguer et al., 1993). Esta subescala utiliza 9 adjetivos multidimensionales que evalúan el afecto y los sentimientos del sujeto (por ej., “descontrolado/a” o “intranquilo/a”) con un rango de respuesta tipo Likert que va de 0 (“Nada en absoluto”) a 4 (“Mucho”).

Por último, para evaluar el sentimiento de culpa se administró el Cuestionario de Culpa del Cuidador (CGQ por sus siglas en inglés *Caregiver Guilt Questionnaire*; Losada et al., 2010), desarrollado en español. Este cuestionario se compone de 22 ítems (por ej., “Me he sentido mala persona por odiar y/o envidiar a otros familiares que podrían hacerse cargo y no lo hacen.”) con un rango de respuesta que oscila entre 0 (“Nunca) y 4 (“Siempre o casi siempre”).

4.3. Análisis de datos

A continuación, se proporciona un resumen de los principales análisis de datos realizados en la presente tesis doctoral, ya que cada estudio cuenta con una sección exclusiva donde se describen detalladamente los diferentes análisis de datos realizados. De manera transversal, los análisis realizados en todos los estudios están basados en el modelo sociocultural de estrés y afrontamiento y en todos se incluyen análisis descriptivos de datos y frecuencias, con las respectivas medias y desviaciones estándar obtenidas de manera específica en cada variable para cada grupo de parentesco (esposas, esposos, hijas e hijos)

En el primer estudio se utilizaron los programas Statistical Package for the Social Sciences (SPSS Statistics 22) y AMOS 6.0 (IBM, Chicago, IL, EE. UU.) para la realización de los análisis. Por un lado, se llevaron a cabo de análisis descriptivos, comparaciones de medias y pruebas de independencia entre las variables sociodemográficas y del sentimiento de soledad. Además, se realizaron análisis de correlaciones entre las diferentes variables para cada grupo de parentesco. Por otro lado, se llevaron a cabo análisis de senderos para evaluar el ajuste de los datos al modelo teórico propuesto. Este modelo pretende estudiar el papel de variables psicosociales (familismo y pensamientos disfuncionales asociados al cuidado) en la explicación del sentimiento de soledad percibido en las personas cuidadoras, mediante su influencia en variables de afrontamiento o recursos (solicitud y petición de ayuda, apoyo social percibido y realización de actividades de ocio). Se analizaron las asociaciones encontradas en el modelo para cada grupo de parentesco.

En el segundo estudio, además de la realización de análisis descriptivos de la muestra, se llevaron a cabo pruebas de chi-cuadrado y ANOVAS de un factor para estudiar las diferencias en las variables seleccionadas en función del parentesco con la persona cuidada. Posteriormente, se realizaron análisis de senderos para cada grupo de parentesco, con el objetivo de estudiar las asociaciones entre las variables seleccionadas en el modelo teórico propuesto. Es decir, por un lado, se evaluó si la deseabilidad social tuvo un impacto en los síntomas de culpa y depresión a través de la reacción a los comportamientos problemáticos o mediante pensamientos disfuncionales, y, por otro lado, se evaluó si el familismo, a través de pensamientos disfuncionales, tuvo un impacto significativo en la sintomatología de culpa y depresiva. Finalmente, se examinó si la frecuencia de los comportamientos problemáticos de la persona con demencia tuvo un impacto significativo en dichas sintomatologías. Además, teniendo en cuenta que estudios anteriores informaron de asociaciones indirectas entre variables culturales y variables resultados (ej. síntomas depresivos), se evaluaron todos los posibles efectos indirectos de las variables seleccionadas en la sintomatología depresiva y de culpa. Por último, se realizó un análisis multigrupo para estudiar las diferencias en los efectos directos e indirectos reflejados en el modelo entre los grupos de parentesco. Se comparó un modelo de estimación libre (con parámetros computados libremente en todos los grupos) con un modelo restringido (se impusieron restricciones de igualdad en los pesos estructurales). Las diferencias entre los modelos (con y sin restricciones) se calcularon mediante pruebas de chi-cuadrado. Todos los análisis se realizaron con el programa Statistical Package for the Social Sciences (SPSS Statistics 22) y el software AMOS 6.0.

En el tercer estudio, se realizó un análisis jerárquico de conglomerados utilizando el método de Ward con el objetivo de identificar agrupamientos homogéneos de sujetos según las puntuaciones obtenidas por los participantes en cinco variables: familismo (obligaciones familiares), pensamientos disfuncionales, evitación experiencial, actividades de ocio y apoyo social. La comparación de las puntuaciones obtenidas en las distintas escalas se realizó mediante el uso de puntaciones z. Se compararon las puntuaciones medias de cada variable en cada grupo para identificar las características comunes de los conglomerados obtenidos (Yim & Ramdeen, 2015). Además, se ejecutaron tablas de contingencia entre los distintos conglomerados y la variable de parentesco para identificar la distribución de los participantes según esta variable. Por último, nuevas tablas de contingencia se llevaron a cabo entre los conglomerados y las variables emocionales (sintomatología depresiva, ansiosa y de culpa) para estudiar si existen diferencias en estas sintomatologías entre los conglomerados. Los análisis implementados en este estudio se realizaron con el programa Statistical Package for the Social Sciences (SPSS Statistics 22).

Por último, en el cuarto estudio, se realizaron análisis de chi-cuadrado y ANOVAs de un factor para evaluar las características descriptivas de la muestra y las diferencias según el papel de parentesco. Después, se estudiaron mediante análisis de regresión jerárquica dos modelos de moderación simple, uno con la sintomatología depresiva como resultado y otro con la sintomatología de ansiedad como resultado. Estos análisis de regresión se llevaron a cabo para cada grupo de parentesco con el objetivo de, por una parte, examinar si la presencia de pensamientos disfuncionales o el funcionamiento familiar están directamente relacionados de manera directa con la presencia de ambas sintomatologías, y por otra parte, si la asociación entre los pensamientos disfuncionales sobre el cuidado y ambas sintomatologías está moderada por niveles de funcionamiento familiar, y si estos hallazgos se obtienen para todos los grupos de parentesco. En caso de que los niveles en la asociación entre la variable independiente (pensamientos disfuncionales) y ambas variables dependientes (sintomatología depresiva y ansiosa) varíen según los niveles del moderador (sugerido por un efecto significativo del producto entre pensamientos disfuncionales y funcionamiento familiar), se considera que se produce moderación, es decir, que el funcionamiento familiar modificaría el efecto que los pensamientos disfuncionales tienen en ambas sintomatologías. Todos los análisis se realizaron con el programa Statistical Package for the Social Sciences (SPSS Statistics 22). Además, se realizaron análisis post-hoc utilizando el script Macro de PROCESS para SPSS (Hayes, 2018) para probar la relación de moderación en ambos modelos.

Tabla 4.1 *Resumen general de las características de los estudios que conforman la tesis*

Título	**Autores**	**Estado de publicación**	**Tamaño muestral**	**Diseño**	**Variables**	**Análisis de datos**
Estudio Uno Sociocultural influences on the feeling of loneliness of family caregivers of people with dementia: the role of kinship.	Huertas-Domingo, C., Márquez-González, M., Cabrera, I., Barrera-Caballero, S., Pedroso-Chaparro, M. D. S., Romero-Moreno, R., y Losada-Baltar, A.	Publicado en la revista *International Journal of Environmental Research and Public Health*	N=273	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas. Capacidad funcional del familiar cuidado. Frecuencia a comportamientos problemáticos. Variables psicosociales (familismo, pensamientos disfuncionales asociados al cuidado). Variables de afrontamiento (petición y recepción de ayuda, apoyo social, actividades de ocio). Sentimiento de soledad.	Análisis descriptivos, ANOVAs y pruebas de independencia. Correlaciones de Pearson. Ecuaciones estructurales
Estudio Dos Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences.	Huertas-Domingo, C., Losada-Baltar, A., Romero-Moreno, R., Gallego-Alberto, L., y Márquez-González, M.	Publicado en la revista *Aging & Mental Health*	N=284	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas. Variables psicosociales (familismo, sesgo de deseabilidad social y pensamientos disfuncionales asociados al cuidado). Variables estresores del cuidado (frecuencia y reacción a comportamientos problemáticos). Sintomatología de culpa y depresiva.	Análisis descriptivos, ANOVAs y pruebas de independencia. Correlaciones de Pearson. Ecuaciones estructurales. Análisis multigrupo

Estudio Tres Profiles of dementia caregivers according to psychosocial and resource variables. Importance of kinship.	Huertas-Domingo, C., Losada-Baltar, A., Gallego-Alberto, L., García-Batalloso, I., García-García L., y Márquez-González, M.	Aceptado para su publicación en *Spanish Journal of Psychology*	N=288	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas Variables psicosociales (familismo, pensamientos disfuncionales asociados al cuidado y evitación experiencial). Variables de recursos (apoyo social y actividades de ocio) Sintomatología depresiva, ansiosa y de culpa	Análisis descriptivos, ANOVAs y pruebas de independencia. Análisis de conglomerados jerárquicos. Análisis factorial exploratorio. Tablas de contingencia.
Estudio Cuatro Moderating effect of family function on the relationship between dysfunctional thoughts associated with caregiving and anxious and depressive symptoms. Importance of kinship.	Huertas-Domingo, C., Losada-Baltar, A., Pillemer, K., Cjaza, S. J., Jiménez-Gonzalo, L., Fernándes-Pires, J. A., y Márquez-González, M.	Enviado para posible publicación	N= 278	Estudio cuantitativo transversal-correlacional	Variables sociodemográficas. Estresores del cuidado (frecuencia y reacción a comportamientos problemáticos). Variables psicosociales (familismo y pensamientos disfuncionales). Variables de recursos (función familiar). Sintomatología depresiva y ansiosa.	Análisis descriptivos, ANOVAs y pruebas de independencia. Análisis de regresión jerárquica. Análsis post-hoc de moderación usando PROCESS

ESTUDIO UNO

Sociocultural Influences on the Feeling of Loneliness of Family Caregivers of People with Dementia: The Role of Kinship

Huertas-Domingo, C., Márquez-González, M., Cabrera, I., Barrera-Caballero, S., Pedroso-Chaparro, M. D. S., Romero-Moreno, R., & Losada-Baltar, A. (2021). Sociocultural influences on the feeling of loneliness of family caregivers of people with dementia: the role of kinship. *International Journal of Environmental Research and Public Health*, *18*(9), 4700. DOI: https://doi.org/10.3390/ijerph18094700

5. Estudio uno: Sociocultural influences on the feeling of loneliness of family caregivers of people with dementia: the role of kinship.

5.1. Abstract

The extent to which familism, dysfunctional thoughts, and coping variables contribute to explaining feelings of loneliness in caregivers, controlling for kinship, is analyzed. Participants were 273 family caregivers of people with dementia. Sociodemographic variables, familism, dysfunctional thoughts, coping strategies for requesting and receiving help, perceived social support, and leisure activities were assessed. The fit of a theoretical model for explaining the effect of cultural and psychological variables on feelings of loneliness in each kinship group was tested. No significant differences in the distribution of loneliness by kinship were found. Higher levels of familism are associated with more dysfunctional thoughts, that are linked to more maladaptive strategies for coping with caring (e.g., less social support and fewer leisure activities). This in turn is associated with higher scores in the feeling of loneliness. The model bore particular relevance to the group of daughters, husbands, and sons, yet not in the case of wives. Sociocultural and coping factors associated with the caring process seem to play an important role in explaining feelings of loneliness in caregivers. Sociocultural factors associated with the care process seem to play an important role in explaining feelings of loneliness in caregivers.

Keywords: caregivers; dementia; familism; dysfunctional thoughts; kinship; loneliness

5.2. Introduction

The progressive aging of the population due to increasing life expectancy is associated with a significant increase in the risk of dementia in Western countries (WHO, 2021) and in the number of people needing care (Christensen et al., 2009) The care of relatives that have dementia is commonly provided by families and, more specifically, by one person who adopts the role of primary caregiver, usually a woman (Schulz et al., 2020) Family care of a relative with dementia is associated with significant negative physical and psychological consequences for the caregiver, among which are the presence of anxious and depressive symptoms (Collins & Kishita, 2020) and loneliness. Loneliness has scarcely been studied in caregiving contexts, despite the presence of studies suggesting its great prevalence among caregivers (Beeson, 2003; Kovaleva et al., 2018) Such negative consequences associated with caregiving appear to occur to a greater extent among women (Pinquart & Sörensen, 2006) with studies suggesting that caregiver daughters in particular are at greater risk of suffering emotional problems (Conde-Sala et al., 2010).

Different theoretical models have explained the presence of emotional distress in caregivers, with the stress and coping model proposed by Lazarus and Folkman (1984) salient among them. According to this model, apart from the sources of the stress itself, the consequences of caregiving-related stress depend on how the person interacts with the situation based on their evaluation of it and the personal and social resources available to them. Based on the Lazarus and Folkman (1984) model, theoretical models adapted to caregiving have been developed, such as the sociocultural stress and coping model, which has significant empirical support (Knight &Sayegh, 2010). This model offers a conceptual framework of caregiver stress and the different coping processes as influenced by cultural factors (Knight &Sayegh, 2010). One of the cultural values which has received the most attention in the study of care is familism (Knight &Sayegh, 2010; Losada et al., 2010). This variable reflects a cultural value related to solidarity between the different members of the family associated with strong feelings of loyalty and dedication to one another (Sabogal et al., 1987). Thus, while factors such as family solidarity or affection may have a role to play in family caregiving, such care also involves the fulfillment of a duty, so that caring for the family member is combined with obligation. The provision of care in a context where the perception of family obligation is strong is associated with a significant negative impact resulting in emotional distress for caregivers (Losada et al., 2010)

The effect of cultural variables in caregiving seems to be greater on women due to the traditional attitudes associating care with the female role, so that this activity continues to fall more heavily on them (Mendez-Luck &Anthony, 2015). This distribution of traditional gender roles may be at the root of why women, in contrast to men, become involved to a greater extent in caregiving tasks and therefore deal with more demands for care and spend more time on it (Pinquart & Sörensen, 2006). Furthermore, the fact that women habitually have to play multiple roles (worker, wife, daughter, mother, etc.) makes them more likely to experience the adverse consequences of caregiving (Sharma et al., 2016)

These considerations are in line with those posited by the cognitive model adapted to caregiving (Losada et al., 2006). This model hypothesizes that culture clearly influences how caregiving is seen and handled (e.g., “Only the closest person to the frail/sick older adult knows how to truly take care of him or her”; “It is selfish for a caregiver to dedicate time to himself/herself when a relative is frail/sick and needs care”). Such thoughts can be linked to behaviors which may have negative physical and psychological consequences for health, such as not asking for help or not engaging in leisure activities. Failure to ask for help can reduce the possibilities of maintaining social relationships (support network), leisure, motivation, and energy, thereby changing the structure of one’s social network, which can result in isolation (Baron et al., 1990) and loneliness (Kovaleva et al., 2018). Although scarce, the available literature on loneliness in caregivers seems to suggest that female caregivers report higher levels of loneliness (Ekwall et al., 2005) and, according to the results obtained by Stefani, Seidmann, Pano, Acrich, and Pupko (2003), daughters show greater loneliness than wives.

Taking into account all of the above, and based on the sociocultural (Knight & Sayegh, 2010) and cognitive (Losada et al., 2006) models of care-related stress and coping, the present study therefore had the following objectives: (a) to assess the degree to which perceived loneliness is present in caregiving and analyze potential kinship-based differences in the degree of perceived loneliness; (b) to evaluate the fit of a theoretical model analyzing the degree to which, by kinship, cultural values are associated with dysfunctional thoughts and the maladaptive coping strategies of requesting and receiving less help, as well as having less social sup- port and fewer leisure activities, and (c) to analyze how these relationships influence the perception of loneliness in family caregivers of people with dementia (see Figure 1).

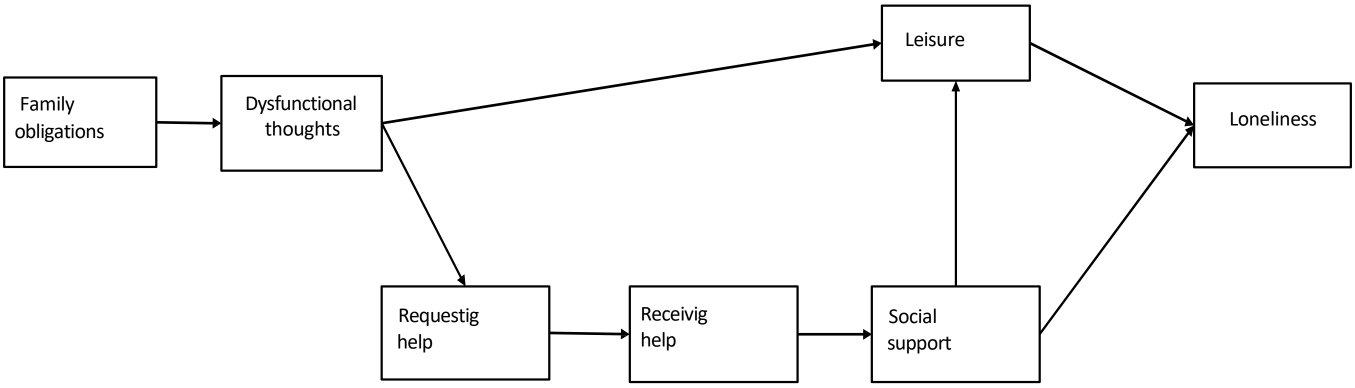


Figure 5.1. The sociocultural stress and coping model tested.

Along these lines, we expected (1) to find a significant percentage of caregivers, especially women and in particular daughters, reporting feelings of loneliness; (2) that a greater presence of the cultural value of familism would be associated with more dysfunctional thoughts about caregiving, which would be linked to the existence of more maladaptive coping strategies for caregiving, that is, requesting and receiving less help, which would in turn lead to a lower predisposition to social support and a lower frequency of leisure activities; and (3) that a greater implementation of such maladaptive coping strategies would be reflected in higher scores in the feeling of loneliness among caregivers. Given the influence of gender roles, the aforementioned consequences were expected to be especially significant in caregiver daughters as they are subject to greater role conflict.

5.3. Method

5.3.1. Participants

The study sample comprised 273 people (women = 68.9%) aged between 28 and 88, all of them caregivers of relatives with dementia residing in the Community of Madrid (Spain). Participants were divided into four kinship-based groups: husbands (n = 56; 20.5%), wives (n = 67; 26.48%), daughters (n = 117; 42.85%), and sons (n = 33; 12.08%). The sociodemographic characteristics of participants by kinship are shown in Table 1.

Participants were recruited through health and social services centers, which facilitated initial contact to confirm criteria for inclusion in the study were met (identifying as the main caregiver of the sick relative, dedicating at least one hour a day to caregiving and having done so for at least the previous 3 months, and being aged over 18). All subjects participated voluntarily and were individually interviewed face-to-face. The study was approved by the Ethics Committee of the Rey Juan Carlos University, and prior to the assessment, informed consent, guaranteeing data confidentiality among other issues, was obtained from each individual.

Table 5.1. *Kinship differences in the assessed variables.*

Variables	0. Daughters		1. Wives		2. Husbands		3. Sons		F/χ^2 (sig)	Diff.
	(n = 117)		(n = 67)		(n = 56)		(n = 33)			
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
Age	54.07	8.22	72.34	8.06	75.21	6.64	52.87	9.94	98.49 (0.00)	1 & 2 > 0 & 3
Loneliness never (%)	43.5		46.2		57		48.5		10.75 (0.29)	n.s.
Loneliness sometimes (%)	30.8		22.3		19.6		24.2			
Loneliness occasionally (%)	17.1		10.4		10.8		15.2			
Loneliness most or all of the time (%)	8.5		20.1		12.5		12.2			
Work outside home (% yes)	51.29		10.5		1.8		60.6		89.64 (0.00)	0 & 3 > 1 & 2
Live with children (% yes)	41.1		17.9		7.2		24.3		25.32 (0.00)	0 > 1, 2 & 3
Care for other relatives (% yes)	35.1		11.9		3.6		9.1		34.87 (0.00)	0 > 1, 2 & 3
Hours of care	11.1	8.46	16.1	7.50	16.59	7.44	8.68	9.16	12.04	0 & 3 < 1 & 2
Frequency of disruptive	37.21	13.98	32.31	12.23	32.89	11.42	31.93	11.17	2.78 (0.03)	0 > 1, 2 & 3
Functional capacity of person cared for	61.96	27.77	71.65	26.17	7663	23.82	65.61	31.07	3.52 (0.01)	0 < 1 & 2
Family obligations	6.39	3.51	10.00	4.12	9.82	4.55	8.60	3.52	13.02 (0.00)	0 < 1, 2 & 3
Dysfunctional thoughts	19.03	11.12	34.78	15.47	37.98	12.18	25.06	12.29	27.94 (0.00)	1 & 2 > 0 & 3
Requesting help	2.95	0.71	1.83	0.97	2.05	1.02	2.18	0.91	2.52 (0.04)	0 > 1, 2 & 3
Receiving help	2.83	1.17	2.85	1.39	2.98	1.31	2.93	1.15	2.08 (0.08)	n.s
Social support	11.52	3.68	11.13	3.72	10.77	4.57	8.72	3.95	3.34 (0.01)	3 < 0, 1 & 2
Leisure	5.71	2.78	5.43	2.70	6.48	2.80	6.12	2.67	1.26 (0.29)	n.s

Note: SD = Standard Deviation; n.s = non-significant differences.

5.3.2. Measures

Drawing upon the sociocultural stress and coping model, the following variables were measured.

-Sociodemographic variables: age, gender, kinship to the person being cared for, daily hours caring, paid work outside the home, living with children at home, and caring for other relatives.

-Care-recipient functional capacity. This was measured through the Barthel Index (Mahoney & Barthel, 1965) which showed internal consistency (Cronbach's alpha) of 0.91 in this study.

-Frequency of behavioral problems associated with dementia. This was measured through the Revised Memory and Behavior Problems Checklist (RMBPC) (Teri et al., 1992). It includes 24 items (e.g., "Asking the same question over and over") which assess the frequency of behavioral problems scored on a 5-point Likert scale ranging from 0 ("Never") to 4 ("Every day"). The internal consistency (Cronbach's alpha) in this study was 0.78.

-Familism: family obligations. This was assessed through the family obligations subscale of the Revised Familism Scale (RFS; Losada et al., 2019). It consists of 5 items (e.g., "One should make great sacrifices in order to guarantee a good education for his/her children") with a response range from 0 ("Totally disagree") to 4 ("Totally agree"). The subscale's internal consistency (Cronbach's alpha) for this study was 0.74.

-Dysfunctional thoughts. The Dysfunctional Thoughts Questionnaire (CPD; Losada et al., 2006) was used to evaluate thoughts, beliefs, and attitudes that hinder adaptive coping related to caregiving. It consists of 16 items (e.g., "Only the person closest to the frail/sick older adult knows how to truly take care of him or her") with a response range from 0 ("Totally disagree”) to 4 (“Totally agree”). Internal consistency (Cronbach’s alpha) in the present study was 0.91.

-Requesting and receiving help. These were assessed by administering two items developed ad hoc for this study (“Do you ask your relatives for help with caring for your sick relative?” and “Do you receive help?”). Both items have a 4-option Likert-type response format ranging from 1 (“Never”) to 4 (“Always”).

-Social support. The Psychosocial Support Questionnaire (PSQ) (Reig et al., 1991) was used to assess the perception of social support, using 6 items (e.g., “My friends and/or relatives pay me visits at home”) in a Likert-type response format with a response range from 0 (“Never”) to 3 (“Very often”). Cronbach’s alpha in the present study was 0.76.

-Frequency of leisure activities. This was measured using the adapted Leisure Time Satisfaction scale (LTS; Stevens et al., 2004). Its 6 items (e.g., “Quiet time by yourself”, “Taking part in hobbies”) measure the extent to which caregivers had participated in leisure activities. Responses are rated on a 5-point Likert-type scale from 0 (“Not at all”) to 4 (“A lot”). Cronbach’s alpha for this scale in the present study was 0.71.

-Feeling of loneliness. Item 14 (“I felt lonely”) of the CES-D scale (Radolff, 1997) with a response range from 0 (“Rarely or never”) to 3 (“All the time”) was used to measure how lonely people felt. This item has been used as an indicator of loneliness in previous studies (e.g., Hughes et al., 2005) and is the same or similar to that included in different instruments to assess loneliness, such as the OARS scale (Losada et al., 2012).

5.3.3. Data analyses

Statistical Package for the Social Sciences (SPSS statistics 22) (IBM, Chicago, IL, USA) and AMOS 6.0 software (IBM, Chicago, IL, USA) were used to carry out the analyses for this study. Considering the small sample size of the group of sons, the associations that are significant at $p < 0.10$ were highlighted for this group. A p value of 0.05 is considered for the rest of the results. First, descriptive analyses, comparison of means, and independence tests were carried out between the sociodemographic variables assessed and the perception of loneliness. Second, correlation analyses were performed between the different variables for each kinship group (presented as Supplementary Materials). Finally, and following the sociocultural model of stress and coping (Knight & Sayegh, 2010) and the cognitive model adapted to caregiving (Losada et al., 2010; 2006), we assessed the fit of the data to the model presented in Figure 1 through path analysis. The cultural variable of family obligations is taken first, followed by dysfunctional thoughts and caregiver resources (asking for help, receiving help, social support and engagement in leisure activities) and, finally, the feeling of loneliness. The associations found in the model for each of the kinship groups were analyzed. The following indices were used to assess the fit of the data from the model: chi-square, incremental fit index (IFI), comparative fit index (CFI), and the root mean square error of approximation (RMSEA).

5.4. Results

5.4.1. Sample Characteristics by Kinship

Table 1 shows the descriptive characteristics for each of the variables studied by kinship group. As can be seen, significant differences were found between these groups for almost all the variables assessed, with the exception of receiving help, leisure and loneliness. The percentage of caregivers who reported feeling lonely occasionally or most or all of the time ranged from 25.6% (daughters) to 30.5 (wives).

The data show that more daughters and sons work outside the home than husbands and wives. Daughters and sons also report a smaller number of daily hours devoted to caregiving compared to wives and husbands. Daughters as a group are those who most report living with children and who seem to be caring the most for other family members. Finally, daughters report caring for people with more problem behaviors than the other kinship groups, and they also care for more people with lower functional capacity than wives and husbands.

In turn, it is also daughters who present differences in family obligations compared to the other groups, where significantly lower scores in this variable are found. Regarding dysfunctional thoughts, results show that husbands and wives present more dysfunctional thoughts about caregiving than sons and daughters. In relation to asking for help, the data suggest that sons as a group ask for the most, while wives are the least likely to implement this caregiving coping strategy. However, in terms of social support, significant differences are seen in this variable between sons and the other groups, with sons in this case scoring lower on social support received. The associations between the assessed variables (correlations) are presented in the Supplementary Materials.

5.4.2. Model Fit and Associations by Kinship Group

The overall model fitted the data very well ($\chi^2 = 67.31$; $p = 0.075$; $\chi^2/\text{df} = 1.29$; IFI = 0.956; CFI = 0.946; RMSEA = 0.033). Table 2 shows the unstandardized estimates for each of the kinship groups assessed. The standardized regression weights for each kinship group are shown in Figure 2.

As can be seen in Table 2 and Figure 2, all the associations between the variables shown in the model are significant in the group of daughters. In this group, the perception of family obligation is associated with more dysfunctional thoughts, which in turn are associated with asking for and receiving less help. Receiving less help is associated with less perceived social support.

Less social support and more dysfunctional thoughts are associated with less engagement in leisure activities. Finally, less engagement in leisure activities and less social support are associated with a greater perception of loneliness. The relationship between these variables explains 27% of the variance of loneliness in daughters.

In the case of wives, results are very similar to those of daughters in terms of the significant relationship between the variables family obligations, dysfunctional thoughts, asking for help, receiving help, and the relationship between receiving help and social support ($p < 0.10$) and dysfunctional thoughts and less leisure. However, contrary to our hypotheses, no significant relationship was found in wives between social support and leisure, and feelings of loneliness (Table 2). The model tested explains only 3% of the variance of loneliness in wives.

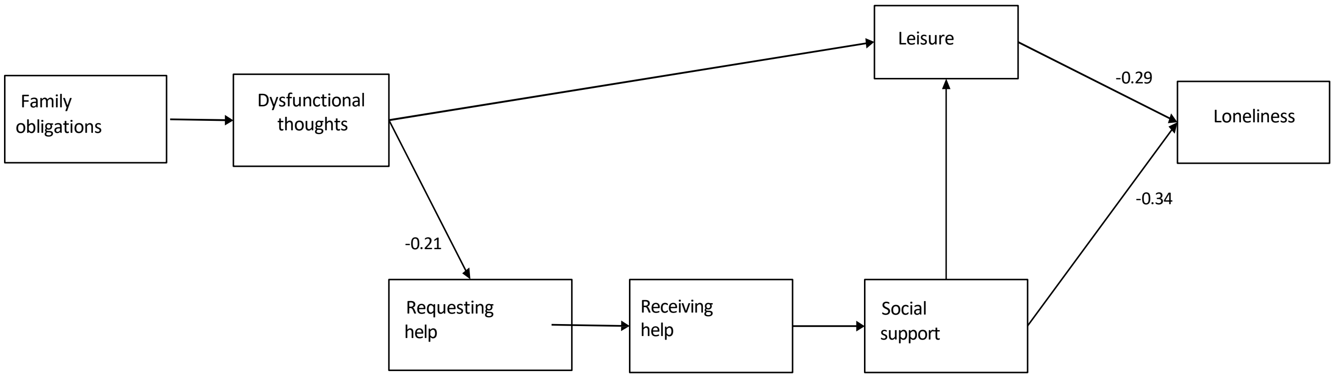
Regarding husbands, practically all the associations observed in daughters and stated in the model are also present (some with a $p < 0.10$), with the exception of the relationship between social support and loneliness, which seems to be mediated by leisure. The model explains 16% of the feeling of loneliness in husbands.

Finally, in the case of caregiver sons, the data obtained are somewhat different from the other groups. In this case, despite finding the significant association observed in all groups between family obligations and dysfunctional thoughts, dysfunctional thoughts were not significantly associated in sons with asking for help or with leisure. As with husbands, the pathway that seems to influence the feeling of loneliness most is that by requesting less help, less help is received, less social support is perceived, there is less engagement in leisure activities, and this influences loneliness. The percentage of variance explained in sons is 25%.

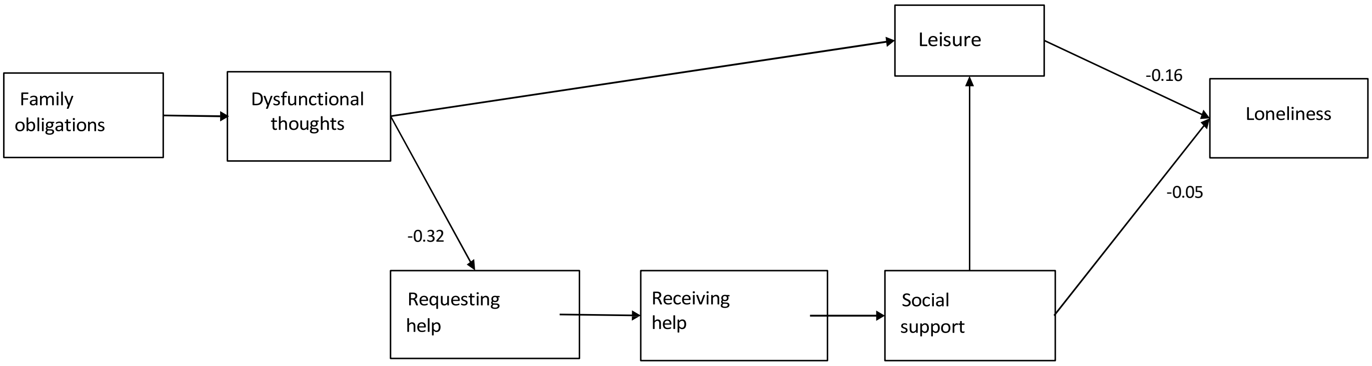
Table 5.2. *Standardized and unstandardized regression weights by kinship.*

			Daughters		
			Unstandardized Estimates	S.E.	C.R.
Family obligations	→	Dysfunctional thoughts	1.942 **	0.233	8.339
Dysfunctional thoughts	→	Requesting help	−0.013 *	0.006	−2.269
Requesting help	→	Receiving help	0.614 **	0.147	4.183
Receiving help	→	Social support	0.855 **	0.284	3.008
Dysfunctional thoughts	→	Leisure	−0.060 **	0.021	−2.867
Social support	→	Leisure	0.282 **	0.063	4.492
Leisure	→	Feeling of loneliness	−0.101 **	0.030	−3.358
Social support	→	Feeling of loneliness	−0.089 **	0.023	−3.911
			Sons		
			Unstandardized Estimates	S.E.	C.R.
Family obligations	→	Dysfunctional thoughts	1.802 **	0.523	3.442
Dysfunctional thoughts	→	Requesting help	0.018	0.013	1.376
Requesting help	→	Receiving help	0.744 **	0.187	3.984
Receiving help	→	Social support	1.093 †	0.572	1.910
Dysfunctional thoughts	→	Leisure	−0.023	0.035	−0.665
Social support	→	Leisure	0.251 *	0.109	2.307
Leisure	→	Feeling of loneliness	−0.214 **	0.066	−3.256
Social support	→	Feeling of loneliness	0.026	0.044	0.587
			Wives		
			Unstandardized Estimates	S.E.	C.R.
Family obligations	→	Dysfunctional thoughts	1.992 **	0.392	5.076
Dysfunctional thoughts	→	Requesting help	−0.020 **	0.007	−2.722
Requesting help	→	Receiving help	0.842 **	0.147	5.710
Receiving help	→	Social support	0.580 †	0.331	1.751
Dysfunctional thoughts	→	Leisure	−0.065 **	0.020	−3.300
Social support	→	Leisure	0.093	0.082	1.141
Leisure	→	Feeling of loneliness	−0.069	0.054	−1.265
Social support	→	Feeling of loneliness	−0.015	0.039	−0.394
			Husbands		
			Unstandardized Estimates	S.E.	C.R.
Family obligations	→	Dysfunctional thoughts	1.117 **	0.327	3.413
Dysfunctional thoughts	→	Requesting help	−0.019	0.011	−1.759
Requesting help	→	Receiving help	0.863 **	0.132	6.536
Receiving help	→	Social support	1.194 **	0.448	2.663
Dysfunctional thoughts	→	Leisure	−0.050	0.029	−1.745
Social support	→	Leisure	0.166 *	0.077	2.170
Leisure	→	Feeling of loneliness	−0.119 *	0.050	−2.394
Social support	→	Feeling of loneliness	−0.042	0.030	−1.397

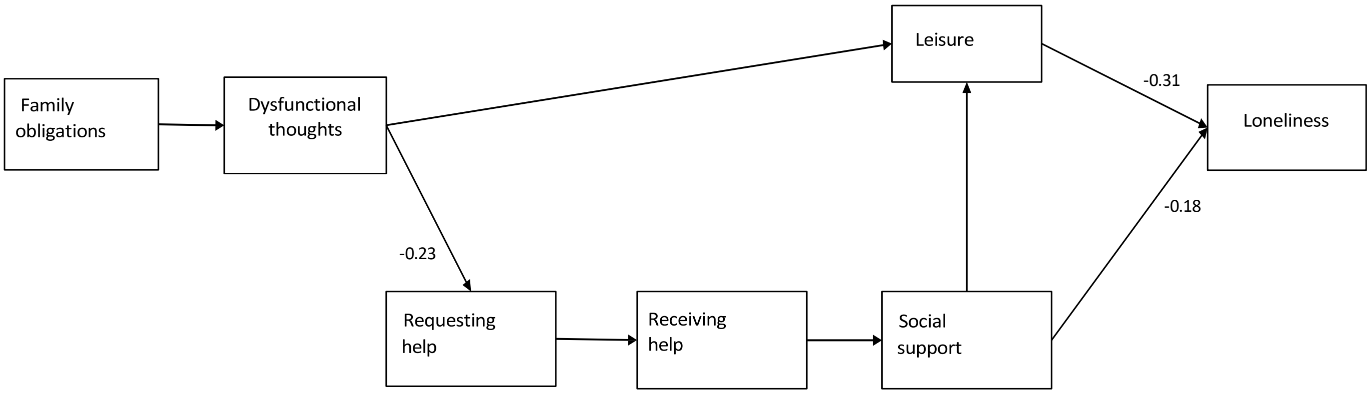
Note: † = $p < 0.10$; * = $p < 0.05$; ** = $p < 0.01$; S.E. = Standard error; C.R. = Critical Ratio.


Leisure
-0.29
Family obligations
Dysfunctional thoughts
Loneliness
-0.34
-0.21
Requesting help
Receiving help
Social support

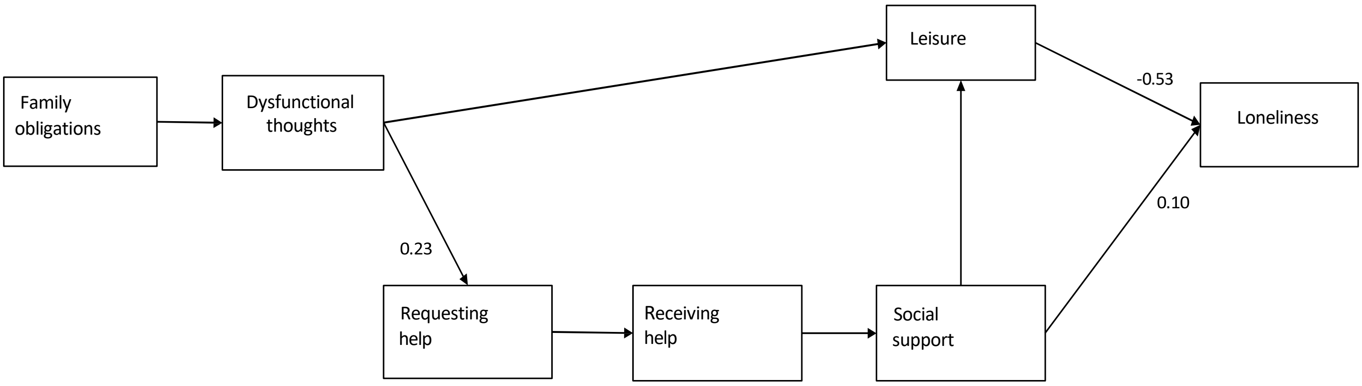
(a)


Leisure
-0.16
Family obligations
Dysfunctional thoughts
Loneliness
-0.05
-0.32
Requesting help
Receiving help
Social support

(b)


Leisure
-0.31
Family obligations
Dysfunctional thoughts
Loneliness
-0.18
-0.23
Requesting help
Receiving help
Social support

(c)



(d)

Figure 5.2. Standardized regression weights for (a) daughters, (b) wives, (c) husbands, and (d) sons.

5.5. Discussion

The main objective of this study was to analyze the degree to which perceived loneliness is present in caregiving and whether there are differences in perceived loneliness based on kinship. The results obtained are consistent with other studies in that they reflect perceived loneliness being present in a significant percentage of caregivers (Stefani et al., 2003). However, although it was expected that daughters would present the highest levels of loneliness due to their being subjected to greater stress and role conflict, the results of this study suggest that there are no kinship-based differences in the degree of perceived loneliness. Therefore, the first hypothesis posited in this study is partially fulfilled, since the data do suggest a high presence of perceived loneliness among caregivers, but not greater loneliness in the group of daughter caregivers compared to other relatives. These results may be due to the fact that a large percentage of daughters have paid work outside the home, a rare occurrence among older groups (husbands and wives). Work is not only a way of earning a salary or gaining social prestige, but it also allows greater participation in social life and can act as a protective factor against the feeling of loneliness (Segel-Karpas et al., 2016). On the other hand, results also show daughters to be the group which most lives with children, most takes care of other family members, and more frequently deals with the disruptive behaviors and functional deterioration of the person in their care. These data seem to confirm that daughters are subjected to more sources of stress (Pinquart & Sörensen, 2006) which can lead to role overload and higher levels of stress, and which in turn may favor or be related to less awareness of their levels of loneliness.

With regard to the second objective, assessing the fit to the data of a stress and coping model based on sociocultural (Knight & Sayegh, 2010) and cognitive (Losada et al., 2006) models, the results appear to confirm the proposed hypotheses, especially in the group of daughters. In relation to daughters, these hypotheses seem to be supported by the data since a greater perception of family obligations is linked to a greater sense of loneliness, given that the influence of such obligations on dysfunctional thoughts regarding caregiving favors the implementation of maladaptive strategies (failure to ask for and receive help) and with it less social support and leisure. In this sense, the data also support the cognitive model adapted to caregiving (Losada et al., 2006). In particular, our data support the pathological way through which culture has an influence on the development of maladaptive thoughts in caregivers (e.g., “I should not ask for help, this is something that should be resolved in the family”), which have negative consequences in terms of behavior (no help seeking, no leisure time) and affective consequences (loneliness). For the groups of male caregivers (husbands and sons), the results obtained are generally similar to those observed in daughters, although some differences were noted. In both husbands and sons, for example, the level of perceived social support does not appear to be of particular relevance in explaining their perception of loneliness. The results suggest that in male groups (husbands and sons) the relationship between social support and loneliness could be indirectly mediated through leisure. Different studies suggest that men, despite requesting help in a similar way to women, receive more social support (e.g., Miller & Guo, 2000). In the case of caregiver sons, this is the group in our study (data not shown) with most singles, where the majority do not have children and practically all of them (all but 3) care for their mother. It is possible that they took on their role as caregivers because no other possible sources of potential caregivers existed in their environment and that the main route of escape from their loneliness was therefore perceived to be through leisure. Future studies should address these issues in more depth.

The most unexpected results were found in caregiver wives, for whom the proposed model explains only 3% of their perceived feeling of loneliness. Although the data obtained suggest that a significant percentage of caregiving wives report loneliness, the variables measured do not seem to contribute to an explanation of this issue in the group in the same way they do in the other kinship groups. It is possible that variables which were not assessed in this study may play a fundamental role in the explanation of loneliness among wives, such as, for example, the loss of a relationship of intimacy and trust with their partner, as well as maladaptive strategies for the regulation of emotions or coping, such as rumination or escape-avoidance coping strategies. Thus, for example, Vikström, Josephsson, Stigsdotter-Neely, and Nygard (2008) reported that many couples attributed their perception of loneliness to the loss of an intimate relationship, since their partner, their confidant, provided them with great emotional support. Regarding rumination, the study by Robinson-Whelen Tada, MacCallum, McGuire, and Kiecolt-Glaser (2001), carried out exclusively with spousal caregivers, mostly women, the authors concluded that the variable that contributed most to the emotional distress of the caregivers was intrusive and avoidant thoughts about caregiving. Robinson-Whelen et al. (2001) also stated that social support received during the caregiving years was not so much related to negative outcomes as social support after the loss of the spouse. Social support during caregiving may not be so relevant for female spouse caregivers because caring for the husband is coherent with the gender-role script. Finally, as reviewed by Yee and Schulz (2000), compared with men, women reported using more escape-avoidance coping strategies, suggesting the usefulness of training them in seeking-support strategies (e.g., assertive communication).

Therefore, although loneliness seems to be a pervasive problem among caregivers, there appear to be different explanations for it depending on the kinship of the caregiver with the person in their care. In terms of the influence of familism and the dimension of family obligations in particular, the data indicate a lower presence of familism (family obligations) in the group of daughters and less perceived social support in the group of sons. In relation to familism in daughters, the reduced presence of this variable may be explained by the conflict that this value can trigger in them with respect to the situation in which they find themselves. Daughters may be aware of how the sense of family obligation falls mainly upon them and, therefore, they question it more than other groups since the consequences are much greater for them (Yee & Schulz, 2000). Montgomery (1992) argues that women, especially those who work outside the home, have greater difficulty in combining work and family, and experience greater social limitations than men, something that contributes to their sense of distress. Regarding perceived social support, the fact that sons show lower levels of this may be explained by taking into account that when sons take on the role of caregiver in a society where the traditional family values prevail and caring seems to be fundamentally associated with the daughters, it may be because there is no one else who can do it, indicating that they are more alone in the caregiving situation. In fact, authors such as Hanlon (2012) identify two types of male caregivers: those who have no other option, that is, who are forced into caregiving, with the result that their participation in the labor market decreases, and those who have nothing to lose. Therefore, although the literature supports the argument that men receive more help with caregiving than women, this may not be enough to generate high levels of perceived social support since they are usually in a vulnerable situation, without their own family or children and without a job or career, and caring for their mother because her spouse can no longer do so.

The present investigation has a series of limitations. First, the design was cross-sectional in nature, and longitudinal studies are necessary to confirm or rule out the relationships found. Second, participation in the study was voluntary, so the general population of caregivers may not be properly represented. Furthermore, as noted above, variables which may be of particular relevance to understanding the feeling of loneliness in caregivers were not included in the study. Future research with larger samples may allow a more detailed inquiry into the relationships studied.

Despite such limitations, the present study provides interesting information on an area that generates significant distress among caregivers: loneliness. First, the data confirm that a significant percentage of caregivers perceives loneliness. Second, data from the present study provide additional support to theoretical models of stress and coping adapted to caregiving which highlight the importance of sociocultural aspects in the explanation of caregiver distress (Knight & Sayegh, 2010; Losada et al., 2010) in this case aimed at explaining the loneliness of caregivers. They also support the cognitive model adapted to caregiving (Losada et al, 2006) since in the case of daughters in particular, they suggest that cultural variables play an important role in the perception of loneliness. These cultural variables include familism (family obligations) and the dysfunctional thoughts of caregivers, which give rise to maladaptive coping with caring, thereby reducing the chances of obtaining help, social support and engagement in leisure activities. Caregiving daughters seem to be particularly vulnerable to this process since the variables measured explain a large percentage of the loneliness they feel.

Finally, the data from this study confirm that loneliness is a pervasive problem in caregiving and suggest an approach to understanding the issue which can be useful in developing interventions. Such interventions could help caregivers towards a more flexible view of the cultural impositions associated with family obligations in caregiving and maladaptive thinking styles, perhaps through culturally sensitive interventions (Cheng et al., 2019).

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ESTUDIO DOS

Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences

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6. Estudio dos: Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences.

6.1. Abstract

Objectives: This study aims to analyze the role that family obligations and social desirability have for understanding guilt and depressive symptoms in family caregivers. A theoretical model is proposed to analyze this significance based on the kinship with the person cared for. **Methods**: Participants are 284 family caregivers of people with dementia divided into four kinship groups (husbands, wives, daughters and sons). Face-to-face interviews were conducted assessing sociodemographic variables, familism (family obligations), dysfunctional thoughts, social desirability, frequency and discomfort associated with problematic behaviors, guilt and depressive symptoms. Path analyses are performed to analyze the fit of the proposed model and multigroup analysis to study potential differences between kinship groups. **Results**: The proposed model fits the data well and explains significant percentages of variance of guilt feelings and depressive symptomatology for each group. The multigroup analysis suggests that, for daughters, higher family obligations were associated with depressive symptomatology through a report of higher dysfunctional thoughts. For daughters and wives, an indirect association between social desirability and guilt was observed through reaction to problematic behaviors. **Conclusion**: The results support the need to consider the significance of sociocultural aspects such as family obligations and the desirability bias in the design and implementation of interventions for caregivers, especially for daughters. Considering that the variables that contribute to explaining caregivers' distress vary depending on the relationship with the person cared for, individualized interventions may be warranted depending on the kinship group.

Keywords: Kinship; dementia; familism; social desirability; guilt; depression

6.2. Introduction

People who care for a family member with dementia must face multiple highly demanding, unpredictable, and variable tasks during many hours a day and for a long time (Alzheimer's Association, 2019). This may have important negative psycho- logical consequences in caregivers (Gilhooly et al., 2016; Jütten et al., 2019; Walter & Pinquart, 2020), especially for women (Erol et al., 2016; Wang et al., 2011).

Depressive symptomatology, which refers to a group of symptoms related to negative affect (e.g. sadness and anhedonia), low behavioral activation, and maladaptive cognitions, is the mental health variable that has received the most attention in the scientific literature on care, while other variables, such as guilt, have not received as much attention, even though they generate significant levels of suffering (Losada et al., 2018). Guilt, defined as the negative feeling generated after recognition of the transgression of a value or an important social standard, contributes significantly to explaining the emotional distress of many caregivers (Gonyea et al., 2008; Losada et al., 2018).

Different theoretical models describe factors that contribute to caregivers' emotional distress. One of the models that has received strong empirical support is the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010). Besides highlighting the importance that behavioral and psychological symptoms associated with dementia have in explaining the emotional symptomatology of caregivers, this model reinforces the influence that cultural variables such as familism have in understanding the care process (Walker et al., 2020). The value of familism is related to the belief that individuals must remain loyal and supportive to the family, sacrificing, if the situation requires it, individual interest for the well-being of the family (Martí & Cid, 2015; Mendez-Luck et al., 2016). Within the European context, this value is more present in some cultures than in others, being predominant in

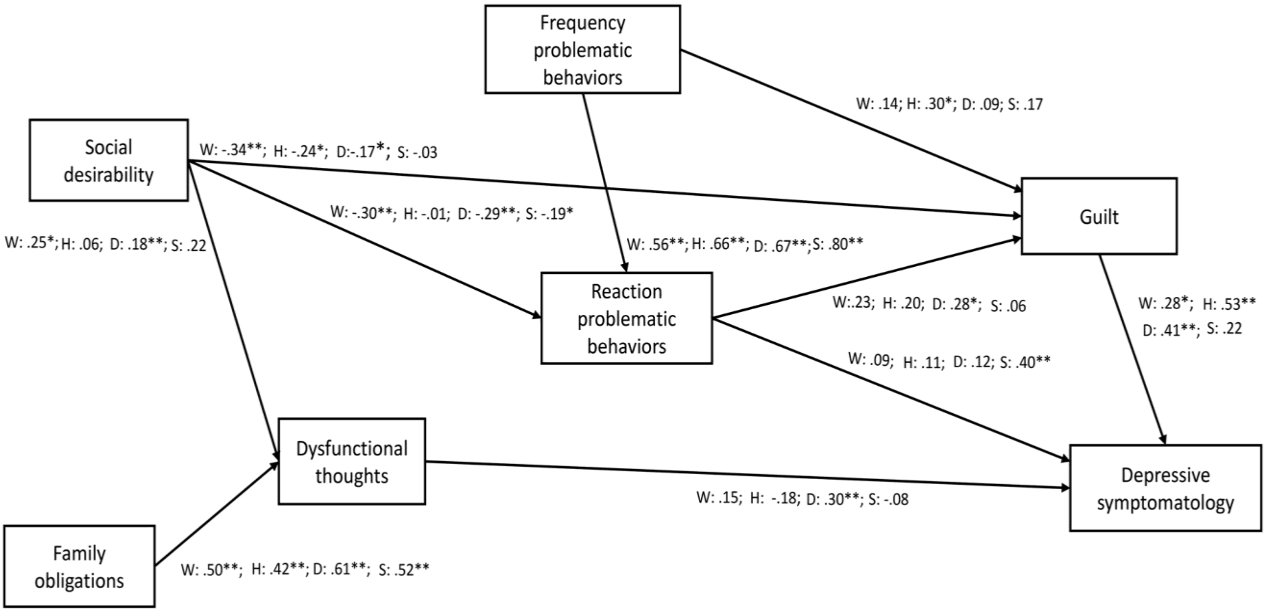
Mediterranean societies, such as Spain, compared to northern European countries (Uccheddu et al., 2019).

One of the main dimensions of familism is family obligations, which refers to the perceived obligation by members of a family to provide emotional and material support and help to each other (Gaugler et al., 2009). Although there are few studies that have analyzed the differences based on sex or kinship in this variable, some studies have obtained results that suggest a greater perception of family obligations in women (Goodman et al., 1994; Van der Lippe & Lippényi, 2020). Due to the traditional attribution of the task of care to the female sex, women appear to further internalize the need to care for dependent relatives as a moral obligation (Bartlett et al., 2018; Meira et al., 2017). The internalization of this obligation occurs through cultural and social processes and seems to have a negative effect on the men- tal health of caregivers (Sayegh & Knight, 2011) because it is related to the appearance of dysfunctional thoughts linked to the task of care (Losada et al., 2010). For example, family caregivers may have thoughts related to the family or cultural norms and be aware that the conflicts or negative feelings that they may experience in relation to the task of caring should not be expressed (e.g. 'No matter how bad they feel, a caregiver should never vent to other people'or'caregivers should avoid discussing their problems with others'). These dysfunctional thoughts can cause negative emotions and lead caregivers to engage in less adaptive behaviors such as not resting or not asking others for help, which has an impact on their emotional distress and could be associated with the presence of depressive symptoms (Kwon et al., 2017; Losada et al., 2006). That is, the presence of dysfunctional thoughts leads caregivers to establish patterns of maladaptive behaviors (Marquez-Gonzalez et al., 2007), influencing their well-being through the implementation of maladaptive coping strategies, which has been related to the presence of emotional discomfort (Losada et al., 2006). In fact, different studies show that the intervention and modification of these dysfunctional thoughts (for example through cognitive restructuring and training caregivers in identifying and modifying them) can reduce caregivers'discom- fort since these thoughts act as barriers to adequate coping with care (Burgio et al., 2003; Gallagher-Thompson et al., 2002; Losada et al., 2011, 2015). Therefore, the internationalization of family obligations could be involved in obstructing the expression or open communication of discomfort or positive emotions associated with care by caregivers. This potential implication of familism has not yet been studied.

A variable that could be related to this potential interference of familism in emotional expression is the social desirability bias, defined as the tendency of the evaluated subjects to deny socially undesirable aspects and admit those that are desirable (Dunn & Shome, 2009; Furnham, 1986; Tyson, 1992). This bias leads to the choice of socially expected responses, rather than those that report their true feelings (Holtgraves, 2004), due to the need to be seen as a subject more oriented towards the values of society and more altruistic than they are (Tyson, 1992). This may influence study results by concealing, moderating, or erroneously generating relationships between relevant variables (Randall et al., 1993). The presence of such a care bias has been scarcely studied in the care literature, although it might be related to the dimension of family obligations discussed as part of the cultural norm of familism; Specifically, care- givers with a greater internalization of the norm of cultural obligations could have a greater tendency towards social desirability, as a reflection of their greater need to adjust more faithfully to what is socially expected from them and to behave according to the family norms. For its part, social desirability could interfere with the care- givers' report, facilitating the tendency to minimize the expression of their discomfort with caring or the frequency or discomfort associated with the behaviors of the care-receiving relative.

Finally, another variable to mention in the study of caregiving and its relationship with emotional distress is the relation- ship with the person being cared for. Previous research has found that kinship with the person cared for has a considerable impact on the stress and well-being of caregivers (Biegel & Schulz,1999; Bourgeois et al., 1996; Kim et al., 2012; Sörensen et al., 2002). It appears that husbands and wives show lower levels of caregiving distress compared to sons and daughters (Conde-Sala et al., 2010) and higher levels of satisfaction with life (Anderson et al., 2013). Additionally, spouses report a higher perceived quality of life for their dementia family member compared to adult child caregivers. However, wives and husbands seem to report more grief than daughters and sons care- givers when the person cared for is transferred to a nursing homes. (Rigby et al., 2019). Furthermore, studies such as Tavero et al. (2018) show that women have a worse self-assessment both in terms of physical, psychological and social health, which affects their quality of life. Especially daughter caregivers have a higher risk of presenting mental health problems due to the stress to which they are subjected by the care task (Romero- Moreno et al. 2014; Stephens et al., 2001) combined with the multiplicity of roles that they face (professional life, raising children, etc.). The conflict experienced by the multiplicity of roles may lead daughters to perform more potentially harmful behaviors towards their relatives with dementia compared to spouse caregivers. In turn, this leads them to present higher levels of feelings of guilt than spouses. (Gonyea et al., 2008; Losada et al., 2010). In fact, the results obtained by Barber and Pasley (1995) showed that, even though daughters and wives provided care in a similar way, the daughters manifested higher levels of strain with the relative they cared for and with other family members.

Taking everything into consideration, and drawing upon the sociocultural model of stress and coping (Knight & Sayegh, 2010), the general objective was to analyze the role that the sociocultural variables familism (family obligations) and the desirability bias have in the explanation of guilt and depressive symptomatology in family caregivers of people with dementia. Figure 1 presents the conceptual model analyzed in the study. Specifically, it was hypothesized that (1) higher scores in perception of family obligations and higher levels of social desirability would be associated with a greater presence of rigid beliefs associated with care (dysfunctional thoughts), and that (2) higher scores in social desirability would be associated with a lower report of discomfort associated with care (discomfort associated with problematic behaviors shown by people with dementia, feelings of guilt and depressive symptomatology). Furthermore, (3) differences based on kinship in the relation- ships were expected, with wives and daughters showing a greater significance of such sociocultural variables (i.e. family obligations and social desirability) in the care process compared to husbands and sons. Considering that previous studies reported indirect effects of familism on outcomes such as depression (e.g. Losada et al., 2010), indirect effects were expected to exist between the tested sociocultural variables of the model and the levels of guilt and/or depressive symptoms.



Note: W: Wives, H: Husbands, D: Daughters, S: Sons; ** p < .01; * p < .05.

Figure 6.1. Tested sociocultural stress and coping model by kinship group (1a: Wives, 1b: Husbands, 1c: Daughters, 1d: Sons). *Note:* ** *p* < .01; * *p* < .05

6.3. Methods

6.3.1. Participants and procedure

A total of 284 caregivers of relatives with dementia living in Madrid, Spain, aged between 28 and 88years (Mean = 62.94; SD = 12.81) participated in this research. The recruitment of the sample took place through various health and social care centers. The centers facilitated a first contact with the participants in which compliance with the inclusion criteria was confirmed: (1) identifying themselves as the main caregiver of the family member diagnosed with dementia; (2) spending at least one hour of care per day per week or a total of 7 h per week; and (3) having been caring for the sick family member for at least the last three consecutive months. These criteria are similar to those used in studies carried out with family caregivers (e.g. Sutter et al., 2014; Yu et al., 2016), and coherent with the general characteristics of the caregiving population (Alzheimer's Association, 2022).

The evaluation of the participants was carried out between January 2015 and March 2020 through face-to-face interviews conducted by psychologists trained for this task. The evaluations lasted approximately 1 h (approximate range: 45 min − 1 h 50 min) and were carried out in Madrid, Spain. The study was approved by the Ethics Committee of the Rey Juan Carlos University and all subjects signed an informed consent for their participation in the study prior to evaluation.

6.3.2. Measures

Sociodemographic variables

Data were collected on age, gender, relationship with the per- son cared for, co-residence, time spent caring, daily hours dedicated to care, paid work outside the home and living with children. Regarding the person cared for, data were collected on age and gender, the type of dementia diagnosed and the patient's cognitive assessment. Specifically, for the assessment of the care-recipients' cognitive status the Global Deterioration Scale (GDS; Reisberg et al., 1988) was used.

Familism

The subscale corresponding to the 'family obligations'dimension of the revised familism scale (RFS; Losada et al., 2020, Spanish version) was used. This is made up of 6 items (e.g. 'most of what a son or daughter does should be done to please their parents') with a response range from 0 'totally disagree' to 4 'totally agree'. Higher scores on the subscale thus correspond to a greater per- ception of family obligations. The internal consistency (Cronbach's alpha) of this dimension in this study is 0.75.

Dysfunctional thoughts

The Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ; Losada, 2005), developed in Spanish, was used. This questionnaire is made up of 16 items (e.g. 'Only the closest per- son knows how to really take good care of their sick family member') with a response range oscillating between 0 and 4 to evaluate the presence of attitudes, thoughts and beliefs associated with caring that could interfere with adaptive coping with care. A higher score corresponds to a greater presence of dysfunctional thoughts. The internal consistency (Cronbach's alpha) of the scale for the present study is 0.91.

Social desirability

Social desirability is the tendency of evaluated subjects to report behaviors that are culturally acceptable. It was measured in this study as an indicator of the potential need of the partic- ipants to respond to culturally accepted behaviors such as pro- viding care for a relative with dementia. The Spanish brief 10-item version (Ávila & Tomé, 1989) of the Marlowe-Crowne Social Desirability Scale (MCSDS; Crowne & Marlowe, 1960) was used. The response range is between 1 (items that the person considers true) and 0 (items that the person considers false), (e.g. ‘I have never disliked anyone’ or ‘I am always polite’). Higher scores on this scale are equivalent to a greater presence of social desirability. Cronbach’s alpha for the study sample is 0.61.

Frequency and discomfort associated with problematic behaviors

The Revised List of Memory and Behavior Problems (RMBPC) was administered (Teri et al., 1992; Spanish version by Nogales- González et al., 2015). This questionnaire consists of 24 items (e.g. ‘Please indicate if, during the past week, your relative has destroyed property’) indicating the frequency of problematic behaviors during the previous week in a response range between 0 ‘never occurs’ and 4 ‘occurs daily’. In addition, the extent to which the same behavior has generated discomfort for the caregiver is also indicated, from 0 ‘it did not stress me at all’ to 4 ‘it stressed me extremely’. For the current sample, Cronbach’s alpha values are 0.77 and 0.85 for the frequency and discomfort subscales, respectively.

Feelings of guilt

The Caregiver Guilt Questionnaire (CGQ) (Losada et al., 2010; developed in Spanish) was used, which measures the feeling of guilt in caregivers. It consists of 22 items (e.g. ‘I have felt guilty for the way I have behaved at times with my family member’), evaluated on a Likert-type scale from 0 ‘never’ to 4 ‘always or almost always’. The total scale presents a Cronbach’s alpha of 0.88 in the present study.

Depressive symptomatology

The Center for Epidemiological Studies - Depression Scale (CES- D; Radloff, 1977; Spanish version by Losada et al., 2012) was used to evaluate this. It is made up of 20 items (e.g. ‘I felt that I could not get rid of sadness even with the help of my family or friends’) with a response range for each item between 0 ‘rarely or never’ and 3 ‘all the time’ to describe depressive symptoms that the subjects could have experienced during the past week. The internal consistency of this scale (Cronbach's Alpha) has a value of 0.87 for the present study.

6.3.3. Data analysis

Sample characteristics and differences in the assessed variables based on kinship were analyzed through chi-square tests and one-factor ANOVAs, while the model described in Figure 1 (1a for wives, 1b for husbands, 1c for daughters, 1d for sons) was analyzed to study the associations between the variables evaluated, following the sociocultural model of stress and coping (Knight & Sayegh, 2010). The associations between the variables observed in the model were studied through path analysis. Caution should be taken when interpreting the results as the sample size for husbands and sons is small, and so the findings of this study should be considered as preliminary and descriptive, with a need for future studies that may replicate the findings. Only those associations that were found to be significant for at least one kinship group are shown in the figures. Those associations that were not significant for any group (e.g. between family obligations and depressive symptoms) were deleted from the tested model. The fit of the data to the model was based on the values obtained in different goodness-of-fit indices: chi-square (CMIN), chi-square/df (CMIN/df), incremental fit index (IFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Data with a well-adjusted fit are those values for CMIN with $p > 0.05$; between 1 and 3 for the CMIN/gl index; values greater than 0.95 for the IFI, CFI indices and for RMSEA values less than 0.08 (Browne & Cudeck, 1993; Hu & Bentler, 1999). Considering that previous studies have reported indirect associations between cultural variables and outcomes such as depressive symptoms (e.g. Losada et al., 2010), all possible indirect effects of the analyzed variables on guilt and depressive symptoms were tested. First, we tested whether social desirability had an impact on guilt and depression symptoms through reaction to problem behaviors or through dysfunctional thoughts. Secondly, we tested whether familism had a significant impact on guilt and depression symptoms through dysfunctional thoughts. Finally, we tested whether the frequency of problematic behaviors of the person with dementia had a significant impact on guilt and depression symptoms through the reaction to such behaviors. Indirect effects were analyzed using bootstrapping, with 2000 bootstrap samples and a bias-correlated confidence interval of 95%. Finally, multigroup analysis was performed to study the differences in the direct and indirect effects reflected in the model between the kinship groups (wives, husbands, daughters, and sons). A freely estimated model (with parameter computed freely across groups) was compared with a restricted model (invariance -equality constraints- was imposed on the structural weights). Differences between the models (with and without restrictions) were computed using chi-square tests. All analyses were carried out with the Statistical Package for the Social Sciences (SPSS Statistics 22) program and the AMOS 6.0 Software.

6.4. Results

6.4.1. Descriptive characteristics of the sample

As shown in Table 1, there was a greater participation of women (*n* = 194; 68.4%) and the largest kinship group was daughters (*n* = 122; 43%), followed by wives (*n* = 72; 25.4%), husbands (*n* = 58; 20.4%) and sons (*n* = 32; 11.3%). In addition, it was observed that the type of dementia predominating in the per- son cared for in the total sample was Alzheimer’s disease (*n* = 162; 56.9%), that the average daily hours dedicated to the task of caring was 13 and that the average value of the patient’s cognitive assessment (GDS) for the total sample was 4.6, corresponding to moderate-severe cognitive impairment. The mean scores for each kinship group in each of the variables evaluated in the study can also be seen in Table 1.

Table 6.1. *Characteristics of the sample and differences by kinship.*

	0-WIVES (25.4%)		1-HUSBANDS (20.4%)		2- DAUGHTERS (43.0%)		3-SONS (11.3%)			
Variables	Mean	SD	Mean	SD	Mean	SD	Mean	SD	F/χ^2 (sig)	Differences between kinship groups ($p < 0.05$)
Caregivers' Age	72.51	7.90	75.19	6.85	54.02	8.30	53.25	9.88	141.68 (< .001)	0 & 1 > 2 & 3
Care-recipients' age	77.96	7.04	75.10	7.34	83.54	7.21	82.00	12.70	17.35 (<.001)	2 & 3 > 0 > 1
Care-recipients' gender (% female)	0.00		100		82.00		93.80		195.03 (<.0.001)	0 < 1, 2 y & 3
Alzheimer (% Yes)	48.6		68.4		57.5		59.4		5.16 (0.16)	No differences
Work outside home (% Yes)	6.9		0		52.1		59.4		93.38 (<.001)	2 & 3 > 0 & 1
Living with children (% Yes)	16,7		8.6		39.7		25.0		24..25 (<.001)	2 > 0, 1 y 3
Living with the care-recipient (% Yes)	98.6		100		50.8		50.0		84.23 (<.001)	0 y 1 > 2 y 3
Family obligations	10.00	4.02	9.88	4.70	6.45	3.52	8.75	3.48	16.90 (<.001)	2 < 0, 1 & 3
Dysfunctional thoughts	34.63	15.06	38.50	12.58	18.91	11.08	25.28	12.42	41.35 (<.001)	0 & 1 > 2 & 3
Social desirability	8.21	1.52	7.95	1.65	6.75	2.07	6.06	2.15	16.25 (<.001)	0 & 1 > 2 & 3
FrequencyBPSD.	31.76	12.10	32.76	12.09	37.73	14.30	32.81	10.15	4.15 (0.01)	2 > 0, 1 & 3
Reaction BPSD	15.69	11.91	15.43	15.57	22.13	16.36	17.72	15.54	4.01 (0.01)	2 > 0, 1 & 3
Guilt	14.46	9.87	16.26	10.61	25.50	13.07	25.47	14.14	17.38 (<.001)	2 & 3 > 0 & 1
Depressive symptomatology	18.18	10.84	13.02	8.44	18.97	11.36	18.31	11.14	4.34 (0.01)	1 < 0, 2 & 3
Time since caregiving (months)	59.38	61.88	47.66	32.20	48.14	36.40	48..50	31.77	1.23 (0.30)	No differences
Daily hours of care	16.49	7.17	16.51	6.80	10.70	7.39	7.55	6.00	20.86 (<.001)	0 & 1 > 2 > 3
Care-recipients' GDS	4.58	1.21	4.42	1.21	4.80	1.26	4.41	1.21	1.54 (0.21)	No differenfes

Note: BPSD = Behavioral and Psychological Symptoms of Dementia; GDS = Global Deterioration Scale; Range of the potential scores for each of the measured variables: Family obligations: 0–24; Dysfunctional thoughts: 0–64; Social desirability: 0–10; Frequency and Reaction problematic behaviors: 0–96; Guilt: 0–88; Depressive symptomatology: 0–60.

The results suggest that there are no significant differences between kinship groups in the type of disease of the relative cared for, with Alzheimer's disease predominant in all of them. Regarding the patient's cognitive assessment, no significant differences were observed between kinship groups. Daughter caregivers was the group reporting more working outside the home and living with children. Wives and husbands devoted more daily hours to the task of care compared to the sons and daughters.

Concerning dysfunctional thoughts and social desirability, as shown in Table 1, wives and husbands reported higher mean scores than sons and daughters. There were no significant differences between husbands and wives nor between sons and daughters. Regarding family obligations, the results suggest that daughters report lower mean levels compared to other kinship groups.

In relation to the frequency and reaction to problematic behaviors, significant differences were observed between the daughters and the other kinship groups, with daughters reporting higher mean scores in both variables (Table 1). Finally, in relation to guilt and depressive symptomatology, the data show that daughters and sons reported higher mean scores in feelings of guilt than wives and husbands (with no significant differences between wives and husbands, nor between daughters and sons), and that husbands was the one reporting lower mean levels of depressive symptomatology.

6.4.2. Path analysis for the explanation of guilt feelings and depressive symptomatology

The results of the path analysis performed by kinship group are shown in Figure 1 (1a for wives, 1b for husbands, 1c for daughters, 1d for sons). The fit indices suggest an excellent fit of the model to the data: chi-square = 45.11 (*p* = 0.43), chi-square/df = 1.03, IFI = 0.99, CFI = 0.99 and RMSEA = 0.01. In spite of this, and as already mentioned, caution is needed when interpreting the results, mainly for husbands and sons, due to the small sample size of the groups.

For wives, the model explained 27% of the variance of guilt and 12% of the variance of depressive symptomatology. For husbands, the model explained 27% of the variance of guilt and 37% of the variance of depressive symptomatology. In the case of daughters, the model explained 18% of the variance of guilt and 29% of the variance of depressive symptoms and, in sons, the model explained 5% of the variance of guilt and 25% of the variance of depressive symptoms. Figure 1 shows the standardized coefficients of the direct relationships between the evaluated variables (the non-standardized coefficients can be consulted in supplemental online material, as well as the standard errors and the critical ratios). The multigroup analysis suggests that the relationships between the variables observed in Figure 1 are different depending on each kinship group, given that a significant decrease in the fit of the evaluated model was observed when moving from the model without restrictions ($p = 0.18$; chi-square/df = 1.19) to the restricted model of structural weights ($p = 0.01$; chi-square/df = 1.43).

The results shown in Figure 1a and 1c suggest that, for wives and daughters, higher scores in social desirability and family obligations are associated with more dysfunctional thoughts. In husbands and sons (Figure 1b and 1d), the only significant association found was between family obligations and dysfunctional thoughts. The relationship between social desirability and dysfunctional thoughts in men did not reach significance.

Although an association between family obligations and dysfunctional thoughts was found in all kinship groups, a significant relationship between these variables and depressive symptomatology was observed only for daughters. Specifically, the results showed the existence in daughters of a significant indirect association between family obligations and depressive symptomatology through dysfunctional thoughts (standardized indirect effect = .18; $p < .01$; SE = .05; CI = .10 − .28). That is, in daughters, a higher score in the perception of family obligations was associated with a higher report of dysfunctional thoughts, and this association helps to explain their levels of depressive symptomatology. According to the multigroup analysis, the relationship observed in daughters between family obligations and depressive symptomatology via dysfunctional thoughts) was statistically different to the relationship between such variables in husbands (the associations observed for daughters are different to those observed for husbands; estimate = .72; CI = .40 − 1.13; *p* = .001) and sons (the associations observed for daughters are different to those observed for sons; estimate = .72; CI = .01 − 1.29; *p* = .046). In summary, familism (family obligations) seems to affect daughters in a particularly negative way with respect to the other groups as it is associated with a greater presence of dysfunctional thoughts and with more depressive symptomatology.

The data shown in Figure 1 reflects that social desirability was directly and significantly associated with a lower report of discomfort associated with problematic behaviors in all kinship groups except in husbands. In addition, it was found that both in wives (standardized indirect effect = −.07; *p* < .05; SE = .05; CI = −.20–−.01) and in daughters (standardized indirect effect = -. 08; *p* < .05; SE = .04; CI = −.17–−.02) there was an indirect relationship between social desirability and guilt, via reaction to problem behaviors. According to the multigroup analysis, the association found in daughters was significantly different to that found in husbands (the associations observed for daughters are different to those observed for husbands; estimate = −.51; CI = −1.21–−.03; *p* = .04). That is, the results suggest that social desirability in women is associated with a lower report of discomfort associated with problematic behaviors, and this association in turn influences women (and, especially, daughters) to report fewer symptoms of guilt.

A significant direct association between social desirability and a lower report of guilt was also found in all groups except sons. In the case of husbands, an indirect relationship was also found between social desirability and depressive symptomatology, via feelings of guilt (standardized indirect effect = −.14; *p* < .05; SE = .08; CI = −.33 − .01). That is, husbands who reported high social desirability reported fewer guilt symptoms, and this ultimately explains lower levels of the variance of depressive symptomatology. In summary, significant negative associations were observed for all kinship groups between social desirability and indicators of discomfort in caregivers (second hypothesis).

Finally, an indirect relationship was found between the frequency of problematic behaviors and depressive symptomatology via reaction to problematic behaviors and guilt for wives (standardized indirect effect = .07; *p* < .05; SE = .05; CI = .00 −.20), husbands (standardized indirect effect = .30; *p* < .01; SE =.10; CI = .11 − .50) and daughters (standardized indirect effect = .19; *p* < .01; SE = .06; CI = .08 − .31). That is, the effect of the frequency of problem behaviors and the distress associated with them on depressive symptomatology was not direct in the case of wives, husbands, and daughters. In other words, for these kinship groups, a higher frequency of problematic behaviors was related to higher levels of discomfort associated with problematic behaviors and guilt symptoms, and this relation- ship implied a greater report of depressive symptoms.

In the case of sons, the relationship between discomfort associated with problematic behaviors and depressive symptomatology was significant and direct, without the indirect effect of guilt, something that was not observed in the other kinship groups.

6.5. Discussion

The objective of this research was to study the impact of the sociocultural variables of familism (family obligations) and the bias of social desirability in the stress process of family care of people with dementia. In particular, it was intended to analyze the relationship of the mentioned variables with the dysfunctional thoughts of caregivers and their reports of discomfort associated with care, through indicators of discomfort associated with problematic behaviors of dementias, feelings of guilt and depressive symptomatology. The above relationships were studied considering the kinship relationship of the caregivers with the person cared for (wives, husbands, daughters and sons). The results suggest that daughters are subjected to higher stress than the other groups. In addition to being the group (along with sons) that most worked outside the home, they are the ones that reported more living with children and the greatest frequency of problematic behaviors and discomfort associated with these behaviors. Although in the study sample no significant differences were observed between the groups in cognitive status, some studies show that female caregivers seem to report a greater impact of problematic behaviors (Bédard et al., 2005). In addition, the results obtained by Neal et al. (1997) reflect that female caregivers who have a job (more likely in the case of daughter caregivers) have greater difficulties with problematic behaviors than men. Specifically, daughter caregivers who work outside the home do not reduce the hours dedicated to providing assistance to their family member with dementia, something that does happen when care is provided by sons (Bédard et al., 2005). This is in relation to the results obtained in the present study, since as can be seen in Table 1, although daughters spend on average fewer hours caring than spouses, they are the group that manifest higher levels of frequency and reaction to problematic behaviors. This shows the greater impact that problem behaviors have on them. Additionally, the presence of problematic behaviors is strongly associated with higher stress levels in caregivers, and a greater feeling of being trapped in the caregiver role (Bertrand et al., 2006).

Moreover, daughters reported fewer feelings of familism (family obligations) than the other kinship groups, something that could be related to being subjected to greater stress and the awareness of the clash between the different roles they must fulfill (Steiner & Fletcher, 2017). Although future studies should try to analyze this hypothesis, we believe that this higher exposure to stress during a long caregiving process may facilitate daughter caregivers' awareness of the objective difficulty and unfair imposition of responding to perceived pressures or demands derived from family values (Meira et al., 2017), which could lead them to a greater questioning of it. In addition, being a caregiver for a family member with dementia, which is a very demanding task, can lead to the appearance of discrepancies between the role of caregiver and other roles that the caregiver may have (e.g. mother, worker, etc.). When the standards or expectations of their relational identities are exceeded, this has been associated with higher levels of burden for caregivers (Savundranayagam & Montgomery, 2010). This may also be a reason for daughter caregivers reporting fewer feelings of family obligations. When daughters report caregiving behaviors that exceed personal expectations for the care- giver role, daughters may further question their perceived family obligations, adjusting their behaviors to identity standards associated with the role of being caregivers, in order to reduce the discrepancies between the caregiver role and their other roles. This discrepancy in roles and its association with the family obligations perceived by daughters is something that future interventions should consider to reduce the burden levels of daughter caregivers. Regarding the specific study hypotheses, the results obtained partially support the first hypothesis because, although significant associations were found for all kinship groups between family obligations and levels of dysfunctional thoughts, the relationship between social desirability and higher levels of dysfunctional thoughts was observed exclusively in the wives and daughters. It is possible that the relationship observed in women between social desirability and greater report of dysfunctional thoughts of care may be influenced by cultural values not evaluated, related to gender stereotypes or related attitudes such as machismo. The social and cultural consideration that care tasks should be assumed mainly by women (Toepfer et al., 2014) may influence the increased pressure on them to express socially desirable ways of acting in the face of care (e.g. ‘help should not be asked for’, ‘care should be carry out by the person who best knows the person being cared for’, etc.).

On the other hand, the results of the multigroup analysis suggest that, exclusively in daughters, levels of familism (family obligations) are indirectly associated with depressive symptomatology, through their influence on dysfunctional thoughts. Although daughters reported a lower perception of family obligation for care, it seems that, perhaps because they are subjected to a multiplicity of roles (Vaquiro & Stiepovich Bertoni, 2010), the difficulty of responding to family values when dealing with care leads them to face it in a more restrictive and maladaptive way, which ends up generating depressive feelings (Losada et al., 2010). That is, family obligations may lead daughter caregivers in particular to present dysfunctional thoughts associated with care (e.g. ‘it is selfish for caregivers to spend time on themselves’ or ‘a caregiver should only ask other people for help in extreme situations’) that may involve the use of dysfunctional coping strategies (for example, fewer self-care actions, less asking for help, etc., which in turn affects their levels of depressive symptomatology. Therefore, although daughter caregivers seem to express lower levels of feelings of familism (family obligations), they seem particularly vulnerable to the effects of familism and their consequences on depression symptoms. As mentioned above, dealing with multiple roles and responsibilities, together with difficulties in fulfilling expectations and family values may be key to understanding this seemingly paradoxical finding. Because of all this, it is very difficult for daughter caregivers to find a balance between caring for their relative and their own families and satisfying their own needs, such as spending time doing things of their interest or taking better care of their physical and mental health (McCabe et al., 2016; Tatangelo et al., 2018). Thus, future interventions focused on daughter caregivers should also include treatment components aimed at questioning feelings of family obligations, dealing with the multiplicity of roles, and providing daughter caregivers with resources and strategies for successful coping such as asking others for help.

However, the awareness of the difficulty to respond to family values would not prevent the emergence of feelings of guilt. It is precisely this distancing from a socially desirable value such as familism that may lead them, in turn, to report more feelings of guilt than wives and husbands, due to the internal conflict generated by the impossibility of responding to the family value of care. In the case of wives and husbands, caring for a spouse can be perceived as a duty that, in addition to not conflicting with other responsibilities (childcare and work), is expected as part of their marital commitment (Greenwood & Smith, 2019). However, no significant association was found between low values of familism and higher levels of guilt in daughter care-givers. This could be explained in that, although daughters may have lower levels of familism due to the great stress to which they are subjected and the awareness of the difficulty of responding to the demands and perceived pressures derived from familism, their approach to caregiving can conflict with the high familistic approach to caregiving of other relatives. This may generate in daughter caregivers what has been labelled as induced guilt: the comments, complaints, and criticisms of other relatives about the way in which the daughters deal with care can also be a source of guilt (Gallego-Alberto et al., 2022).

Regarding the second hypothesis of the study, which suggested that social desirability would be associated with a lower report of discomfort by caregivers, it is supported for the husbands, wives and daughters: higher social desirability was associated with a lower report of reaction to problem behaviors in wives and daughters, and a lower report of feelings of guilt in husbands, wives and daughters. The results of the multigroup analysis suggest that, in the case of daughters, the indirect relationship between social desirability and a lower report of guilt, through its influence on a lower report of reaction to problematic behaviors, is statistically higher than that observed in husbands. This is in accordance with the social context of the study, that is, given that care has traditionally been linked to the family and specifically to women, showing complaints or reactions to the problematic behavior of the family member or carrying out activities not linked to care (going out, letting off steam, etc.) would go against what is socially expected. For this reason, in order to fulfill their role as caregiver and not feel guilty for not reaching the norm or the ideal standard, caregivers (especially daughters) with high levels of social desirability could present difficulties when it comes to recognizing negative emotions and carrying out pleasant activities without the cared relative. In this way, the report of lower levels of guilt may reflect rigid behavior patterns developed to avoid feeling bad. Future stud- ies should delve into this analysis and explore the possible mechanisms involved in the relationships between social desir- ability, guilt, adaptive coping with caregiving and depression. Given the known relationship between feelings of guilt and depressive symptomatology, the results of this study suggest that psychosocial aspects such as social desirability may lead people to report being less affected by care (less discomfort associated with problem behaviors) and discomfort (less guilt and depressive symptomatology), which would limit the possibility of identifying vulnerable profiles in socially desirable caregivers. Specifically, the results of mean differences in the variables of problematic behaviors, guilt and depressive symptomatology suggest that daughters report more stress and guilt than the other groups, and similar levels of depressive symptomatology. However, the results of this study suggest that these levels could be higher than those reported, given that social desirability could be softening actual levels of discomfort, so that husbands, wives and daughters with high levels of social desirability could in fact have higher levels of discomfort than reported. This highlights the importance of using alternative assessment methods to self-report in certain profiles such as implicit information processing tasks. These, unlike self-report scales, are not subject to cultural bias, so they prevent the sub- ject from having time to reflect before responding (Cabrera et al., 2021; Márquez-Gónzalez et al. 2018).

Additionally, cultural values such as familism and the influence on it of the social desirability bias, could affect the judgment and thoughts of caregivers of family members with dementia, and thus their behaviors (Losada et al., 2010; Toepfer et al., 2014). This influence seems to occur unconsciously and automatically (Cabrera et al., 2021), which is why, with a view to the intervention with caregivers of people with dementia, the identification and discussion of dysfunctional thoughts is recommended (Losada et al., 2011; Toepfer et al., 2014). To this end, the use of well-established techniques that have empirical support, known as ‘cognitive restructuring’, is suggested. Therefore, as authors such as Márquez-González et al. (2007) and Toepfer et al. (2014) recommend, it is proposed in the first place to train caregivers in strategies that may help them to become aware of those dysfunctional thought patterns that take place automatically. Secondly, those dysfunctional thoughts that, after being evaluated, are concluded to be rigid or inflexible, and to be related to maladaptive coping strategies, will be modified in order to facilitate a more adaptive coping with the caregiving demands.

Regarding the last hypothesis of the study, related to differences in the kinship relationships studied, the results seem to confirm that there are differences depending on the kinship group in the care process. Although significant levels of depressive symptomatology and guilt seem to be found in all groups, the results suggest that daughters may be especially vulnerable to the process of care stress. They are the group that reported living more with children and working more outside the home. Although working outside the home may be felt as a relief by some caregivers (Segel-Karpas et al., 2018), the findings of the study show that daughter caregivers are subject to higher levels of behavioral and psychological symptoms of dementias and discomfort associated with them than the other kinship groups, and they reported more feelings of guilt than wives and husbands. Daughter caregivers are more likely to belong to what is known as the *sandwich generation*, a concept that refers to women between 40 and 60 who care for both their children and their parents (Miller, 1981; Sinha, 2013), and who also have to cope with the demands of a job. This multiplicity of roles leaves them with little time and energy to be able to meet the demands successfully, thus leading them to experience high levels of tension (Pierret, 2006). At the same time, it is in daughters that a clear negative/harmful relationship was observed in the influence of the familism value on their depressive symptomatology.

In daughters, the internalization of the cultural value of familism (family obligations) and their difficulty in reaching the socially established standard may be implicated in a greater presence of depressive symptoms. At this point, it is important to high- light that the variable family obligations measured in this study is taken from the revised familism scale (RFS; Losada et al., 2020). This scale is composed of items that were originally part of the 'familial obligations' and 'family as referents' subscales of the Sabogal et al. (1987) familism scale. Similar to findings in this study, these two subscales were found to be indirectly associated with depressive symptomatology through their effect on dysfunctional thoughts (Losada et al., 2010). Although in the Sociocultural Stress and Coping Model (Aranda & Knight, 1997) it was originally hypothesized that familism would be associated with positive effects, the findings of the current study are in agreement with Knight and Sayegh (2010), who developed the Updated Sociocultural Stress and Coping Model and concluded that familism did not have 'the consistently positive effects that we had originally hypothesized' (p. 7).

In terms of the evaluated model, relevant percentages of explained variance were obtained for guilt and depressive symptoms for all study groups (ranging between 18% and 37%) except for depressive symptoms in wives (12%), and feelings of guilt in sons (5%). Given that wives showed similar levels of depressive symptomatology to daughters, and sons similar lev- els of guilt symptomatology to daughters, the low percentage variance in depressive symptomatology for wives and the low percentage for guilt in sons seems to suggest that variables explaining these dimensions in them may be different from those evaluated in this study. For example, variables such as leisure activities or the presence of feelings of ambivalence are variables observed in the previous literature that can also influence the levels of these symptoms of informal caregivers (Losada et al., 2018; Schüz et al., 2015).

The results of this study provide additional support for the assumptions made by Knight and Sayegh (2010) in the socio- cultural stress and coping model. Thus, support is provided for the impact that the core model, formed by the frequency of problematic behaviors and reaction to them, has on the discomfort of caregivers of relatives with dementia. As suggested in Losada et al. (2018), the impact of problematic behaviors associated with dementia on depressive symptomatology is largely explained through guilt. In addition to con- firming the core model, the results of this study confirm the relevant role of sociocultural variables such as familism (specifically, family obligations), social desirability and dysfunctional thoughts, in explaining caregivers' discomfort. Furthermore, this study adds to the sociocultural model the importance of considering kinship profiles.

This study has a number of limitations that should be noted. First, although the sample size is similar to that of other studies carried out with caregivers, the sample is not representative of the population of caregivers as it is made up of voluntary participants, and the sample size of some of the groups may be considered small, something that might have influenced the results. This might be the case especially for husbands and sons. Caution is recommended when interpret-ng the results as the number of participants in these groups is small, and all the more so considering the number of assessed variables. Therefore, future studies with larger samples of male caregivers are needed in order to confirm the findings of this study. Secondly, it is a cross-sectional study, so the results cannot determine the existence of a causal relationship between the selected variables. Also, the relation- ships shown in the model, although based on the sociocultural stress and coping model, must be taken with caution since the possibility that other models may also be relevant cannot be disregarded. Longitudinal and experimental studies are needed to confirm the obtained findings. Thirdly, the present study is framed within the European context, specifically in a Mediterranean society, that may have cultural characteristics different to other regions (e.g. the north of Europe; Uccheddu et al., 2019). Thus, future studies are needed in different cultural contexts in order to confirm the generalizability of the findings. In addition, regarding the social desirability measure, given that Cronbach's alpha levels are lower than recommended, the results that suggest a tendency of caregivers to give socially desirable answers should be interpreted with caution. The variables that make up the proposed model are based on self-report responses from caregivers. Thus, these may be influenced by this tendency to appear desirable. It would be recommended that future research includes information from a second source to control for the effects of social desirability. Finally, because in this investigation only the dimension of family obligations was analyzed, it would be interesting if future studies could analyze other dimensions of familism and their effect on desirability and feelings of guilt and depression. In addition, given that some of the items of the family obligations scale refer to the obligations that adult children could have to their parents, these could be interpreted differently by the child caregivers than by spousal caregivers.

Despite the aforementioned limitations, the present study is the first to analyze the joint influence of the variables social desirability and familism (family obligations) in the process of care stress, taking into account the kinship relationship of the caregivers with the people cared for. The results suggest that the levels of discomfort of caregivers who report high social desirability could be higher than those already indicated and show that daughters may be in a situation of special vulnerability to the stress of care, perhaps due to being subjected to more sources of stress and being more affected by the negative effects of culturally accepted values such as familism. These results support the need to take into account the influence of sociocultural aspects in the evaluation and in the design and implementation of interventions for caregivers (Cheng et al., 2019). In cultural contexts influenced by values such as familism, it would be convenient for the interventions to include treatment components aimed at reducing the pressure exerted by this cultural value and the norms associated with it on the dysfunctional thoughts associated with care and the consequences that this could have in the presence of feelings of guilt and depression of family caregivers.

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ESTUDIO TRES

Profiles of dementia caregivers according to psychosocial and resource variables. Importance of kinship.

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7. Estudio tres: Profiles of dementia caregivers according to psychosocial and resource variables. Importance of kinship.

7.1. Abstract

Objectives: The present study aims to analyze the existence of different profiles in family caregivers of people with dementia according to psychosocial and resource variables. In addition, it aims to study whether there is a greater representation of each kinship group in each of the profiles and if there are differences in emotional distress among such profiles considering the kinship with the care-recipient. **Design**: information on psychosocial variables (familism, dysfunctional thoughts and experiential avoidance), resource variables (leisure activities and social support) and outcomes variables (depressive, anxious and guilt symptomatology) was collected. A hierarchical cluster analysis using Ward's method, an exploratory factor analysis of two fixed factors and contingency tables were performed. **Setting**: community-welling of dementia family caregivers. **Participants***:* 288 family dementia caregivers, divided into four kinship groups (wives, husbands, sons and daughters). **Measurement**: The scales RFS (familism), CPD (dysfunctional thoughts), EACQ (experiential avoidance), Leisure Time Satisfaction (leisure), PSQ (social support), CGQ (guilt symptomatology, CESD (depression) and POMS (anxiety) were assessed **Results**: Five clusters were obtained: *Low psychosocial vulnerability-High resources, Low psychosocial vulnerability-Low resources*, *Mixed*, *High psychosocial vulnerability-High resources*, and *High psychosocial vulnerability-Low resources*. Results suggested that clusters associated with lower distress were the Low psychosocial vulnerability-High resources and the High psychosocial vulnerability-High resources. Clusters associated with higher distress were the Low psychosocial vulnerability-Low resources and Mixed. **Conclusions***:* High levels of dysfunctional thoughts, familism and experiential avoidance do not always have a maladaptive function.

This could depend on sociocultural and resource variables such as the kinship with the caregiver or perceived social support. The identification of profiles of family caregivers potentially needing protection and vulnerable to psychological distress could help to increase the effectiveness of interventions aimed at this population.

Keywords*: kinship, dementia caregivers, vulnerability, psychosocial variables, resources,*

7.2. Introduction

Caring for a family member with dementia is considered a chronically stressful experience due to the many varied and variable tasks caregivers face for many hours a day over an extended period of time (Alzheimer's Association, 2023). Caregiving for a family member with dementia is primarily performed by women, with caregiving more likely to be undertaken by daughters and wives than by husbands and sons (Stall et al., 2019).

Different theoretical models have tried to explain the process of stress associated with the task of caregiving, among which Knight and Sayegh's (2010) sociocultural model of stress and coping adapted to caregiving stands out. This model, following what was proposed in the stress and coping model posited by Lazarus and Folkman (1984), in addition to highlighting the influence on the consequences that the stress associated with care can generate based on the evaluation of the individual’s personal and social resources, also highlights the influence of cultural values on the different processes of coping with care.

Specifically, the sociocultural model of stress and coping highlights the significant role that cultural variables such as familism play in the caregiving process through their influence on the caregiver's social support and coping strategies (McCleary & Blain, 2013). The value of familism, defined as strong feelings of attachment, loyalty, reciprocity and solidarity among family members (Aranda & Knight, 1997), is especially characteristic of some societies, such as Mediterranean societies (Cordella & Rojas-Lizana, 2020). One of its main dimensions is the dimension of family obligations. This dimension refers to the obligation perceived by an individual to provide material and emotional help to other family members, generating the belief that taking care of the family is a duty and that it should be taken into account in decision making (Eifert et al., 2015). Due to socialization into different gender roles, caregiving is attributed to and performed primarily by women, and it is women who internalize to a greater extent the perception of caring for a sick family member as a moral obligation (Meira et al., 2017).

The literature points to a negative influence of the perception of family obligations on the mental and physical health of family caregivers (Knight & Sayegh, 2010; Losada-Baltar et al., 2022), being related to the presence of dysfunctional thoughts associated with caregiving (Losada et al., 2010). For example, they may give rise to (1) thoughts related to the family's duty of care (e.g., "only the closest person knows how to take truly good care of a sick relative"); (2) not asking for help (e.g., "a caregiver should only ask for help from other people when the situation is limiting"); or (3) full dedication to the sick relative (e.g., "when a person cares for a sick relative, he/she should leave his/her interests aside and dedicate him/herself completely to the sick person"). These thoughts can facilitate maladaptive behaviors in caregivers and can have important consequences on their emotional distress (Losada et al., 2006). In addition, dysfunctional thoughts have been found to be associated with experiential avoidance (Losada et al., 2014), another variable that is significantly associated with caregiver distress (Cheng et al., 2019). This variable refers to the tendency to avoid contact with negative internal experiences (e.g., thoughts, emotions, and images) and to avoid the events or contexts that provoke them (Hayes et al., 1996). High experiential avoidance in caregivers, aimed at rigidly controlling unwanted internal experiences, could be associated with the occurrence of depressive (Spira et al., 2007) and anxious symptomatology and physical health problems (Márquez-González et al., 2018; Whitebird et al., 2013;) Thus, the existence of dysfunctional thoughts hinders the building of broad social support and carrying out adequate coping strategies such as the performance of self-care or leisure/pleasurable activities, favoring the appearance of depressive (Losada et al., 2018), anxious (Sullivan et al., 2016) and guilt symptomatology (Losada et al., 2015).

Regarding the mental health of caregivers of people with dementia, there is a large literature that supports higher rates of psychological morbidity in family caregivers of people with dementia compared to caregivers of other chronic diseases, such as cancer or stroke (Collins & Kishita, 2020; Pinquart & Sörensen, 2003) and to the general population (D'Aoust et al., 2015). Within this psychological morbidity, the study of depression and, to a lesser extent, anxiety, has received a great deal of attention from researchers due to their high prevalence in that population (Hopkinson et al., 2019). However, guilt feelings have been scarcely studied by previous literature, despite being considered, in addition to depressive and anxiety symptomatology, a highly prevalent emotion in dementia family caregivers (Losada et al., 2010, 2018). Cultural values that facilitate the perception of caregiving as an obligation to which one must respond in the most "perfect" way possible, or the belief that one does not achieve what is expected of a good caregiver, are some of the reasons that seem to be related to the appearance of the feeling of guilt (Gallego-Alberto et al., 2020). It is female caregivers, especially daughters, who present higher levels of emotional distress, both depressive and anxious symptomatology and guilt (Erol et al., 2016; Losada et al., 2010). Thus, although the kinship of caregivers has not been taken too much into account, different studies suggest that caregiving daughters, probably due to the multiplicity of roles they must cope with (e.g., work, motherhood, etc.), are at a higher risk of presenting mental health problems (Romero-Moreno et al., 2014; Conde-Sala et al., 2010).

Taking into consideration all of the above, and in accordance with the sociocultural model of stress and coping (Knight & Sayegh, 2010), the present study aims to analyze the existence of different profiles of family caregivers of people with dementia, according to the levels manifested in different psychosocial and resource variables: familism (family obligations), dysfunctional thoughts, experiential avoidance, perceived social support and leisure activities. In addition, the aim is to study whether there is a greater representation of each kinship group in each of the profiles and to analyze if there are differences in the levels of depressive, anxious and guilt symptomatology among them. In this respect, a further aim is to study whether the most vulnerable profiles are predominantly represented by women, especially caregiving daughters, considering the above-mentioned previous literature. This may improve the identification of vulnerable caregivers and dedicate more resources according to kinship.

Specifically, (1) different profiles are expected to be obtained depending on the combination of high or low levels in the psychosocial variables and high or low levels in the resource variables. Secondly, it is hypothesized that (2) those profiles characterized by high levels of familism, dysfunctional thoughts and experiential avoidance (high scores in these variables are considered psychosocial vulnerability) and presenting low levels of perceived social support and leisure activities (low levels of resources) will manifest greater depressive, anxious and guilt symptomatology. Conversely, (3) those profiles with low levels of familism, dysfunctional thoughts and experiential avoidance (low scores in these variables are considered low psychosocial vulnerability) and with higher levels of social support and leisure activities (high levels of resources) will present lower levels of these symptomatologies. Finally, it is expected that (4) those profiles with higher levels of emotional distress, that is, higher levels of anxious, depressive and guilt symptomatology, will correspond to a predominance of the wife and daughter kinship groups. Specifically, it is expected that the profile with higher levels of the aforementioned symptomatologies will have a greater presence of caregiving daughters.

Therefore, the present study contributes to the field of dementia caregivers by identifying vulnerable profiles according to psychosocial and resource variables considering their influence based on the kinship relationship with the cared person. In this way, it is intended to inform practitioners about potential vulnerability profiles that may benefit from specific interventions and resources that might be offered to caregivers according to the identified profiles.

7.3. Methods

7.3.1. Participants and procedure

A total of 288 family caregivers of people with dementia, aged between 28 and 88 years (mean = 62.98; S.D. = 12.78), residing in Madrid (Spain), participated in this cross-sectional study. A greater number of women (68.11%; n =196) than men (31.89%; n= 92) participated in the present investigation, divided into four groups according to kinship with the cared-for person, namely: wives (n=74), husbands (n=59), daughters (n =122) and sons (n= 33).

Participants were recruited through different health centers and social services of this community, where, in an initial contact with the subjects, compliance with the criteria for inclusion in the study was confirmed, namely: (1) be recognized as the primary caregiver of the family member diagnosed with dementia; (2) spend at least one hour of care per day or a total of 7 hours per week; and (3) have been caring for the ill family member for at least the last three consecutive months. These criteria are consistent with the general characteristics of the caregiving population (Alzheimer’s Association, 2023), and are similar to the criteria used in different research with a sample of caregivers (e.g., Sutter et al., 2014; Yu, et al., 2016). Three hundred forty-nine persons were initially contacted via telephone. Of those, 61 finally did not take part in the study because they did not meet the inclusion criteria (n=19), because it was impossible to contact them (n=24), or because they changed their mind and refused to participate (n=18). No specific sample size was previously determined, all the caregivers that who contacted through the study were assessed.

Assessment of the caregivers participating in the study was carried out in face-to-face interviews by trained psychologists between January 2017 and March 2020. The evaluations were performed in Spanish and took between 45 minutes and 1 hour 50 minutes. The present study was approved by the ethics committee of Rey Juan carlos University and prior to evaluation all subjects signed an informed consent for participation.

7.3.2. Variables and instruments

The instruments used were self-administered questionnaires carried out face to face by trained psychologists. These questionnaires are designed to be completed without the help or bias of the interviewer.

Sociodemographic variables. Caregivers' age, gender, kinship relationship with the person cared for, time spent caring, and daily hours dedicated to care were collected. The type of illness and the cognitive status of the care recipient were also collected. Cognitive status was measured using the Global Deterioration Scale (GDS; Reisberg et al., 1982) that consist of the clinical description of 7 phases of dementia progression ranging from (1) normality to (7) severe dementia.

-*Familism*. The "family obligations" subscale of the Revised Familism Scale (Revised Familism Scale, RFS; Losada et al., 2019, Spanish version), composed of five items (e.g., "people should always obey their parents without arguing even if they thought they were right"), was administered. The response range lies between 0 "*strongly disagree*" and 4 "*strongly agree*", with higher scores corresponding to higher perceptions of family obligations. This scale had an internal consistency (Cronbach's Alpha) for the present study of 0.75.

-*Dysfunctional thoughts*. The Dysfunctional Thoughts Questionnaire (CPD; Losada et al., 2006), developed in Spanish, was used. It is composed of 16 items (e.g., "when a person takes care of a sick person, he/she should leave his/her interests aside and devote him/herself completely to the sick person"). The response range is between 0 and 4, with higher scores on the scale corresponding to a greater presence of dysfunctional thoughts and beliefs that hinder adaptive coping with the task of caregiving. The scale presented an internal consistency (Cronbach's Alpha) of 0.91 in the present study.

-*Experiential avoidance*. The Experiential Avoidance in Caregiving Questionnaire (EACQ; Losada et al., 2014, Spanish version) scale was used, consisting of 15 items (e.g., "If a caregiver has negative thoughts about his or her family member, it is best to try to ignore them") with a response range from 1 "*not at all*" to 5 "*very much*". Higher scores on this scale correspond to higher levels of experiential avoidance. The internal consistency (Cronbach's Alpha) in the present study was 0.69.

-*Social support*. The Social Support Questionnaire (PSQ; Reig et al., 1991) developed in Spanish was administered and it is composed of 6 items (e.g., “When I need it, I have someone who can give me important financial or material help”) with a response range between 0 "*neve*r" and 3 "*always*". Higher scores correspond to a higher perception of social support and the internal consistency (Cronbach's Alpha) for the selected sample was 0.77.

-*Frequency of leisure activities*. This was evaluated using an adaptation of the Leisure Time Satisfaction scale (LTS; Stevens et al., 2004;) composed of 6 items (e.g., "During the past month I have had time to spend good times with other people") with a response range between 0 "*not at all*" and 2 "*very much*". This scale, administrated in Spanish (Romero-Moreno et al., 2014), allows the effect of caregiving on leisure time satisfaction to be evaluated. The internal consistency (Cronbach's Alpha) for the present study was 0.71.

Outcomes variables

-*Feelings of guilt.* The Caregiver Guilt Questionnaire (CGQ; Losada et al., 2010; developed in Spanish) composed of 22 items (e.g., “I have felt bad about leaving my family member in someone else's care while I was having fun") was used, with a response range from 0 "*never*" to 4 "always or almost always". Higher scores correspond to a greater feeling of guilt in the caregiver, with the cut-off point for clinically relevant scores being established at scores equal to or higher than 22. The scale presented an internal consistency (Cronbach's Alpha) for the sample studied of 0.88.

-*Anxious symptomatology*. The Tension subscale of the Profile of Mood States (POMS; McNair et al., 1971) was used. The Spanish version (Balaguer et al., 1993) was administered, which uses 9 multidimensional adjectives (e.g., restless or nervous) with a response range between 0 "*not at al*l" and 4 "very much" to evaluate the person's affect and feelings. Higher scores on the scale correspond to higher levels of anxious symptomatology, whose cut-off point is established at scores equal to or higher than 13 (Losada et al., 2015). The internal consistency (Cronbach's Alpha) of the scale for the present study was 0.82.

-*Depressive symptomatology*. The Center for Epidemiological Studies - Depression Scale (CES-D; Radloff, 1977; Spanish version by Losada et al., 2012) consisting of 20 items (e.g., "I thought my life had been a failure") with a response range between 0 "r*arely or never*" and 3 "*all the time*" was administered. This scale sets the cut-off point at scores equal to or higher than 16 (Radloff, 1977) and assesses the presence of different depressive symptoms that participants may have experienced during the last week. The internal consistency of this scale (Cronbach's Alpha) for the present investigation presented a value of 0.89.

7.3.3. Data analysis

On the one hand, descriptive and frequency analyses were carried out to identify the characteristics of the total sample. On the other hand, a hierarchical cluster analysis was performed using Ward's method with the aim of identifying homogeneous groupings of subjects according to the scores obtained by the study participants on 5 variables: familism (family obligations), dysfunctional thoughts, experiential avoidance, leisure activities and social support. Z-scores were used to compare the scores obtained on these scales. In addition, mean comparisons were made between the scores obtained for each variable in each of the clusters in order to identify the common characteristics of each of the clusters/profiles obtained (Yim & Ramdeen, 2015). Subsequently, an exploratory factor analysis of two fixed factors was performed, which allowed the generation of a scatter plot according to these clusters (Ward's method variable; Revelle, 2020). Contingency tables were run between the 5 clusters/profiles found and the variable of kinship with the cared-for person to find the distribution of participants according to this variable. Finally, considering the distribution in the clusters of the participants according to kinship, contingency tables were also made between the clusters and the emotional variables depressive symptomatology, anxious symptomatology and dichotomized guilt symptomatology to identify whether there are differences in these symptomatologies among clusters. For this purpose, the cut-off points in each of these scales were used to identify people with clinically significant levels in each variable. The analyses performed in the present investigation were carried out with the Statistical Package for the Social Sciences (SPSS Statistics 22). Data collection was not preregistered. The study materials, analytic methods, and data are available from the corresponding author on reasonable request.

7.4. Results

7.4.1. Characteristics of the sample

The characteristics of the sample are shown in Table 1. It was observed that the average time the participants had spent caring was 50.62 months (S.D. = 42.96) and that the average daily hours dedicated to care was 13. Wives was the group which presented higher levels of time spent caring, with an average of 58.05 months (S.D. = 61.02), and both wives and husbands were the groups which dedicated more daily hours of care, with an average of 16 hours (wives: S.D. = 7.31, husbands: S.D. = 6.82). In addition, the results show that the predominant type of dementia in the sick relative was Alzheimer’s disease (n = 165; 57.30%) and the mean value of the patient´s cognitive assessment (GDS) was 4.62, corresponding to moderate-severe cognitive impairment. In Table 1, the means obtained by each kinship group for each the assessed variables can be seen.

Table 7.1. *Characteristics of the sample*

	TOTAL SAMPLE		1.WIVES (25.71%)		2. HUSBANDS (20.48%)		3. DAUGHTERS (42.40%)		4.SONS (11.41%)	
Variables	Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	S. D
Alzheimer´s dementia (N)	165		36		41		69		19	
Age	62.98	12.78	72.31	7.85	75.07	6.78	54.02	8.30	52.88	9.94
Time spent caring	50.62	42.96	58.05	61.02	47.28	31.72	48.14	36.40	48..84	31.32
Daily hours of care	13.02	7.83	16.26	7.31	16.76	6.82	10.70	7.39	7.43	5.84
Cognitive status	4.62	1.25	4.58	1.22	4.40	1.21	4.80	1.26	4.50	1.28
Family obligations	8.31	4.20	9.93	4.00	9.82	4.64	6.45	3.52	8.76	3.43
Dysfunctional thoughts	27.59	15.03	34.41	14.98	38.41	12.49	18.91	11.08	25.06	12.29
Experiential avoidance	44.35	9.55	48.11	9.05	47.20	9.90	41.50	9.24	41.33	6.60
Leisure activities	5.90	2.74	5.60	2.68	6.52	2.71	5.72	2.80	6.12	2.68
Social support	10.92	3.97	11.40	3.78	10.57	4.47	11.39	3.66	8.72	3.96
Depressive symptomatology	17.42	10.90	18.13	10.93	13.05	8.68	18.97	11.36	18.00	11.11
Anxious symptomatology	16.22	7.98	16.25	7.58	11.65	7.58	18.50	7.64	16.07	7.56
Guilt	20.66	12.95	14.15	9.80	16.30	10.55	25.50	13.10	25.40	13.92

7.4.2. Classification of participants according to clusters

Figure 1 shows the dendogram obtained after performing the cluster analysis, which suggests the existence of 5 possible grouping clusters for the variables familism, dysfunctional thoughts, experiential avoidance, social support and leisure activities.

Table 2 shows the mean scores on each variable for each cluster. These results show that the first cluster, called *Low psychosocial vulnerability-High resources*, had levels below average of CPD and familism, at average levels of avoidance and levels above average of leisure and social support. The second cluster, called *Low psychosocial vulnerability-Low resources,* shows levels below average of the cultural-cognitive variables (CPD, familism and experiential avoidance) and levels below average of leisure and social support. Thirdly, the cluster called Mixed presents levels below average of CPD and familism, levels above average of experiential avoidance, at average levels of leisure and levels below average of social support. Fourth, *the High psychosocial vulnerability-High resources* cluster presents levels above average of CPD, familism and experiential avoidance, as well as levels above average of leisure and social support. Finally, the fifth cluster, labeled *High psychosocial vulnerability-Low resources,* reflects levels above average of CPD and familism, at average levels of experiential avoidance and social support, and levels below average of leisure.

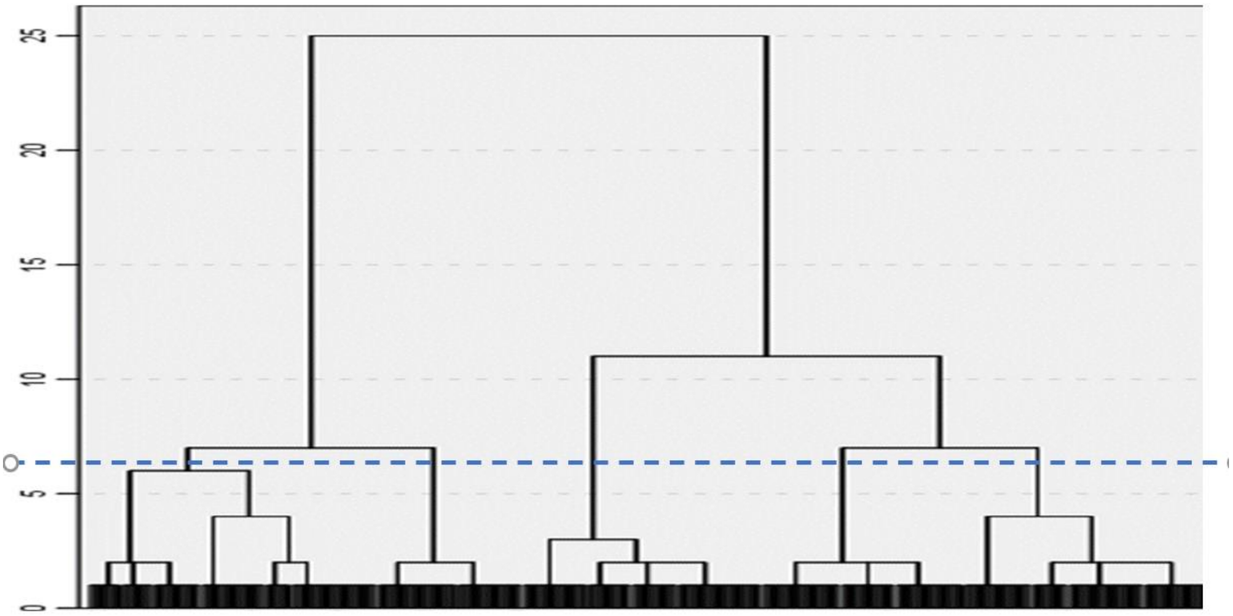

Figure 7.1. *Cluster dendrogram using Ward method. Dashed line identifies the 5-cluster solution* Figure 1 shows the dendrogram created by the SPSS program. The X-axis represents the individual cases and the hierarchical brackets above them reflects the gradual hierarchical grouping at each stage. The horizontal line added to the Y-axis (the rescaled distance cluster combine) indicates the optimal cut-off point for clustering, showing that the cases were merged into 5 groups in the second to last hierarchy: *1. Low psychosocial vulnerability-High resource, 2. Low psychosocial vulnerability-Low resources, 3. Mixed, 4. High psychosocial vulnerability-High resources, 5. High psychosocial vulnerability-Low resources.*

Table 7.2. *Means in each variable for each cluster.*

Cluster	N	Dysfunctional thoughts (CPD)	Familism	Experiential avoidance	Leisure activities	Social support
1-Low psychosocial vulnerability-High resources	63	16.26	7.83	43.62	8.58	19.49
2-Low psychosocial vulnerability-Low resources	52	14.00	6.02	35.32	4.80	11.77
3-Mixed	61	24.85	8.10	46.02	5.17	6.67
4-High psychosocial vulnerability-High resources	38	42.76	16.40	54.68	7.63	13.68
5-High psychosocial vulnerability-Low resources	74	41.90	13.21	44.88	4.26	10.43
Total	288	27.68	10.05	44.38	5.94	10.97

7.4.3. Factor analysis and scatterplot of the clusters

The results obtained from the exploratory factor analysis of the 5 psychosocial and resources variables evaluated (dysfunctional thoughts, familism, experiential avoidance, leisure and social support) suggest the existence of two factors (KMO and Bartlett's test: 0.60 < 0.001). A first factor is composed of the three cultural/cognitive variables: familism, CPD and experiential avoidance. The second factor is composed of the two resource variables: leisure activities and social support. The factor loadings of each variable on each factor are in all cases greater than .70. The factor loadings of each variable on the other factor do not exceed .20 in any case.

7.4.4. Relationship between the groups obtained and the relationship with the caregiver

The results show the existence of significant differences between the groups according to kinship with the cared-for person (*chi-square* = 104, 07; p = 0.001< 0.05). As can be seen in Table 3, compared to the other kinship groups, the wives group is mainly grouped in cluster 5 (High psychosocial vulnerability-Low resources); the husbands group in cluster 4 (High psychosocial vulnerability-High resources); the daughters group in clusters 1 and 2 (Low psychosocial vulnerability-High resources and Low psychosocial vulnerability-Low resources), and for the sons group there are more than expected compared to other groups in cluster 3 (Mixed profile).

Table 7.3. *Relationship between obtained clusters and kinship with the care-recipient*

		1-Low psychosocial vulnerability-High resources	2-Low psychosocial vulnerability-Low resources	3-Mixed	4-High psychosocial vulnerability-High resources	5-High psychosocial vulnerability-Low resources	Total
Wifes	Count	10.00	7.00	11.00	12.00	34.00	74.00
	Expected count	16.20	13.40	15.70	9.80	19.00	
	Corrected residual	-2.00	-2.20	-1.50	0.90	4.60	
Husbands	Count	6.00	2.00	11	19.00	21.00	59.00
	Expected count	12.90	10.70	12.5	7.80	15.20	
	Corrected residual	-2.40	-3.30	-0.5	4.80	2.0	
Daugthers	Count	38.00	42.00	25.00	5.00	12.00	122.00
	Expected count	26.70	22.00	25.80	16.01	31.30	
	Corrected residual	3.3	6.2	-0.2	-3.99	-5.3	
Sons	Count	9.00	1.00	14.00	2.00	7.00	33.00
	Expected count	7.20	6.00	7.00	4.40	8.50	
	Corrected residual	0.80	-2.40	3.20	-1.30	-0.6	

7.4.5. Relationship between the groups obtained and depressive symptomatology

The results show the existence of significant differences in the presence of depressive symptomatology between the different profiles/clusters (*chi-square* = 33.47; $p = 0.001 < 0.05$). As can be seen in Table 4, the data show that for the Low psychosocial vulnerability-High resources (1) and High psychosocial vulnerability-High resources (4) profiles, there is a lower-than-expected number of cases with clinically significant depressive symptomatology, with means for this symptomatology of 13.66 and 11.89, respectively. In contrast, for the Low psychosocial vulnerability-Low resources (2) and the Mixed (3) profiles, whose means were 19.69 and 20.59, the opposite occurred, with more cases than expected with clinically significant depressive symptomatology. In the case of the High psychosocial vulnerability-Low resources (5), no differences were found in the distribution of people in this profile according to depressive symptomatology. The depressive symptomatology mean in this group was 19.13.

Table 7.4. *Relationship between cluster groups obtained and depressive, anxious and guilt symptomatologies.*

		Depressive symptomatology significant		Anxious symptomatology significant		Guilt symptomatology significant		
		No	Yes	No	Yes	No	Yes	total
1-Low psychosocial vulnerability-High resources	Count	45.00	18.00	27.00	36.00	27.00	36.00	63
	Expected count	33.70	29.30	21.90	41.10	35.40	27.60	
	Corrected residual	3.20	-3.20	1.50	-1.50	-2.40	2.40	
2-Low psychosocial vulnerability-Low resources	Count	20.00	32.00	8.00	44.00	23.00	29.00	52
	Expected count	27.80	24.20	18.10	33.90	29.30	22.80	
	Corrected residual	-2.40	2.40	-3.20	3.20	-2.00	2.00	
3-Mixed	Count	23.00	38.00	12.00	47.00	29.00	32.00	61
	Expected count	32.60	28.40	21.00	39.80	34.30	26.70	
	Corrected residual	-2.80	2.80	-2.20	2.20	-1.50	1.50	
4-High psychosocial vulnerability-High resources	Count	29.00	9.00	20.00	18.00	31.00	7.00	38
	Expected count	20.30	17.70	13.20	24.80	21.40	16.60	
	Corrected residual	3.00	-3.00	2.50	-2.50	3.40	-3.40	
5-High psychosocial vulnerability-Low resources	Count	37.00	37.00	31.00	43.00	52.00	22.00	74
	Expected count	39.60	34.40	25.7	48.30	41.60	32.40	
	Corrected residual	-0.70	0.70	1.50	-1.50	2.80	-2.80	
Total		154.00	134.00	100.00	188	162.00	126.00	288

7.4.6. Relationship between the groups obtained and anxious symptomatology.

The data obtained reveal the existence of significant differences in the presence of anxious symptomatology between the different profiles/clusters (*chi-square* = 27.88; p = 0.001< 0.05). As can be seen in Table 4, it is observed that for the High psychosocial vulnerability-High resources profile (4), there are fewer cases than expected with clinically relevant levels of anxious symptomatology, with a mean of 11.92 for this symptomatology. In contrast, for the Low psychosocial vulnerability-Low resources profile (2) and the mixed profile (3), there were more cases than expected with clinically significant levels of such symptomatology. The mean obtained for profile 2 was 19.94, with 18.02 for profile 3. Finally, for the Low psychosocial vulnerability-High resources (1) and High psychosocial vulnerability-Low resources (5) profiles, the cases are distributed as expected. The means of anxious symptomatology in both groups were 15.14 and 15.26, respectively.

7.4.7. Relationship between the obtained groups and guilt symptomatology.

The results show the existence of significant differences in the presence of guilt symptomatology between the different profiles/clusters (*chi-square* = 21.69; p = 0.001< 0.05). As can be seen in Table 4, the data reflect that the High psychosocial vulnerability-High resources (4) and High psychosocial vulnerability-Low resources (5) profiles present fewer cases than expected with clinically relevant levels of guilt, with means for this symptomatology of 13.87 and 16.47. In contrast, the Low psychosocial vulnerability-High resources (1) and Low psychosocial vulnerability-Low resources (2) profiles have more caregivers than expected with clinically relevant levels of guilt. The mean obtained for profile 1 was 23.44, with 24.10

for profile 2. For the Mixed profile (3), guilt levels were consistent with those expected, with a mean of 24.36.

7.5. Discussion

The aim of this study was to identify the existence of profiles of family caregivers of people with dementia according to the levels manifested in different psychosocial and resource variables and to analyze if there is a greater representation of each kinship group in each of the profiles. In this way, it was attempted to analyze which profile appears to be more vulnerable and which more protected against the emotional distress associated with the task of caregiving according to kinship. In addition, it was also intended to study if the most vulnerable profiles are represented mostly by women, especially by caregiving daughters.

The results of this research suggest, in relation to the first hypothesis, the existence of 5 clusters formed from the variables family obligations, dysfunctional thoughts, experiential avoidance, perceived social support and leisure activities. Specifically, the identified clusters have been named (1) Low psychosocial vulnerability-High resources, (2) Low psychosocial vulnerability-Low resources, (3) Mixed, (4) High psychosocial vulnerability-High resources and (5) High psychosocial vulnerability-Low resources.

As hypotheses 2, 3 and 4 suggested, the results show, on the one hand, differences in the significance of emotional distress depending on the cluster and, on the other hand, that the distribution of participants in each of the clusters is significantly related to the relationship of kinship. This is, as mentioned in the previous section, the wives group primarily in cluster 5 (High psychosocial vulnerability-Low resources), husbands in cluster 4 (High psychosocial vulnerability- High resources), daughters in clusters 1 and 2 (Low psychosocial vulnerability-

High resources and Low psychosocial vulnerability-Low resources), and sons to a greater extent than the other groups in cluster 3 (Mixed Profile).

Furthermore, the results obtained suggest that profile 2 (Low psychosocial vulnerability-Low resources), in which the majority of caregiving daughters are distributed, seems to be particularly vulnerable to presenting higher levels of emotional distress. This profile, while manifesting low levels of familism, experiential avoidance and dysfunctional thoughts associated with caregiving, also presents low levels of leisure and social support and high levels of depressive, anxious and guilt symptomatology. According to previous literature, caregiving daughters are subjected to higher levels of stress due to the multiplicity of roles they must cope with (Steiner & Fletcher, 2017). This would lead them to question to a greater extent the socially imposed pressures derived from the familistic values that characterize Mediterranean society (Meira et al., 2017). On the other hand, questioning and rationalization of the existing difficulties in complying with social demands does not protect them from presenting high levels in such symptomatologies, since moving away from a socially desirable value such as familism can lead them to an internal conflict derived from the impossibility of responding as society expects. Therefore, the presence of high levels of psychological distress in this profile seems to indicate that social norms could be having an implicit influence on the daughters. That is, although explicitly the caregiving daughters seem not to adhere to the socio-familial norms to which they are subjected, implicitly these seem to still be present (Márquez-González et al, 2018). In addition, this profile presents greater social vulnerability, so it could be called *Maladaptive Functional*, because although the levels of psychosocial vulnerability are low, the levels of resources are also low, presenting high levels of psychological discomfort.

Following profile 2, profiles 3 (Mixed) and 5 (High psychosocial vulnerability-Low resources) also appear to be vulnerable to psychological distress. In relation to profile 3 (Mixed), although the levels of familism and dysfunctional thoughts are below average, the presence of social support is low. For this group, comprising more son caregivers than expected, coming to adopt the role of primary caregiver usually implies that they are alone and do not have the support of other women in the environment (Huertas-Domingo et al., 2021). This, in turn, leads them to have an environment with few reinforcers, which would explain the presence of psychological distress, especially high levels of depressive symptomatology. With respect to profile 5, represented mostly by wives, although the number of caregivers with high levels of guilt is lower than expected, 50% of the subjects present clinically significant depressive symptomatology. One possible explanation for the lower levels of guilt is that although this profile is characterized by high levels of familism and dysfunctional thoughts, these do not conflict with other roles, so these caregiving wives "can afford" to act as expected. However, acting in accordance with these socially imposed norms leads wives to reduce their levels of leisure and reinforcers, as they "must put their interests aside and devote themselves to the sick family member," influencing levels of depressive symptomatology. Therefore, this profile could be called *Pathological* since the levels in the variables studied are related to vulnerability to psychological discomfort.

In relation to profile 1 (Low psychosocial vulnerability-High resources), although the levels of depressive symptomatology are lower than expected, this does not occur with the levels of guilt symptomatology. The fact that profile 1 is mostly represented by caregiving daughters could explain the high levels of such symptomatology. As mentioned above, because of the social pressures to which they are subjected, presenting high levels of leisure and social support (unlike profile 2) could at the same time facilitate lower levels of depressive symptomatology and high levels of guilt due to the existence of internal conflict caused by not acting in accordance with what is expected of them. Consequently, this profile could be called *Adaptive*, while considering that the high levels of guilt symptoms could, in the long term, modify the use of resources and increase the vulnerability to psychological distress

Finally, the results also suggest that the presence of high levels of familism (family obligations) and dysfunctional thoughts associated with caregiving do not always have a maladaptive function, but that their impact could depend on sociocultural variables such as kinship with the caregiver or perceived social support. For example, in profile 4 (High psychosocial vulnerability-High resources), mostly represented by husbands, presenting high levels in familism and dysfunctional thoughts, in addition to generating satisfaction for "doing what they should, since their wives have always taken care of them and now it is their turn" (Doris et al., 2018; Conde-Sala et al., 2010), does not conflict with performing leisure activities or having the support of other people in the environment, who are likely to be women (Larrañaga et al., 2009). This means that their levels of psychological distress, i.e., depressive, anxious and guilt symptomatology, are lower than the rest of the groups. Bearing this in mind, this profile could be called *Adapted Pathological,* because although the levels obtained in the variables studied are associated with greater vulnerability to psychological distress, this does not occur due to sociocultural variables.

Something similar would occur with the levels of experiential avoidance, because although the results of previous studies support a greater presence of depressive and anxious symptomatology in caregivers with high levels of experiential avoidance (Lappalainen et al., 2021), the results of the present research suggest that this could differ according to variables such as kinship with the cared-for person or the gender of the caregiver. Again, regarding profile 4 (High psychosocial vulnerability-High resources; mostly husbands), despite having high levels of experiential avoidance, their caregiving situation does not conflict with the perception of high social support nor with engaging in leisure activities. On the one hand, given that caregiving is socially expected to be carried out by women, they tend to take greater responsibility for caregiving and, consequently, tend to offer their support to male caregivers (Urbano & Villanueva, 2012). On the other hand, male caregivers attach great importance to leisure activities, dedicating more time and space to them than female caregivers (Larrañaga et al., 2009). On the contrary, profile 2 (Low psychosocial vulnerability-Low resources; mostly daughters), which shows low levels of experiential avoidance, is the profile with the highest levels of depressive, anxious and guilt symptomatology. That is, caregiving daughters reflect to a greater extent on their caregiving situation, since the obligation to the family falls primarily on them (Yee & Schulz, 2000). However, because of the difficulties they face in combining family and work, and because they connect with the negative thoughts associated with caregiving, they report a greater negative impact on their emotional distress.

Considering the above, the results suggest that the interventions for each identified group should be different. Thus, for example, for the group of caregiving daughters who present high levels of distress (profiles 1 and 2) it would be appropriate to carry out interventions aimed at validating the feeling of guilt, with the objective of releasing the pressures to which they are subjected, as well as offering them resources that allow them to reconcile the different roles they have to face, something that could also benefit the caregiving sons (profile 3) who have low support to cope with the caregiving situation. Finally, for the group of husbands (profile 4), and especially for the wives (profile 5), psychological interventions focused on the restructuring of acquired dysfunctional beliefs, derived from cultural values such as familism, would be appropriate, favoring greater self-care and leisure behaviors that would benefit their emotional state.

The present study has a number of limitations. Given that this is a cross-sectional study, it is not possible to establish causal relationships between the variables studied. Second, because caregivers participating in the study were volunteers and the sample size for the group of sons may be somewhat low, the study sample is not representative of the population of caregivers of relatives with dementia. In addition, the sample size could be low for the use of cut-off points in the scales used to evaluate emotional distress. This information must be taken into consideration when interpreting the results. Third, there are other variables (e.g., cognitive fusion, frequency of disruptive behaviors, etc.) that also appear to be relevant in the identification of family caregiver profiles (Barrera-Caballero et al., 2021) that were not studied in the present research.

Furthermore, in relation to the familism variable, given that in the present research only the dimension of family obligations has been analyzed, it would be interesting for future studies to study the identification of caregiver profiles considering other dimensions of familism. It should also be mentioned that the Cronbach´s alpha level of the Experiential Avoidance in Caregiving Questionnaire is slightly lower than recommended, so the results in relation to this variable must be interpreted with caution. The variables of the study are based on self-report responses given by caregivers, so in some cases they could be influenced by social desirability bias, that is, the tendency of participants to appear to be acting correctly (Huertas-Domingo et al., 2023). Future studies should take this possibility into consideration when using this questionnaire and try to establish a source of control for the possible effects of social desirability. Moreover, since the variables were always evaluated in the same order, the possibility that the halo effect existed when responding must be considered. Finally, the work has been carried out in a country with a Mediterranean culture, so the findings here may not be generalizable to other cultural environments (Losada et al., 2006).

Despite the above limitations, the results obtained in this study are relevant for understanding dementia family caregivers´ emotional distress. High levels of dysfunctional thoughts, familism and experiential avoidance are not always associated with greater psychological distress but depend on sociocultural and resource variables such as the kinship relationship or the perceived social support. Therefore, the results suggest the importance of considering specific profiles of family caregivers of people with dementia based on psychosocial and resource variables and kinship groups, this study being a pioneer in considering these variables in the identification of profiles of caregivers of people with dementia. The consideration of these profiles in the design of interventions for caregivers could be necessary, in addition to helping to increase the effectiveness of interventions aimed at this population, which so far are at best moderate (Cheng et al., 2020).

7.6. References

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ESTUDIO CUATRO

Moderating effect of family function on the relationship between dysfunctional thoughts associated with caregiving and anxious and depressive symptoms. Importance of kinship

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8. Estudio cuatro: Moderating effect of family function on the relationship between dysfunctional thoughts associated with caregiving and anxious and depressive symptoms. Importance of kinship

8.1. Abstract

Introduction: Caring for a relative with dementia has psychological consequences for caregivers. Caregiving daughters appear to be more affected by caregiving, perhaps because of the multiplicity of roles to which they must respond. Due to cultural influences, caregivers' may have rigid perceptions linked to the tasks of care that may make caregiving overly demanding. Depending on the quality of family support available, the impact of these ideas on caregivers' distress may vary. **Objectives**: The present study aims to analyze the role of dysfunctional thoughts and family function for understanding caregivers' depressive and anxiety symptoms, focusing on the potential moderating effect of family function in the relationship between dysfunctional thoughts and distress. In addition, it aims to study the potential differences in the obtained associations considering the kinship between the caregiver and care-recipient. **Methods**: 278 family caregivers of people with dementia were divided into four groups (70 wives, 58 husbands, 118 daughters and 32 sons). Sociodemographic variables, family obligations, dysfunctional thoughts, frequency and discomfort associated with problematic behaviors, family function, anxious symptomatology and depressive symptomatology were assessed. Regression analysis were conducted for each kinship group. **Results**: The results showed that the moderation effect of family function is only significant for daughters. When levels of family function are low or intermediate in this group, high levels of dysfunctional thoughts are associated with high depressive and anxious symptoms. On the other hand, when daughters report high levels of family function this association is not found. **Conclusions**: A functional family may be protective even in cases where caregivers hold rigid beliefs about how to cope with caregiving. The obtained data suggest the importance of including in interventions for improving adaptive family dynamics aimed at increasing levels of family functioning. This may allow caregivers, especially daughters, to feel more supported and strengthened by their family, reducing their distress levels.

Keywords: dementia caregivers, kinship, family functioning, depressive symptoms, anxious symptoms

8.2. Introduction

Dementia is an illness characterized by a global deterioration in cognitive, emotional, and functional areas and ultimately individuals with dementia require constant care because it renders the person unable to function independently (Alzheimer´s Association, 2023; Frias et al., 2020; Livingston et al., 2020). Between 60%-80% of dementia cases are diagnosed as Alzheimer's disease, around 5% of the population aged over 60 years live with dementia, and the number of cases is expected to double every five years. (Buckley et al., 2015; Cao et al., 2020). The care of the person with dementia is primarily carried out by a family member who assumes the primary caregiver role, especially women (Xiong et al., 2020; Sharma et al., 2016; Alvira et al., 2014).

Caregivers devote an average of 30 hours per week to care tasks, reaching an average of 65 hours per week during the last year of the disease, throughout a period between 4 and 8 years on average (Alzheimer´s Association, 2023). Caregivers must cope with increasing and variable demands that include managing behavioral and psychological symptoms of dementia (BPSD), supervising the daily life of the care-recipient, and in many cases coping with other family issues. These demands help explain why caring for a relative with dementia is considered a situation of chronic extreme stress (e.g., Robinson-Whelen et al., 2001). In fact, family caregiving for a relative with dementia has important consequences on the physical and mental health of caregivers, who are sometimes forced to quit their jobs and change their social activities to devote themselves to the caregiving role (Goren et al., 2016). These restrictions in activities often co-occurs with high caregiving demands and lack of training and professional knowledge to be able to meet the needs of the care recipient (Sutter et al., 2014). This configuration has been linked to increased levels of depressive and anxious symptomatology in family caregivers (Cooper et al., 2007). Caregivers of people with dementia appear to show higher levels of such symptomatologies compared to caregivers of older adults with different medical conditions (Fisher & Lieberman, 1994) and to non-caregiver populations (Goren et al., 2016).

A theoretical model that was developed for understanding the caregiving stress process is the sociocultural stress and coping model (Knight & Sayegh. 2010), which has received strong empirical support with respect to the explanation of caregivers' emotional distress. According to this model, not all caregivers who are exposed to the stress associated with caregiving show the same negative mental and physical health consequences. There are several cultural and coping variables that can influence the process, buffering or increasing the impact of stressors on caregivers` health.

One cultural variable that may play a relevant role in the caregiving process is familism. The familism value incorporates the belief and perception that individuals should remain loyal and supportive to their families, prioritizing the well-being of the family over the individual (Martí, & Cid, 2015; Mendez-Luck et al., 2016). Familism has been found to be related to the presence of maladaptive or dysfunctional thoughts associated with caregiving (Losada et al., 2010; Falzarano et al., 20222). Specifically, this is the case with familial obligations, a dimension of familism that refers to the perceived obligation of family members to offer support and help to each other.

The impact of cultural values on caregiving outcomes may be exerted through influence on caregiving coping processes, including caregivers’ ways of thinking about caregiving (Knight & Sayegh, 2010). Dysfunctional thoughts about caregiving have been characterized as inflexible and unrealistic thoughts about what one must do to be a good caregiver and are related to attitudes and behaviors such as not asking for caregiving help, staying cheerful at all times, and the absence of complaining and venting to others (Cabrera et al, 2021; Corcoran, 2011; Losada et al., 2003). In this case, caring for a dependent family member is perceived as a moral obligation, that caregivers should be able to handle on their own (Mittelman et al., 2003). This is especially true for women, due to the attribution of the task of caregiving to the female role (Stewart et al., 2016; Meira et al., 2017). These dysfunctional thoughts interfere with the adaptive coping of caregiving and increase the presence of depressive and anxious symptomatologies (Losada et al., 2010).

Another relevant factor for understanding the mental health of caregivers is family dynamics (Sutter et al., 2014), although this issue has been scarcely studied in the scientific literature (Cheng et al., 2019). The family is usually the closest and most influential interpersonal context throughout a person's life and plays an important role in the emotional functioning of caregivers (Smith et al., 2022). Previous studies have found a relationship between family factors, such as marital cohesion, communication patterns, the presence of conflict and ambiguous boundaries between family members, and depressive and anxious symptomatology in family caregivers (Mitrani et al., 2006). In fact, social support offered by family members seems to be associated to a greater extent with caregivers' resilience when compared to caregivers who receive social support from friends (Sutter et al., 2014). The quality of the relationship between the primary caregiver and the rest of the family members may act as a protective or as a vulnerability factor of emotional stress for caregivers (Smith et al., 2022). Previous research reflects a moderating effect of family function on individual and cultural factors, among others, in caregivers of people with dementia (Mitrani et al., 2006).

Finally, gender and kinship are additional variables that have shown to play an important role in understanding the sociocultural impact of caregiving on the caregivers. Regarding gender, due to the traditional attribution of the task of caregiving to women, female caregivers generally have a greater internalization of the feeling of family obligations (Bartlett et al., 2018). This expectation causes women to assume the primary caregiver role to a greater extent and invest more time in caregiving compared to men (Sharma et al., 2016). In addition, due to the multiplicity of roles that they must cope with (employees, daughters, mothers, house chores, etc.), women are more vulnerable to the consequences of caregiving (Erol et al., 2016; Losada et al., 2023). In addition, the gender of the caregiver can also influence family functioning (Heru et al., 2004), as it is socially expected that a woman will be in charge of care, taking the role of primary caregiver.

On the other hand, when men assume the primary caregiver role, women in the family seem to offer more help to them, thus providing more support than received by women caregivers (Huertas-Domingo et al., 2021). In terms of kinship, daughter caregivers seem to be especially vulnerable (Martín-María et al., 2022; Watson et al.,2019). One reason for this higher vulnerability of daughter caregivers is related to the multiplicity of role-demands that they face and associated role conflicts. This conflict occurs when excessive demands make it incompatible to meet the expectations of each role (including the perceived family obligations that are culturally transmitted), increasing the levels of feeling trapped in different roles (Campbell et al., 2008). This conflict can lead to negative consequences such as emotional problems (anxiety, depression, etc.), exhaustion, fatigue, and resentment towards the caregiver (Prince 2009; Lin et al., 2011).

In light of this review, and drawing upon the sociocultural stress and coping model, the aims of this study were to (a) analyze the role of dysfunctional thoughts and family function in understanding caregivers depressive and anxiety symptoms, (b) examine the possible moderating effect of family function in the relationship between dysfunctional thoughts and the levels of both symptomatologies and (c) examine the potential differences in the obtained associations when kinship between the caregiver and care-recipient is considered. We hypothesize that (1) the inclusion of the proposed variables will significantly contribute to the tested model explaining caregivers' distress (depressive and anxious symptomatology); (2) caregivers' dysfunctional thoughts will be related with distress only for those caregivers who report low family functioning, as their way of thinking will be in conflict with the perceived support from the family; and (3) the findings will be particularly relevant for wives and daughters when compared to husbands and sons caregivers, as they have been exposed to a greater extent to cultural expectations about women been responsible for caregiving.

8.3. Method

8.3.1. Participants and procedure

The study sample consisted of 278 family caregivers of people with dementia residing in the community of Madrid (Spain), aged between 22 and 88 years (Mean = 62.97; S.D = 12.78). Participants were divided into four groups according to kinship to the care recipient: wives (n=70); husbands (n=58), daughters (n=118) and sons (n=32).

The recruitment was carried out through different health and social services centers that facilitated a first contact with the participants. Initially, a telephone screening contact with each caregiver occurred to confirm the fulfilment of the inclusion criteria: (1) identify as the primary caregiver of a family member diagnosed with dementia; (2) devote at least one hour a day or a total of 7 hours a week to caregiving; (3) having cared for their relative for at least 3 consecutive months; and (4) being 18 years old or older. All subjects participated on a voluntary basis and assessments were conducted face-to-face by trained psychologists. The study was approved by the Ethics Committee of the Universidad Rey Juan Carlos and all participants signed an informed consent prior to their participation.

8.3.2. Variables and instruments

Caregiver Sociodemographic variables: age, gender, hours devoted to caregiving, time since being a caregiver and family relationship with the care-recipient. The care recipeint’s cognitive status was measured using the Global Deterioration Scale (GDS; Reisberg et al., 1982). The GDS consists of clinical description of 7 phases of global function ranging from (1) normality to (7) severe dementia and is used to determine the stages of cognitive function among patients diagnosed with dementia.

Caregiving Stress. Caregiver stress was measured through the assessment of the frequency and reaction to behavioral and psychological symptoms of the dementias (BPSD), using the Revised Memory and Behavior Checklist and Problem Behavior Checklist (RMBPC; Teri et al.,1992; Spanish version by Nogales-González et al., 2014). The RMBPC is composed of 24 items (e.g., "your family member loses or changes things out of place") that measure frequency of occurrence of care recipient symptoms during the previous week, with a response range between 0 ("never occurs") and 4 ("occurs daily). In addition, whether the problem behavior upset the caregiver was assessed, with a response range between 0 ("did not stress me at all") and 4 "("stressed me a lot"), through the reaction subscale of the RMBPC. For the current sample, the internal consistency values (Cronbach's alpha) for the frequency and reaction subscales were 0.79 and 0.88, respectively.

Familial Obligations. The "family obligations" subscale of the Revised Familism Scale (RFS; Losada et al., 2019), consisting of 5 items (e.g., “Most of what a son or daughter does should be done to please their parents”), was used. Answers ranged from 0 ("strongly disagree") to 4 ("strongly agree"), with higher scores reflecting higher perceived family obligations. The internal consistency of the subscale (Cronbach's alpha) for this study was 0.75.

Caregiver’s D*ysfunctional Thoughts*. The Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ; Losada et al., 2006) was used to assess the presence of attitudes, thoughts and beliefs that hinder adaptive coping with caregiving. The scale is composed of 16 items (e.g., "Asking for help from non-family members is the last thing a caregiver should do, since caregiving should be carried out within the family") with answers ranging from 0 ("strongly disagree") to 4 ("strongly agree"). The scale presents an internal consistency (Cronbach's alpha) of 0.91 in the present study.

Family Function. The Family APGAR questionnaire (Smilkstein, 1978; Spanish version by Bellón et al., 1996) was administered. This questionnaire assesses family adaptability, companionship, growth, affection, and resolution through 5 items (e.g., "important decisions are made in the family") with 3 response options: 0 ("almost never"), 1 ("sometimes"), 2 ("always"). Higher scores correspond to better family functioning. The internal consistency of the scale (Cronbach's alpha) for the present study was 0.76.

Depressive Symptomatology. The 20- Item Center for Epidemiological Studies - Depression Scale (CES-D; Radloff, 1977; Spanish version by Losada et al., 2012) was used to assess depressive symptomatology. Item response (e.g., I felt that everything I did was an effort") range between 0 ("rarely or never") and 3 ("all the time"). Higher scores correspond to a greater presence of depressive symptomatology during the last week. The cut-off point for depressive symptoms is equal to or higher than 16 (Radloff, 1977). The internal consistency (Cronbach's Alpha) of the scale in the present investigation was 0.89.

Anxiety *symptomatology*. The Tension subscale of the Profile of Mood States (POMS; McNair et al., 1971; Spanish version by Balaguer et al., 1993) was used to evaluate the caregiver's affect and feelings. The scale is composed of 9 multidimensional adjectives (e.g., agitated, anxious) whose response range is from 0 ("not at all") to 4 ("very much"). Higher scores correspond to higher levels of anxious symptomatology, with a cut-off point set at scores equal to or higher than 13 (Losada et al., 2015). The internal consistency (Cronbach's Alpha) for the study sample was 0.90.

8.3.3. Data analysis

First, chi-square analyses and one-factor ANOVAs were performed to assess the descriptive characteristics of the sample and differences according to kinship role. Second, drawing upon the sociocultural stress and coping model, two simple moderation models (one with depressive symptomatology as an outcome, and another with anxiety symptoms as an outcome; see Figure 1) were analyzed through hierarchical regression analysis. Sociodemographic variables (caregivers' age, gender, daily hours spent caregiving), caregiving stressors (frequency and reaction to BPSD) and family obligations were included in the first step; in a second step the variable dysfunctional thoughts was added; in a third step the variable family functioning was added; and in the last step the interaction between dysfunctional thoughts and family functioning was added. These regression analyses were performed for each kinship group in order to study (a) whether the presence of dysfunctional thoughts associated with caregiving or family functioning are directly related to the presence of depressive and anxious symptomatology and (b) whether the association between dysfunctional thoughts about caregiving and both symptomatologies is moderated by levels of family functioning, and if these findings are obtained for all kinship groups.

As a previous step, all predictors and moderators of the model were centered to the mean to decrease the collinearity between the interaction term and its constituents (Aiken & West, 1991). In the case that the levels in the association between the independent variable (dysfunctional thoughts) and both dependent variables (depressive and anxious symptomatology) vary according of the levels of the moderator (suggested by a significant effect of the product between dysfunctional thoughts and family functioning), moderation is considered to take place. This imply that family function would modify the effect that dysfunctional thoughts have on depressive anxious and symptomatology. All analyses were performed with the Statistical Package for the Social Sciences (SPSS Statistics 22) program.

In addition, post-hoc analyses were conducted using the PROCESS Macro script for SPSS (Hayes, 2018) to test the moderation relationship in both models. Process generated three conditional effects as a function of moderator levels: 1) when the moderator (family function) is at one standard deviation below its mean, 2) when it is at medium levels, and 3) when it is at one standard deviation above its mean.

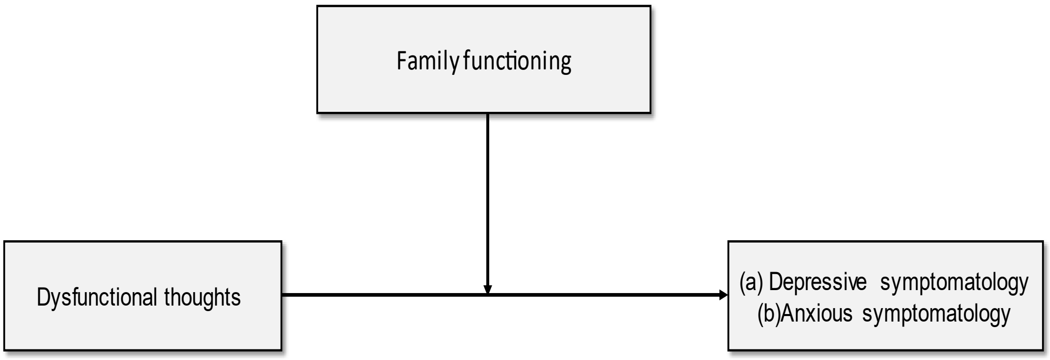

Figure 8.1. Moderation model. The direct association between the dysfunctional thoughts and the (a) depressive and (b) anxious symptomatology varies as function of the levels of family functioning.

8.4. Results

8.4.1. Sample Description

The caregiving sample was primarily female (67.63%; n = 188), and daughters were the predominant kinship group (42.90%; n = 118) (Table 1). In addition, the average time that the caregivers had been providing care was 50.62 months (S.D. = 42.96 S.D.) and the mean value of the cognitive assessment of the care recipient (GDS; Reisberg et al., 1982) was 4.62, corresponding to moderate-severe cognitive impairment. Table1 presents the means obtained by each kinship group for each of the assessed variables.

The results indicated that daughters most frequently live with their children and work most outside the home. Wives and husbands are more likely to live with the care recipient and devote the highest number of hours per day to caregiving, while the sons are the group that devotes the least hours to caregiving.

Regarding family obligations, daughters reported significantly lower levels than the other kinship groups, and with respect to dysfunctional thoughts, daughters and sons reported lower levels than wives and husbands. With respect to family functioning, wives and husbands reported higher levels of family functioning than daughters and sons. Concerning the frequency and reaction to problematic behaviors, the data indicated that daughters reported higher levels for both dimensions. Finally, with respect to the levels of depressive and anxious symptomatology, husbands reported the lowest levels in both symptomatologies.

Table 8.1. *Characteristics of the sample and differences by kinship*

	0- WIVES (25.40%)		1- HUSBANDS (20.40%)		2- DAUGHTERS (42.90%)		3- SONS (11.30%)			
Variables	Mean	SD	Mean	SD	Mean	SD	Mean	S. D	F/χ^2 (sig)	Differences between kinship groups ($p<0.05$)
Caregivers' Age	72.31	7.85	75.07	6.78	54.02	8.30	52.87	9.94	141.68 (< .001)	0 & 1 > 2 & 3
Work outside home (% Yes)	8.57		0		53.40		62.50		83.78 (<.001)	2 & 3 > 0 & 1
Living with children (% Yes)	17.14		8.62		40.68		25.00		25.84 (<.001)	2 > 0, 1 y 3
Living with the care-recipient (% Yes)	98.6		100		52.54		53.12		86.32 (<.001)	0 y 1 > 2 y 3
Family obligations	9.93	4.01	9.81	4.64	6.45	3.52	8.76	3.43	16.77 (<.001)	2 < 0, 1 & 3
Dysfunctional thoughts	34.41	14.98	38.41	12.49	18.91	11.08	25.10	12.29	41.44 (<.001)	0 & 1 > 2 & 3
Family Functioning	8.38	1.59	7.87	2.42	7. 07	2.54	6.91	2.58	5.94 (<.001)	0 & 1 > 2 & 3
Frequency BPSD.	31.68	11.96	32.98	12.07	37.73	14.30	31.94	11.17	4.41 (0.01)	2 > 0, 1 & 3
Reaction BPSD	15.73	11.81	15.55	15.57	21.89	15.80	17.18	15.60	3.87 (0.01)	2 > 0, 1 & 3
Anxious symptomatology	16.25	7.58	11.65	7.58	18.49	7.64	16.06	7.58	10.86 (<.001)	1 < 0 < 2 & 3
Depressive symptomatology	18.13	10.93	13.05	8.68	18.97	11.36	18.00	11.11	4.32 (0.01)	1 < 0, 2 & 3
Time since caregiving (months)	58.05	61.02	47.27	31.72	48.14	36.40	48..85	31.32	1.02 (0.38)	No differences
Daily hours of care	16.26	7.32	16.76	6.82	10.70	7.39	7.43	5.84	21.82 (<.001)	0 & 1> 2 > 3
Care-recipients' GDS	4.58	1.22	4.40	1.21	4.80	1.26	4.50	1.28	1.48 (0.22)	No differences

8.4.2. Regression analysis for depressive symptomatology

The results obtained in the regression analyses for depressive symptomatology for each kinship group are shown in Table 2. The data show that the final model was only significant for daughters (F= 4.804; p < 0.01), explaining 28.60% of the variance in depressive symptomatology. For daughters, significant main effects on depressive symptomatology were found for the variables: *reaction to problematic behaviors, dysfunctional thoughts, and family functioning.* In addition, a moderating effect of family functioning was found such that the interaction between dysfunctional thoughts and family functioning was significant. That is, for caregiving daughters, reporting higher reaction to BPSD, higher dysfunctional thoughts about caregiving, and lower family functioning was positively and significantly associated with depressive symptomatology. When the levels of family functioning reported by daughters were low or intermediate, the association between dysfunctional thoughts and depressive symptomatology remained significant (Low Level: B= .648; S.S. =.157; t = 4.107; p < 0.001; Medium Level: B= .403; S.S. =.089; t = 0.518; p < 0.001). However, when levels of family functioning were high, such association was not significant (High Level: B= .159; S.S. =.119; t = 1.331; p > 0.050) (Figure 2). Figure 2a shows how the slope of the line of association between dysfunctional thoughts and depressive symptomatology is significantly less pronounced when family functioning levels were high than when they were intermediate or low. That is, when high levels of family functioning were reported, the mean levels of depressive symptomatology were below the cut-off point (16 points), irrespective of the scores in dysfunctional thoughts.

Table 8.2. *Moderation analyses of family functioning on the relationship of dysfunctional thoughts and depressive symptomatology*

	Depressive symptomatology					
	Wives			Husbands		
	Standard coefficient *B*	t	*p*	Standard coefficient *B*	t	*p*
1. Age	0.30	1.51	0.14	0.01	0.08	0.94
2. Daily hours of care	-0.10	-0.55	0.59	-0.23	-1.37	0.18
3. Family obligations	-0.22	-0.51	0.61	-0.05	-0.21	0.84
4. Frequency BPSD.	-0.04	-0.28	0.78	-0.05	-0.38	0.70
5. Reaction BPSD	0.19	1.34	0.18	0.22	2.42	0.02
6. Dysfunctional thoughts	0.05	0.4	0.69	-0.07	-0.63	0.53
7. Family Functioning	-1.01	-0.74	0.46	-0.52	-0.65	0.52
8. Dysfunctional thoughts x Family Functioning	-0.03	-0.67	0.51	-0.01	-0.35	0.73
R^2	14.40%			24.20%		

	Depressive symptomatology					
	Daughters			Sons		
	Standard coefficient *B*	t	*p*	Standard coefficient *B*	t	*p*
1. Age	-0.25	-2.09	0.04	0.01	0.06	0.95
2. Daily hours of care	-0.12	-0.88	0.38	0.19	0.49	0.63
3. Family obligations	-0.08	-0.24	0.81	1.34	1.69	0.10
4. Frequency BPSD.	-0.01	-0.16	0.87	0.23	0.80	0.43
5. Reaction BPSD	0.17	2.02	0.05	0.21	0.92	0.37
6. Dysfunctional thoughts	0.42	3.76	0.00	-0.21	-0.98	0.34
7. Family Functioning	-1.35	-3.50	0.00	-0.76	-0.91	0.37
8. Dysfunctional thoughts x Family Functioning	-0.10	-2.29	0.02	-0.03	-0.41	0.68
R^2	28.60%			40.5%		

However, when the reflected levels of family functioning were intermediate or low, higher dysfunctional thoughts were associated with higher values of depressive symptomatology, exceeding the clinically significant cutoffs. Therefore, the influence of dysfunctional thoughts associated with caregiving on depressive symptoms seems to be lower for daughters with good/high family functioning.

8.4.3. Regression Analysis for Anxiety Symptomatology

Table 3 shows the results obtained from the final model in the regression analyses for anxious symptomatology for each kinship group. In this case, the data reflect that the final model was significant for husbands (F=3.437; $p < 0.05$) and daughters (F=4.065; $p < 0.01$). Regarding husbands, the model explained 35.90% of the variance for anxious symptomatology, showing a significant main effect for reaction to BPSD. However, a moderating effect of family functioning on the relationship between dysfunctional thoughts and anxious symptomatology was not found for this group.

Regarding daughters, the model explained 23.90% of the variance of anxious symptomatology, there were significant main effects for reaction to BPSD and family functioning. Differing from the findings for depressive symptomatology, no direct significant effects were found for the variable dysfunctional thoughts. In contrast, a moderating effect of family functioning was observed in the relationship between dysfunctional thoughts and anxious symptomatology (see Table 3). That is, for daughters, dysfunctional thoughts were indirectly and significantly associated with anxious symptomatology through family function. When levels of family functioning reported by daughters were low or intermediate, the association between dysfunctional thoughts and anxious symptomatology was significant (Low Level: B= .329; S. S. =. 110; t = 2. 983; $p < 0.001$; Medium Level: B= . 157; S. S. =. 062; t =

2. 518; p < 0. 001). However, when levels of family functioning were high, the association was not significant (High Level: B= -. 014; S. S. =. 083; t = -. 173; p > 0. 050).

Figure 2b shows that the slope of the association between dysfunctional thoughts and anxiety symptoms is significantly less pronounced when levels of family functioning were higher as opposed to when they were intermediate or low. When high levels of family functioning are reported, the mean levels of anxiety symptoms are considerably lower and closer to the cut-off point established for the POMS questionnaire (13 points), irrespective of the scores in dysfunctional thoughts. In summary, the influence of dysfunctional thoughts associated with care on anxiety symptoms seems to be lower daughter caregivers who report good family functioning.

Table 8.3. *Moderation analyses of family functioning on the relationship of dysfunctional thoughts and anxiety symptomatology*

	Anxiety symptomatology					
	Wives			Husbands		
	Standard coefficient *B*	t	*p*	Standard coefficient *B*	t	*p*
1. Age	0.06	0.45	0.66	-0.16	-1.08	0.28
2. Daily hours of care	-0.06	-0.49	0.63	0.14	1.02	0.31
3. Family obligations	-0.07	-0.25	0.80	-0.13	-0.62	0.54
4. Frequency BPSD.	0.04	0.43	0.67	0.12	1.19	0.24
5. Reaction BPSD	0.14	1.50	0.14	0.16	2.12	0.04
6. Dysfunctional thoughts	-0.04	-0.44	0.66	0.06	0.64	0.52
7. Family Functioning	-1.20	-1.35	0.18	-0.23	-0.35	0.73
8. Dysfunctional thoughts x Family Functioning	-0.02	-0.49	0.63	-0.02	-0.77	0.45
R^2	20.60%			35.90%		

	Anxiety symptomatology					
	Daughters			Sons		
	Standard coefficient *B*	t	*p*	Standard coefficient *B*	t	*p*
1. Age	-0.06	-0.73	0.47	0.07	0.40	0.69
2. Daily hours of care	-0.10	-1.05	0.29	0.11	0.38	0.71
3. Family obligations	0.21	0.88	0.38	0.47	0.77	0.45
4. Frequency BPSD.	0.01	0.17	0.86	0.03	0.15	0.88
5. Reaction BPSD	0.15	2.55	0.01	0.11	0.60	0.55
6. Dysfunctional thoughts	0.12	1.53	0.13	-0.15	-0.91	0.37
7. Family Functioning	-0.62	-2.29	0.02	-0.43	-0.65	0.52
8. Dysfunctional thoughts x Family Functioning	-0.06	-2.19	0.03	-0.03	-0.58	0.57
R^2	23.90%			20.10%		

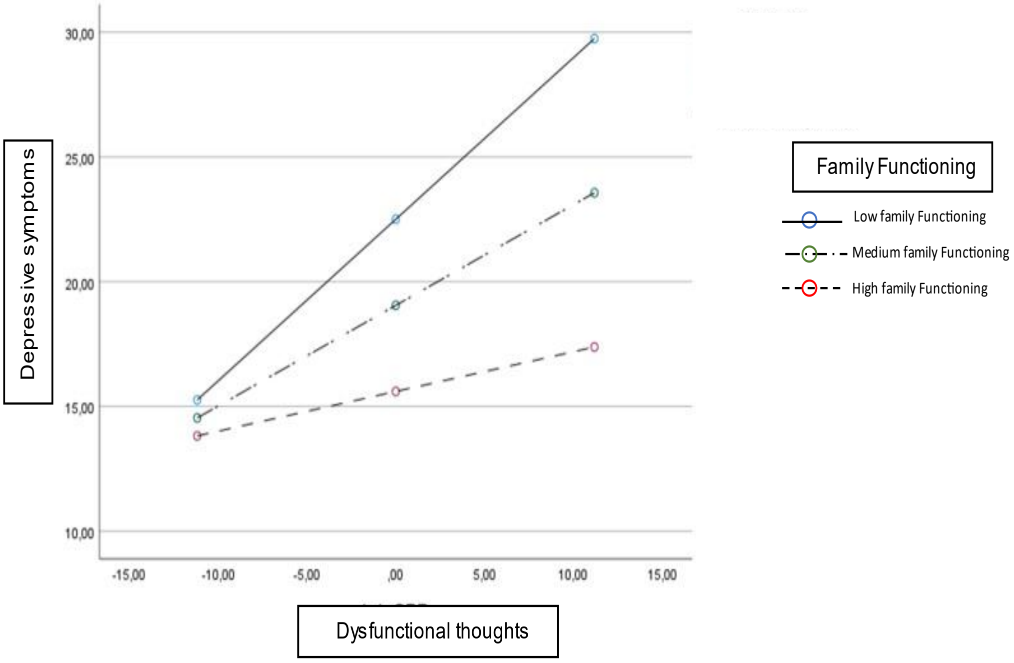

Figure 8.2a. Levels of moderation of family functioning in the relationship between dysfunctional thoughts and depressive symptoms

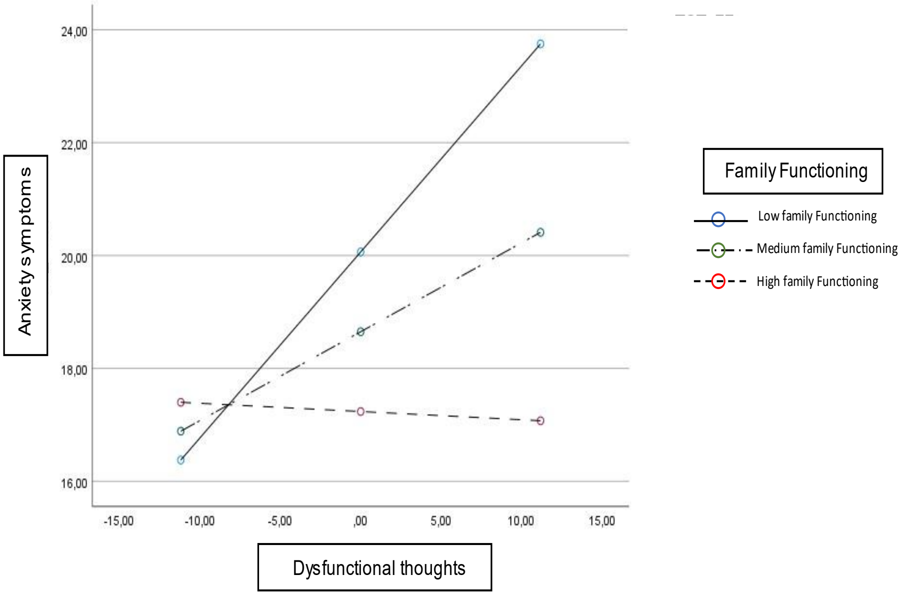

Figure 8.2b. Levels of moderation of family functioning in the relationship between dysfunctional thoughts and anxious symptoms

8.5. Discussion

Drawing upon the sociocultural stress and coping model (Knight & Sayegh, 2010), this study was aimed to examine the role of caregivers' dysfunctional thoughts and family function with respect to family caregivers depressive and anxious symptoms, while considering caregiving kinship. We also examined the potential moderating effect of family function in the relationship between dysfunctional thoughts and distress. The associations were tested for each caregiving kinship group (wives, husbands, daughters, and sons). We hypothesized that including measures of dysfunctional thoughts and family function would have a significant contribution in the explanation of depressive and anxious symptomatology among family caregivers. Specifically, we hypothesized that high levels of dysfunctional thoughts would be related to a higher presence of both symptomatologies only when the reported level of family function was low. Also, we hypothesized that these realtionships would be observed to a greater extent in female caregivers.

The results partially support our hypothesis. Firstly, the proposed model was only significant in explaining the depressive symptomatology for daughters, while for the anxious symptomatology it was significant for both daughters and husbands. Regarding daughters, dysfunctional thoughts showed a significant impact in the explanation of depressive symptomatology (as well as to reaction to problematic behaviors, family function and the interaction between CPD and family function), but to anxiety symptoms. The association between dysfunctional thoughts and depressive symptoms may be related to the expectation of needing to be fully dedicated to family care without asking for help for this task. Such thoughts may promote reduced engagement in self-care and leisure behaviors and prevent the development of an adequate social support network, which in turn could be associated with a greater occurrence of depressive symptomatology (Losada et al., 2018). The fact that these associations were only observed in daughter caregivers may be related with the traditional attribution of caregiving tasks to the females (Ruiz & Nicolás, 2018; Stewart et al., 2016) and to the multiplicity of roles (professional life, raising children, etc.) that daughter caregivers may have to face (Huertas-Domingo et al. 2023). Regarding the findings for husbands, reaction to problematic behaviors was the only significant variable explaining anxious symptomatology. These findings are not surprising, as problematic behaviors have been considered important risk factors for emotional stress of caregivers (Cheng, 2017).

Hypotheses 2 and 3, which suggested a moderating effect of family function between dysfunctional thoughts and depressive and anxious symptomatologies, and a greater relevance of this effect for women caregivers, was only found for daughters. The findings show that when levels of family function reported by daughters are low or intermediate, the association between dysfunctional thoughts and anxiety and depressive symptomatology is significant. However, for higher levels of family function, the relationship between dysfunctional thoughts and both anxiety and depressive symptomatology is not significant; daughters do not experience clinically significant levels of depressive symptoms.

Therefore, family functioning seems to act as a buffer for emotional distress for daughter caregivers, even for those who show a pattern of coping with caregiving characterized by rigid thoughts about how caregiving “must” be faced (that is, with strong dysfunctional thoughts about caregiving). This is consistent with the findings of previous studies that have shown that, in the presence of a stressor such as dementia, the family plays an important role in the stress process of caregivers (Victoria et al., 2006). As noted earlier, how the family responds to the care of a sick relative can protect against the emotional consequences of caregivers or act as a risk factor for them (Smith et al., 2022).

Additionally, the fact that the moderating effect of family function is significant only for the daughters may be understood as each individual caregiver responds differently to the stressors of care (Zarit et al., 1998). As the sociocultural stress and coping model shows (Knight & Sayegh, 2010), there are numerous factors that influence the relationship between the demands of care and the emotional distress of the caregiver such as the characteristics of the care recipient for (e. g. degree of dependence, relationship of kinship), characteristics of the caregiver (e. g. gender, age), and contextual characteristics (e. g. social support). The knowledge of the factors that influence the process of stress associated with care is necessary for the development of effective interventions (Mitrani et al., 2006). In particular, daughter caregivers, as mentioned above, may be especially vulnerable to the consequences of caregiving and should be a target for intervention.

The findings of this study provide additional support to the importance of the family functioning for understanding caregivers distress (Tramonti et al., 2019). Although scarce, intervention studies that include a family or systemic approach to help caregivers may be helpful a approach with respect to remediating the challenges of caregiving (Czaja et al., 2000; Mitrani et al., 2006). Interventions aimed at increasing levels of family function (e.g., increasing levels of family cohesion, including the caregiver in family activities, improving the resolution of family disagreements, and increasing expressions of affection among members) can prevent or alleviate the levels of emotional distress felt by caregivers ((Mitrani et al., 2006). The findings of this study suggest that these strategies may be especially helpful for daughter caregivers. Improving family functioning and providing quality social support by family members to the primary caregiver, may be helpful for reducing levels of emotional stress in the daughters (Nissen et al., 2016).

The present study has a number of limitations that must be mentioned. First, although the sample size is similar to that of other studies with caregivers, caution is required when interpreting the results. The number of participants for some kinship groups, especially the groups of men (husbands and sons), may be considered small given the number of variables evaluated. This may have reduced the significance of the observed relationships between variables for these groups. Future studies with a larger sample of male caregivers are needed. Further, the study subjects decided to participate voluntarily, which makes the sample not representative of the population of caregivers.

The design of the study cross-sectional and therefore it is not possible to establish causal relationships between the variables evaluated. Experimental or longitudinal studies should be conducted to confirm the results. Additionally, there are other variables that have not been assessed in this study (e. g. leisure activities, perceived social support, etc.) that may be relevant in explaining the emotional distress of family caregivers (Lee et al., 2020; Ruisoto et al., 2020). Finally, the study was conducted in a Mediterranean society within the European context, so there are contextual characteristics that may differ from other regions (Uccheddu et al., 2019). Thus, the findings may not be generalizable to other cultural contexts (Losada et al. , 2006, 2023). The association between the variables included in this study and the mental health of caregivers may be particularly relevant in societies where there is a high presence of family values and a sense of obligation to the family, as is the case in Mediterranean or Latin societies (Sutter et al., 2014). Future studies in different cultural contexts are needed to confirm and the findings of the present study.

Despite these limitations, the results contribute to our understanding of the emotional distress of caregivers and the identification of protective factors (family functioning), with a special focus on the kinship relationship between the caregiver and the care recipient. A functional family may be protective even in cases where caregivers hold rigid beliefs about how to cope with caregiving. The obtained data support the importance of considering psychological interventions for caregivers aimed at improving adaptive family dynamics (e. g. communication, family connection, leadership, etc.) by increasing the levels of family functioning. This may allow caregivers, especially daughters, to feel more supported and strengthened by their family members and thereby protecting their mental health.

8.6. References

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9. Discusión general

A continuación, se realizará una reflexión final de los resultados y contribuciones clave de los distintos estudios que conforman esta tesis doctoral. En primer lugar, se examinarán las características generales de la muestra, considerando estudios previos realizados con población cuidadora, con el propósito de evaluar la aplicabilidad de los resultados obtenidos en esta investigación. Seguidamente, se abordarán los objetivos y los resultados más relevantes de cada estudio, así como las contribuciones específicas que cada uno ha aportado. Tras esto, se llevará a cabo una reflexión global acerca de las contribuciones de los cuatro estudios en la comprensión del papel de las variables psicosociales en el malestar emocional de los familiares cuidadores de personas con demencia. Por último, se discutirán las implicaciones prácticas de los hallazgos, se identificarán las limitaciones de los estudios y se ofrecerá una conclusión general sobre las principales aportaciones de la tesis doctoral.

9.1. Características de la muestra

Los participantes en los cuatro estudios comparten características sociodemográficas similares a los participantes de investigaciones anteriores, tanto a nivel nacional como internacional. En primer lugar, el número total de participantes oscila entre 273 (primer estudio) y 288 (tercer estudio), con edades que van desde los 22 hasta los 88 años, con una edad promedio de 63.12 años. Además, la mayoría de la muestra está compuesta por mujeres, representando entre el 67.63% (n = 188; cuarto estudio) y el 68.9% (n = 184; primer estudio) del total. Estas características son consistentes con estudios previos realizados en diferentes países, incluyendo España (Losada et al., 2017), el Reino Unido (Crellin, 2015; Feast et al., 2017) y Japón (Takai et al., 2011), que muestran similitudes en el tamaño de la muestra, la proporción de mujeres participantes y la edad media de las personas cuidadoras.

Además, el grupo de parentesco mayoritario en la presente investigación es el grupo de las hijas, representando entre el 42.36% (n = 122; tercer estudio) y el 43.0% (n=122; segundo estudio) de la muestra total. Esta predominancia de hijas cuidadoras se refleja también en investigaciones previas, como las llevadas a cabo por Conde-Sala et al. (2010) y Amorim et al. (2017). Los resultados muestran también que las hijas cuidadoras son el grupo que más trabaja fuera de casa (junto con los hijos cuidadores; Wang et al., 2018), que más vive con los hijos y que más cuida de otros familiares, lo que apoya a lo planteado por estudios previos (Wang et al., 2018; Steiner & Fletcher, 2017; Peacock et al., 2020).

Con respecto al familiar cuidado, el tipo de demencia predominante en la presente investigación es la enfermedad de Alzheimer, pues según la literatura previa, es la más común de las demencias (Alzheimer's Association, 2023), y el grado de deterioro cognitivo promedio es moderado-severo, siguiendo la Escala De Deterioro Global (GDS; Reisberg et al., 1982), similar al manifestado en estudios previos (Klapwijk et al., 2016). Por último, el tiempo medio que llevan cuidando los participantes es de 50.88 meses (4.24 años), con un promedio de 13 horas diarias invertidas en el cuidado. La media de horas invertidas en el cuidado va en consonancia con lo planteado por Reina et al. (2019), quienes atribuyen una media de horas dedicadas a cuidar de entre 8 y 24 horas cuando los niveles de deterioro (GDS) son moderados y severos.

9.2. Principales aportaciones de los estudios incluidos en la tesis doctoral

El objetivo principal de esta investigación fue ampliar nuestra comprensión sobre cómo los factores socioculturales afectan el bienestar emocional de los cuidadores familiares de personas con demencia. Se buscó explorar cómo variables psicosociales como el valor del familismo, centrándose en las obligaciones familiares, y la presencia de pensamientos disfuncionales, influyen en las consecuencias emocionales negativas asociadas al cuidado. Además, se analizó cómo el impacto de estas variables puede variar dependiendo de la relación de parentesco con la persona cuidada, con el fin de entender mejor las necesidades específicas de cada grupo de cuidadores.

Con este propósito, se llevaron a cabo cuatro estudios independientes. En el primer estudio se evaluó el nivel de soledad percibida en los cuidadores familiares y se examinó un modelo teórico propuesto para explicar este sentimiento, considerando la relación de parentesco con la persona cuidada. Dicho modelo plantea que las obligaciones familiares influyen en la percepción de solead mediante la presencia de pensamientos disfuncionales asociados al cuidado y la realización de diferentes estrategias de afrontamiento, como la búsqueda y recepción de ayuda, el apoyo social percibido y la participación en actividades de ocio.

El segundo estudio, se dirigió a analizar cómo factores socioculturales como el familismo y el sesgo de deseabilidad social impactan en los síntomas de culpa y depresión en los cuidadores familiares. Se propuso un modelo teórico para examinar la relación entre las obligaciones familiares, el sesgo de deseabilidad social, los pensamientos disfuncionales y la percepción de comportamientos problemáticos, y cómo estas variables contribuyen a explicar los síntomas de culpa y depresión. Además, se investigó si estas asociaciones variaban según el tipo de relación de parentesco.

En el tercer estudio, se exploró la presencia de diferentes perfiles de cuidadores familiares de personas con demencia, según los niveles manifestados de variables psicosociales y de recursos (familismo, pensamientos disfuncionales relacionados con el cuidado, evitación experiencial, apoyo social percibido y participación en actividades de ocio). Asimismo, se analizaron diferencias entre los perfiles en los niveles de sintomatología depresiva, ansiosa y de culpa, y si estaban asociados con diferentes tipos de relación de parentesco.

Por último, el cuarto estudio tuvo como objetivo estudiar cómo los pensamientos disfuncionales y el funcionamiento familiar influyen en la sintomatología depresiva y ansiosa de los cuidadores familiares, además de explorar si la función familiar actúa como un moderador en esta relación. A su vez, se buscó determinar si la relación de parentesco con la persona cuidada podría afectar estas asociaciones.

9.3. Resultados y conclusiones de cada artículo

A continuación, se analizarán los resultados fundamentales y las aportaciones derivadas de cada estudio. Un análisis en mayor profundidad de los hallazgos puede verse en el apartado de discusión específico de cada estudio.

Estudio uno: Sociocultural Influences on the Feeling of Loneliness of Family Caregivers of People with Dementia: The Role of Kinship

Los resultados obtenidos en el primer estudio mostraron que el porcentaje de cuidadores que reportaron sentirse solos ocasionalmente o la mayor parte del tiempo varió del 25.6% (hijas) al 30.5% (esposas), sin diferencias significativas entre los grupos de parentesco. El modelo teórico propuesto para la explicación del sentimiento de soledad reflejó un ajuste excelente a los datos, con porcentajes de varianza explicados del sentimiento de soledad que oscilaron desde el 3% (esposas) hasta el 27% (hijas). El modelo propuesto presentó una relevancia particular para el grupo de hijas, esposos e hijos, pero no para el grupo de esposas.

En el grupo de las hijas, todas las asociaciones entre las variables mostradas en el modelo fueron significativas. Esto es, una mayor presencia de obligaciones familiares se asoció con mayores niveles de pensamientos disfuncionales asociados al cuidado, lo que repercute en la solicitud de ayuda y en la recepción de esta y en una menor percepción de apoyo social. Además, la presencia de pensamientos disfuncionales y un menor apoyo social se asoció con una menor participación en actividades de ocio, y finalmente, con una mayor presencia de sentimiento de solead.

Con respecto a los otros grupos de parentesco, los resultados en las esposas fueron muy similares a los de las hijas en términos de las relaciones significativas entre las variables, excepto que el ocio y el apoyo social no se asociaron con la soledad. En los esposos, si bien la mayoría de las asociaciones observadas en las hijas también estuvieron presentes, la asociación entre el apoyo social y el sentimiento de solead no resultó significativa, si no que esta relación pareció estar mediada por las actividades de ocio, algo que también ocurre para el grupo de los hijos. Sin embargo, el grupo de hijos es el único grupo en el que la asociación entre los pensamientos disfuncionales y la petición de ayuda no resultó significativa.

Por tanto, los hallazgos de este estudio resaltan que la soledad es un problema significativo en el cuidado, estando presente en un porcentaje considerable de personas cuidadoras. Además, los hallazgos respaldan la validez del modelo teórico de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010) y del modelo cognitivo adaptado al cuidado (Losada et al., 2006), subrayando la importancia de los factores socioculturales en la comprensión del malestar experimentado por los cuidadores. La cultura parece influir en la presencia de pensamientos disfuncionales asociados al cuidado, lo que puede llevar a la realización de comportamientos desadaptativos y generar un impacto negativo en los sentimientos de soledad de las personas cuidadoras, especialmente en las hijas, quienes parecen ser particularmente vulnerables al impacto de los factores culturales. Asimismo, los datos destacan la importancia de considerar la relación de parentesco con la persona cuidada en el abordaje de la soledad en el contexto del cuidado y de proporcionar un apoyo adecuado a las personas cuidadoras.

Estudio dos: Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences

Los resultados de este estudio indicaron un excelente ajuste del modelo propuesto a los datos obtenidos, con una varianza explicada que osciló entre el 27% y el 37% para la culpa, y entre el 18% y el 29% para la sintomatología depresiva, dependiendo del grupo de parentesco. Sin embargo, se observaron las excepciones de los hijos, cuya varianza explicada para la culpa fue del 5%, y de las esposas, cuya varianza explicada para la depresión fue del 12%. Además, el análisis multigrupo reveló diferencias significativas entre los grupos de parentesco en las relaciones identificadas en el modelo.

En cuanto a las relaciones específicas entre las variables, se encontró que, tanto en esposas como en hijas, existía una asociación significativa entre la deseabilidad social y los pensamientos disfuncionales, así como entre la deseabilidad social y una menor expresión de reacciones ante comportamientos problemáticos. En los grupos de esposas, esposos e hijas, se detectó una relación indirecta significativa entre la frecuencia de los comportamientos problemáticos y la sintomatología depresiva, mediada por los niveles de reacción a dichos comportamientos y por sentimientos de culpa.

Particularmente en el grupo de hijas se observó que mayores niveles de obligaciones familiares se relacionaban con una mayor presencia de sintomatología depresiva, mediada por los pensamientos disfuncionales. Además, se encontró que mayores niveles de deseabilidad social tenían un efecto indirecto en los sentimientos de culpa de las hijas cuidadoras, al influir en un menor reporte de reacciones ante comportamientos problemáticos. Estos resultados son especialmente relevantes teniendo en cuenta que existe una asociación directa entre los sentimientos de culpa y la sintomatología depresiva.

En conclusión, los hallazgos sugieren, apoyando lo planteado por el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), que factores socioculturales como el familismo y la deseabilidad social pueden influir en la manera en que los cuidadores, especialmente las mujeres, informan del malestar emocional relacionado con el cuidado. Por lo tanto, es posible que los niveles de malestar expresados por los cuidadores sean más altos de lo que realmente informan cuando tienen altos niveles de familismo y deseabilidad social, ya que podrían estar ajustando sus respuestas para cumplir con las expectativas sociales.

Estudio tres: Profiles of dementia caregivers according to psychosocial and resource variables. Importance of kinship.

El propósito de este estudio fue identificar distintos perfiles o clústeres de familiares cuidadores de personas con demencia, según sus niveles en distintas variables psicosociales (obligaciones familiares, pensamientos disfuncionales y evitación experiencial) y recursos (ocio y apoyo social). Además, se analizó cómo se distribuían los participantes en estos clústeres según su relación con la persona cuidada y si existían diferencias entre ellos en términos de su malestar emocional, es decir, en sus niveles de culpa, ansiedad y depresión.

Los resultados de los análisis mostraron cinco clústeres distintos identificados a través de un análisis de conglomerados jerárquicos usando el método de Ward. Estos clústeres se agruparon con base en dos factores principales identificados mediante un análisis factorial exploratorio: uno relacionado con aspectos cognitivo-culturales y otro con recursos como actividades de ocio y apoyo social. Estos factores fueron fundamentales para distinguir entre clústeres con alta o baja vulnerabilidad psicosocial, es decir, niveles altos o bajos en variables cognitivo-culturales, así como niveles altos o bajos en variables de recursos.

Los perfiles identificados fueron los siguientes: (1) Baja vulnerabilidad psicosocial - Altos recursos, (2) Baja vulnerabilidad psicosocial - Bajos recursos, (3) Mixto, (4) Alta vulnerabilidad psicosocial - Altos recursos y (5) Alta vulnerabilidad psicosocial - Bajos recursos.

Se encontraron diferencias significativas en la distribución de estos clústeres según la relación de parentesco con la persona cuidada, lo que sugiere que la relación de parentesco está vinculada a las características psicosociales y de recursos de la persona cuidadora. Los perfiles estuvieron mayormente representados por hijas, hijos, esposos o esposas, dependiendo del clúster al que pertenecieran. Así, los perfiles 1 y 2 estuvieron mayoritariamente representados por las hijas, el perfil 3 por los hijos, el perfil 4 por los esposos y el perfil 5 por las esposas.

Además, en relación con la sintomatología emocional, se observaron diferencias significativas entre los perfiles en la presencia de depresión, ansiedad y culpa. Los datos reflejaron que los grupos asociados con menor malestar emocional fueron los perfiles 1 (Baja vulnerabilidad psicosocial - Altos recursos) y 4 (Alta vulnerabilidad psicosocial - Altos recursos). Por el contrario, los perfiles asociados con mayor malestar emocional fueron, en primer lugar, el perfil 2 (Baja vulnerabilidad psicosocial - Bajos recursos), seguido por el perfil 3 (Mixto)

En conclusión, estos resultados sugieren que altos niveles de pensamientos disfuncionales, familismo y evitación experiencial no siempre tienen un impacto negativo en el malestar emocional de las personas cuidadoras, sino que esto puede depender de variables socioculturales y de recursos, como la relación con la persona cuidada o el apoyo social percibido. Estos hallazgos destacan la importancia de considerar tanto los recursos disponibles como la vulnerabilidad psicosocial al diseñar intervenciones para cuidadores familiares de personas con demencia.

Estudio cuatro: Moderating effect of family function on the relationship between dysfunctional thoughts associated with caregiving and anxious and depressive symptoms. Importance of kinship

El objetivo fundamental de este estudio fue examinar cómo los pensamientos disfuncionales y el funcionamiento familiar influyen en los síntomas de depresión y ansiedad de los cuidadores familiares de personas con demencia. Esto se llevó a cabo mediante análisis de regresión jerárquica, teniendo en cuenta la relación de parentesco con la persona cuidada.

Además, se analizó el efecto moderador del funcionamiento familiar en la relación entre los pensamientos disfuncionales y ambas sintomatologías.

Los resultados mostraron que el modelo final para la sintomatología depresiva fue significativo únicamente para las hijas, explicando un 28.60% de la varianza. Se encontraron efectos significativos en variables como la reacción a comportamientos problemáticos, pensamientos disfuncionales y funcionamiento familiar para este grupo. Además, se observó un efecto moderador del funcionamiento familiar en la relación entre pensamientos disfuncionales y la sintomatología depresiva.

En cuanto a la sintomatología de ansiedad, el modelo final fue significativo tanto para esposos como para hijas. Para los esposos, el modelo explicó un 35.90% de la varianza, con un efecto principal significativo en la reacción a comportamientos problemáticos. Sin embargo, no se encontró un efecto moderador del funcionamiento familiar en la relación entre pensamientos disfuncionales y ansiedad. Para las hijas, el modelo también fue significativo, explicando un 23.90% de la variabilidad en la ansiedad, con efectos principales significativos en la reacción a comportamientos problemáticos y el funcionamiento familiar. Además, se observó un efecto moderador del funcionamiento familiar en la relación entre pensamientos disfuncionales y ansiedad para las hijas.

En conclusión, los resultados indicaron que el funcionamiento familiar actúa como un protector del malestar emocional, especialmente para las hijas. Cuando el funcionamiento familiar es bajo o intermedio en este grupo, altos niveles de pensamientos disfuncionales están asociados con mayores síntomas de depresión y ansiedad. Sin embargo, cuando las hijas reportan un alto funcionamiento familiar, esta asociación no se encuentra. Esto sugiere que el funcionamiento familiar puede mitigar el malestar emocional incluso en presencia de creencias rígidas sobre el cuidado, especialmente entre las hijas.

9.4. Discusión general de los resultados de los estudios

El aumento considerable de las demencias debido al envejecimiento progresivo de la población ha conllevado un aumento significativo del cuidado informal en el hogar, principalmente realizado por mujeres del entorno familiar (Collins & Kishita, 2020; Rexhaj et al., 2023). El cuidado familiar de una persona con demencia puede acarrear consecuencias negativas en la salud física y mental de las personas cuidadoras, incluyendo depresión, ansiedad, culpa y soledad (Losada et al., 2018; Walter & Pinquart, 2020). Además, en España, al tratarse de una sociedad mediterránea, donde prevalece el valor del familismo y persiste la tradicional atribución del cuidado al rol femenino, las esposas y, en mayor medida, las hijas adultas son quienes principalmente asumen el papel de cuidadoras principales (López-Cerdá et al., 2019).

La presente tesis doctoral, basándose en el modelo sociocultural de estrés y afrontamiento adaptado al cuidado (Knight y Sayegh, 2010), buscó profundizar en cómo variables culturales y psicológicas influyen en las consecuencias emocionales de los cuidadores familiares, prestando especial atención a las variables del familismo, la presencia de pensamientos disfuncionales asociados al cuidado y la relación de parentesco con la persona cuidada.

En primer lugar, los resultados de la presente investigación avalan la presencia de niveles significativos de malestar emocional en los familiares cuidadores. Esto está en consonancia con lo encontrado por diferentes estudios anteriores que reflejan un mayor número de consecuencias emocionales negativas en los familiares de personas con demencia en comparación con la población general (D'Aoust et al., 2015) y la población cuidadora de otras patologías (Pinquart & Sörensen, 2003)

En segundo lugar, los hallazgos encontrados en los distintos estudios indican que existen diferencias significativas en cómo influyen las variables psicosociales en el malestar emocional de las personas cuidadoras según la relación de parentesco con la persona cuidada. Específicamente, se observa que el valor del familismo, que está relacionado con una mayor presencia de pensamientos disfuncionales, tiene un impacto más pronunciado en la salud mental de las mujeres cuidadoras, en especial de las hijas. Este impacto se refleja en una mayor tendencia a utilizar estrategias de afrontamiento desadaptativas, como solicitar menos ayuda o participar en menos actividades de ocio, así como en una mayor tendencia al sesgo de deseabilidad social al informar sobre su malestar emocional. Estos resultados van en consonancia con lo planteado en investigaciones anteriores, que señalan que los valores culturales desempeñan un papel fundamental en el proceso de estrés asociado al cuidado (Knight y Sayegh, 2010), conllevando un mayor riesgo en las hijas de sufrir problemas de salud mental que los cónyuges o hijos cuidadores (Losada et al., 2010; Romero-Moreno et al., 2014).

En tercer lugar, los resultados resaltan la importancia del apoyo social percibido y del funcionamiento familiar en el manejo del estrés derivado del cuidado, ya que niveles bajos en estas variables parecen aumentar la vulnerabilidad de los cuidadores familiares a experimentar malestar emocional, intensificando el impacto de las variables culturales en su salud emocional. Coincidiendo con esto, se encontró que las hijas con bajos niveles de familismo y pensamientos disfuncionales experimentan niveles significativos de malestar emocional cuando también tienen bajos niveles de apoyo social. De igual manera ocurre con el funcionamiento familiar, pues se observó una asociación directa en las hijas entre la presencia de pensamientos disfuncionales y la sintomatología ansiosa y depresiva cuando los niveles de funcionamiento familiar fueron bajos o intermedios.

Además, la literatura disponible sugiere que las mujeres que cuidan a familiares con demencia experimentan mayores consecuencias emocionales negativas debido a que son las principales responsables del cuidado (Losada et al., 2023), tal como se evidencia en los resultados de esta investigación. Las mujeres cuidadoras se comprometen más y dedican más tiempo a las tareas de cuidado que los hombres cuidadores, lo que las hace más susceptibles a sufrir consecuencias psicológicas negativas derivadas de esta labor (Bartlett et al., 2018; Sharma et al., 2016). Por consiguiente, los hallazgos encontrados en la presente tesis doctoral arrojan luz sobre este aspecto al indicar que la tradicional atribución de la responsabilidad de cuidar al género femenino, que resulta en una mayor inversión de tiempo y responsabilidad en el cuidado por parte de las mujeres, junto con el sentimiento de obligación fortalecido por los valores familistas y la presencia de pensamientos disfuncionales asociados, contribuyen a esta vulnerabilidad emocional en las mujeres.

Asimismo, los resultados encontrados apoyan el papel significativo de la relación de parentesco en la salud emocional de los cuidadores familiares, pues reflejan, al igual que ocurre en estudios previos (Erol et al., 2016; Donnellan et al., 2021), que las hijas cuidadoras manifiestan niveles superiores de malestar psicológico, lo que afecta su calidad de vida. La combinación anteriormente mencionada de la responsabilidad del cuidado atribuida a las mujeres y el sentimiento de obligación derivado de los valores familistas, sumado a las múltiples responsabilidades que enfrentan las hijas en roles como trabajadoras, madres, esposas e hijas, las sitúa en una posición de mayor riesgo de experimentar problemas de salud mental en comparación con otros cuidadores como cónyuges o hijos adultos, un aspecto también respaldado por los datos de esta investigación. Específicamente, las hijas informan de niveles más elevados de sintomatología depresiva y ansiosa, así como de sentimientos de culpa y soledad.

Finalmente, los hallazgos destacan la importancia de tomar en cuenta factores socioculturales y la relación de parentesco al desarrollar evaluaciones e intervenciones dirigidas a cuidadores familiares de personas con demencia, especialmente en las hijas cuidadoras con el propósito de mejorar su calidad de vida y facilitar la gestión de los múltiples roles sociales que desempeñan. Los datos revelan que las hijas cuidadoras enfrentan desafíos particulares debido a la carga adicional de estrés, el conflicto entre diferentes roles y las expectativas familiares.

Por tanto, dada la diversidad de experiencias y necesidades entre los cuidadores familiares, se destaca la importancia de abordar estas necesidades de manera personalizada y con sensibilidad hacia las diferencias culturales.

9.5. Implicaciones prácticas y limitaciones

Los resultados obtenidos en esta tesis doctoral plantean diversas implicaciones prácticas destinadas a mejorar la eficacia de los diseños de evaluación e intervención psicológica dirigidos a abordar el malestar emocional experimentado por los familiares cuidadores de personas con demencia. Esta población es especialmente vulnerable a sufrir consecuencias psicológicas, como plantean los resultados encontrados por diferentes investigaciones previas (Kovaleva et al., 2018; Schulz et al., 2020) y los datos recopilados en los distintos artículos que conforman esta tesis.

Los hallazgos respaldan la existencia de malestar emocional significativo entre los familiares cuidadores, destacando diferencias notables en función del género y la relación de parentesco. Específicamente, las mujeres cuidadoras, y especialmente las hijas, parecen experimentar niveles más altos de malestar, lo que concuerda con lo encontrado por revisiones bibliográficas actuales (Collins & Kishita, 2020; Kaddour y Kishita, 2020; Watson et al., 2019). Además, en línea con el modelo sociocultural de estrés y afrontamiento propuesto por Knight y Sayegh (2010), los resultados subrayan la importancia de los factores culturales en la comprensión del malestar emocional de los cuidadores. Específicamente, en contextos como España, se destaca el impacto del valor cultural del familismo en el afrontamiento del cuidado, particularmente relevante para las mujeres cuidadoras y, en especial, para las hijas. Por lo tanto, se recomienda incluir componentes en las intervenciones dirigidos a capacitar a los cuidadores para adoptar una perspectiva más flexible hacia el afrontamiento del cuidado, considerando las expectativas culturales asociadas con las responsabilidades del cuidado y los pensamientos disfuncionales que conllevan.

Asimismo, considerando la influencia encontrada de factores psicosociales como la deseabilidad social en el informe del malestar emocional relacionado con el cuidado, especialmente en las mujeres cuidadoras, particularmente en las hijas, se resalta la importancia de utilizar métodos de evaluación alternativos, como tareas de procesamiento de información implícita, para obtener una comprensión más precisa de la angustia emocional de los cuidadores y reducir el impacto de los sesgos culturales. Sumado a esto, los datos subrayan la necesidad de diseñar intervenciones que aborden los desafíos específicos que enfrentan las hijas cuidadoras al equilibrar las expectativas familiares con sus propias necesidades. Para ello, se subraya la importancia de desafiar y modificar los pensamientos disfuncionales que pueden interferir en el adecuado afrontamiento del estrés asociado al cuidado y contribuir al malestar emocional, y de ofrecer estrategias prácticas para que puedan manejar los conflictos entre sus múltiples roles. De igual manera, dado el papel moderador de la función familiar en la relación entre los pensamientos disfuncionales y la sintomatología depresiva y ansiosa en las hijas, se sugieren intervenciones dirigidas a mejorar la dinámica familiar para reducir su angustia emocional. Esto podría incluir técnicas para establecer límites saludables, priorizar el autocuidado y negociar el apoyo de otros miembros de la familia, lo que podría promover estrategias de afrontamiento más adaptativas y, en última instancia, reducir los niveles de malestar emocional.

Por último, los resultados destacan la importancia de considerar perfiles específicos de cuidadores familiares de personas con demencia al diseñar intervenciones psicológicas para abordar su angustia emocional. Esto implica tener en cuenta variables psicosociales y de recursos, así como la relación de parentesco con el receptor de cuidados. Los hallazgos sugieren que las intervenciones deben adaptarse a las necesidades y vulnerabilidades específicas de cada grupo identificado, lo que podría mejorar la efectividad de las intervenciones dirigidas a esta población. Por ejemplo, para los perfiles de hijas cuidadoras con altos niveles de malestar emocional, sería adecuado validar sus sentimientos de culpa y proporcionar recursos y estrategias para ayudarlas a equilibrar las demandas derivadas de sus diferentes roles, algo que también parece recomendable para los perfiles de hijos cuidadores. Del mismo modo, para los esposos y especialmente para las esposas, podrían ser útiles intervenciones centradas en reestructurar creencias disfuncionales derivadas de valores culturales como el familismo.

Las investigaciones incluidas en esta tesis doctoral presentan varias limitaciones generales que es importante señalar. Si bien las limitaciones específicas de cada estudio se detallan en la sección de discusión correspondiente a cada uno de ellos, aquí se destaca, en primer lugar, que el diseño de los cuatro estudios fue transversal, lo que impide establecer relaciones causales entre las variables estudiadas. Son necesarios estudios futuros longitudinales o experimentales para confirmar o refutar las relaciones encontradas. En segundo lugar, aunque el tamaño de la muestra en general es similar al de otros estudios de cuidadores, no es representativo de la población de cuidadores, ya que consiste en participantes voluntarios. Estos participantes pueden diferir de la población general de cuidadores de personas con demencia, lo que afecta la generalización de los hallazgos en los diversos estudios. Además, el tamaño de la muestra para algunos grupos puede considerarse pequeño, especialmente para esposos e hijos, lo que podría haber influido en la representatividad de los resultados y la capacidad para detectar relaciones significativas en esos grupos específicos. Por lo tanto, se recomiendan estudios futuros con muestras más grandes de cuidadores masculinos para confirmar los hallazgos. En tercer lugar, hay otras variables que podrían ser relevantes en el estudio de la angustia emocional de los cuidadores familiares de personas con demencia que no fueron seleccionadas en esta tesis doctoral. Por lo tanto, la investigación futura podría explorar el impacto de variables adicionales (por ejemplo, fusión cognitiva; Barrera-Caballero et al., 2021) y otros aspectos relacionados con el contexto cultural y social de los cuidadores (por ejemplo, estereotipos de género; Toepfer et al., 2014) para obtener una comprensión más profunda de la experiencia del cuidado familiar. Por último, esta tesis doctoral se realizó en una sociedad mediterránea dentro del contexto europeo, lo que puede limitar la generalización de los resultados a otras regiones o contextos culturales diferentes (por ej., el norte de Europa; Uccheddu et al., 2019).

La asociación entre las variables estudiadas y la salud mental de los cuidadores puede ser especialmente relevante en sociedades donde prevalecen los valores familiares y un sentido de obligación hacia la familia. Se necesitan estudios futuros en diferentes contextos culturales para confirmar los hallazgos de la presente tesis.

A pesar de las limitaciones mencionadas, los hallazgos de la presente tesis doctoral contribuyen al desarrollo de intervenciones psicológicas prácticas dirigidas a abordar las necesidades específicas de los cuidadores familiares para hacer frente a los desafíos del cuidado. De esta manera, se resaltan la necesidad de considerar factores socioculturales y la relación de parentesco al diseñar evaluaciones e intervenciones para cuidadores familiares de personas con demencia. Es crucial que estas intervenciones reconozcan y aborden las diversas experiencias y necesidades de los cuidadores familiares, especialmente de las hijas cuidadoras, quienes son las más vulnerables al malestar emocional. Las hijas cuidadoras enfrentan desafíos únicos, incluida una mayor exposición al estrés debido al conflicto entre sus múltiples roles y la dificultad para cumplir con las expectativas sociales y familiares.

9.6. Futuras líneas de investigación

A continuación, se proponen áreas para futuras investigaciones sobre cómo las variables socioculturales afectan el bienestar emocional de los cuidadores familiares de personas con demencia, basadas en los resultados y limitaciones identificadas. En primer lugar, dado que los estudios realizados en la presente investigación son de tipo transversal, se requieren investigaciones futuras de carácter experimental y longitudinal que permitan confirmar la existencia de relaciones causales entre las variables examinadas. Además, considerando que la muestra utilizada en esta tesis consistió en participantes voluntarios y que el tamaño de muestra de los cuidadores masculinos, especialmente los hijos, puede considerarse pequeño, son necesarios estudios futuros con muestras más grandes y una selección de participantes más aleatoria. que permita obtener resultados más representativos y generalizables. Esto mejoraría la capacidad de representatividad de la población cuidadora y de generalización de los hallazgos.

En segundo lugar, la presente tesis doctoral se desarrolló en una sociedad mediterránea donde el valor del familismo tiene una fuerte presencia cultural (Van der Lippe, y Lippényi, 2020). Sin embargo, se necesitan estudios adicionales en diferentes contextos culturales para validar los resultados encontrados. Respecto al familismo, este estudio se centró exclusivamente en la dimensión de las obligaciones familiares, basándose en investigaciones anteriores como la realizada por Losada et al. (2010), que sugiere que esta dimensión es un factor potencial para la aparición de malestar en cuidadores. No obstante, sería interesante explorar cómo otras dimensiones del familismo afectan la salud mental de los cuidadores familiares. Por otro lado, se planteó que las hijas cuidadoras podrían experimentar una menor percepción de obligación familiar debido a su exposición prolongada al estrés del cuidado, lo que las hace más conscientes de las demandas de los valores familiares y los desafíos de sus múltiples roles, llevándolas a un mayor cuestionamiento de las presiones familistas. Sería de utilidad que investigaciones futuras examinen este planteamiento al estudiar la discrepancia entre los roles y su relación con las obligaciones familiares percibidas por las hijas cuidadoras.

En tercer lugar, dado que resultados de esta tesis muestran cómo el sesgo de deseabilidad social influye en cómo los cuidadores expresan su malestar asociado al cuidado, lo cual coincide con investigaciones anteriores que indican que las personas con altos niveles de este sesgo tienden a dar respuestas que consideran socialmente aceptables en lugar de expresar sus verdaderos sentimientos (Holtgraves, 2004), es importante tener en cuenta que esto puede ocultar, moderar o crear relaciones entre variables (Randall et al., 1993). Dado que las variables del estudio se basan en las respuestas de autoinforme proporcionadas por los propios cuidadores, sería recomendable que futuras investigaciones incluyan medidas para contrarrestar estos efectos y así mejorar la precisión de las evaluaciones del malestar emocional.

Por último, cabe mencionar que las nuevas tecnologías están desempeñando un papel cada vez más importante en la investigación y el desarrollo de intervenciones para mejorar la salud mental de los cuidadores familiares (Wójcik et al., 2021). Su uso ofrece ventajas significativas, como una recopilación de datos más eficiente y la participación de un mayor número de cuidadores de diferentes regiones del mundo. Esto abre la puerta a futuras investigaciones transculturales que podrían arrojar luz sobre el estrés asociado al cuidado en diferentes contextos culturales (Guzman-Parra et al., 2020). Además, las herramientas tecnológicas podrían permitir la incorporación de evaluaciones e intervenciones adaptadas a diferentes culturas, lo que puede enriquecer la comprensión de las experiencias de cuidado desde diversas perspectivas. Por último, el uso de nuevas tecnologías también facilita el acceso al apoyo social y reduce el aislamiento social sin necesidad de contacto en persona, lo que se ajusta mejor a los horarios y responsabilidades de los cuidadores (Czaja et al., 2013).

9.7. Conclusión final

El aumento en la esperanza de vida y la disminución de la tasa de natalidad están resultando en un envejecimiento progresivo de la población, lo que ha llevado a un aumento en el número de personas mayores dependientes (Ritchie, & Roser, 2023). Esto ha impulsado un aumento en la provisión de cuidado informal, especialmente para aquellas personas que sufren de demencia (Durante et al., 2022). El cuidado de personas con demencia implica una carga física y emocional significativa para los cuidadores familiares, quienes enfrentan mayores niveles de consecuencias adversas en comparación con otros cuidadores o la población en general (Collins & Kishita, 2020; D'Aoust et al., 2015).

La presente tesis doctoral se ha centrado en investigar el impacto de variables culturales en el estrés asociado al cuidado, con el propósito de comprender mejor este proceso y sus repercusiones en la salud mental de los cuidadores. Los hallazgos revelan que, en sociedades mediterráneas como España, el valor del familismo influye en la salud emocional de los cuidadores al estar asociado con una mayor presencia de pensamientos disfuncionales relacionados con el cuidado. Estos pensamientos pueden obstaculizar el adecuado afrontamiento del cuidado y aumentar el malestar emocional. Además, se analizó cómo la relación de parentesco con la persona cuidada influye en este proceso de estrés, para obtener una mayor comprensión de las experiencias individuales de los cuidadores.

Los resultados de esta investigación contribuyen al desarrollo de intervenciones psicológicas prácticas dirigidas a satisfacer las necesidades específicas de los cuidadores familiares, especialmente de las hijas cuidadoras, que son particularmente vulnerables al malestar emocional y constituyen una parte significativa de la población de cuidadores (Rexhaj et al., 2023). Se destaca la importancia de considerar factores socioculturales como el familismo y la relación de parentesco al diseñar evaluaciones e intervenciones para los cuidadores familiares de personas con demencia, con el objetivo de ofrecer un apoyo más efectivo y personalizado. Asimismo, los hallazgos de esta investigación respaldan la utilización de intervenciones centradas en modificar los pensamientos disfuncionales asociados al cuidado y en fortalecer la capacidad de los cuidadores para manejar estos pensamientos. La literatura previa sugiere la importancia delmanejo adecuado de los pensamientos para obtener resultados positivos sobre el malestar del cuidador, destacándose como un componente clave en las intervenciones psicológicas (Cheng et al., 2019). Además, estos pensamientos disfuncionales, especialmente en contextos culturales donde prevalece fuertemente el valor del familismo, pueden generar una mayor presencia de sentimientos de culpa significativos que requieren atención en las intervenciones.

Por lo tanto, la consideración de las variables analizadas en esta tesis en intervenciones dirigidas a cuidadores podría contribuir a incrementar el tamaño del efecto de las intervenciones existentes, que es en el mejor de los casos medio o moderado (Cheng et al., 2020). Adicionalmente, dada la necesidad de profundizar en la comprensión de los aspectos culturales del cuidado y mejorar la aplicabilidad transcultural de las intervenciones (Steffen et al., 2019), esta tesis doctoral busca contribuir en esta dirección.

10. General Conclusions

The various studies comprising this doctoral thesis, that are guided by the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010), provide useful information for understanding the impact of sociocultural and psychological factors for understanding the emotional distress of family caregivers of people with dementia. Specifically, the findings reflect the importance of considering kinship relationship with the care recipient in studying the effect of sociocultural and psychological variables on the caregiving-related stress process.

On one hand, the results obtained in the first study emphasized the significant prevalence of loneliness among family caregivers. Furthermore, cultural aspects, notably the value of familism, emerged as crucial for comprehending this feeling, particularly among daughters who seem especially susceptible to its influence. These results underscore the importance of culturally tailored interventions aimed at promoting a more adaptable outlook on cultural norms associated with caregiving responsibilities, while also addressing detrimental thought patterns.

On the other hand, the findings from the second study represent the first attempt to analyze the combined impact of social desirability and familism (family obligations) on caregiving stress, considering the caregivers' kinship relationship with the care recipients. The results indicate that family caregivers exhibiting high levels of social desirability may experience elevated distress, particularly daughters who may face increased stressors and be more susceptible to the negative effects of culturally endorsed values like familism. These findings underscore the importance of incorporating sociocultural factors in the assessment and design of interventions for caregivers. It is recommended that interventions tailored to cultural contexts influenced by values like familism should aim to alleviate the pressure exerted by these cultural norms on caregivers' dysfunctional thoughts, guilt, and depression.

Lastly, considering the findings from the third and fourth studies, it is recommended to consider specific profiles of family caregivers based on psychosocial and resource variables, as well as the kinship relationship, which can assist in designing more effective interventions targeted at the caregiver population. Furthermore, the importance of psychological interventions aimed at enhancing adaptive family dynamics, including communication, family cohesion, and leadership, to strengthen caregivers' family support networks, especially daughters, and safeguard their mental well-being is highlighted. Functional family dynamics can serve as a protective buffer even when caregivers hold rigid beliefs about caregiving.

In conclusion, this doctoral thesis offers valuable insights into the influence of sociocultural and psychological factors on the emotional well-being of family caregivers of people with dementia and the significance of taking into account the caregiver's kinship relationship with the care recipient. Specifically, according to the various findings, daughters' caregivers appear to be the most vulnerable group to experiencing negative consequences stemming from the caregiving stress process and to experiencing a greater impact of cultural variables on these consequences. Moreover, the information provided by these studies contributes to the development of practical psychological interventions aimed at addressing the specific needs of family caregivers in coping with the challenges of caregiving.

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ANEXOS

Anexo 1: Instrumentos de Evaluación

a) Variables contextuales

Escala Revisada de Familismo (RFS; *Revised Familism Scale*; Losada et al., 2020).

¿En qué medida piensa usted que…?

	Totalmente de acuerdo	De acuerdo	Indiferente	En desacuerdo	Totalmente en desacuerdo
Las personas deben hacer grandes sacrificios con el objetivo de garantizar una buena educación para sus hijos	0	1	2	3	4
La mayoría de lo que hace un hijo o una hija debería hacerse para agradar a sus padres	0	1	2	3	4
Las personas deben avergonzarse por las cosas malas hechas por sus hermanos o hermanas	0	1	2	3	4
Los hijos deberían vivir en casa de sus padres hasta que se casen	0	1	2	3	4
Uno de los objetivos más importantes en la vida es tener hijos	0	1	2	3	4
Las personas deberían obedecer siempre a sus padres sin discutir incluso aunque pensasen que tienen razón.	0	1	2	3	4

Pensamientos disfuncionales sobre el cuidado (DTCQ; Losada et al., 2006)

A continuación, se presentan diferentes enunciados sobre el cuidado de personas mayores. Por favor, señale **hasta qué punto está usted de acuerdo o se identifica concada uno de ellos.**

	Totalmente en desacuerdo	En desacuerdo	Indife-rente	De acuerdo	Totalmente de acuerdo
1. Solo la persona más cercana sabe cuidar verdaderamente bien de su familiar enfermo	0	1	2	3	4
2. Es egoísta que un cuidador dedique tiempo para sí mismo/a teniendo un familiar enfermo y necesitado.	0	1	2	3	4
3. Llegar a ser un buen cuidador significa no cometer errores en el cuidado de un familiar enfermo	0	1	2	3	4
4. Un buen cuidador es aquel que ayuda a su familiar en todas las tareas, incluso en aquellas que este podría hacer por sí mismo, si esto significa facilitarle la vida	0	1	2	3	4
5. Sería imperdonable que un cuidador pensara algo parecido a "sería mejor para todos que mi familiar muriese".	0	1	2	3	4
6. Si un cuidador tiene sentimientos de vergüenza y rechazo hacia su familiar, es que está fallando de alguna manera como cuidador.	0	1	2	3	4
7. Los buenos cuidadores deben mantenerse alegres todo el día para afrontar adecuadamente el día a día del cuidado	0	1	2	3	4
8. Un buen cuidador nunca debe enfadarse o perder el control con la persona que cuida.	0	1	2	3	4

9. Es lógico que los cuidadores pasen sus propias necesidades a un segundo plano, dejando de lado su satisfacción en favor de las necesidades del familiar	0	1	2	3	4
10. Un cuidador únicamente debe pedir ayuda a otras personas en aquellos casos en los que no sepa cómo resolver una situación	0	1	2	3	4
11. Por muy mal que se encuentre, un cuidador nunca debe desahogarse con otras personas, ya que es una falta de respeto a la persona enferma	0	1	2	3	4
12. Los cuidadores deben evitar hablar de sus problemas con los demás, ya que éstos tienen sus propias vidas y no tienen por qué verse implicados en más problemas	0	1	2	3	4
13. Un cuidador únicamente debe pedir ayuda a otras personas o buscar una alternativa cuando la situación sea límite o ya no pueda más	0	1	2	3	4
14. Pedir ayuda a personas que no son de la familia es lo último que debe hacer un cuidador, ya que el cuidado debe ser llevado en la familia.	0	1	2	3	4
15. Cuando una persona cuida a un enfermo debe dejar sus intereses a un lado y dedicarse por completo al enfermo	0	1	2	3	4
16. Como cuidador, considero que debo hacer todo lo que me pida la persona enferma, incluso aunque crea que es demasiado exigente.	0	1	2	3	4

Escala de Deseabilidad Social de Marlowe-Crowne (MCSDS; Crowne y Marlowe, 1960)

Señale hasta qué punto se identifica con dada una de las cuestiones listadas a continuación.

	Verdadero	Falso
1. Nunca vacilo en cambiar mis planes si se trata de ayudar a alguien que lo necesita.	☐	☐
2. Nunca nadie me ha caído excesivamente mal.	☐	☐
3. En alguna ocasión he sentido envidia de la suerte de otras personas.	☐	☐
4. Nunca se me ha pasado por la cabeza el permitir que alguien fuese castigado por mis equivocaciones.	☐	☐
5. En algunas ocasiones siento resentimiento si no consigo lo que quiero.	☐	☐
6. En alguna ocasión he tenido ganas de rebelarme contra personas con autoridad incluso sabiendo que tenían razón.	☐	☐
7. Soy siempre una persona cortés, incluso ante gente antipática.	☐	☐
8. Cuando no sé algo, nunca me ha importado admitirlo.	☐	☐
9. Recuerdo alguna ocasión en la que “me hice el enfermo” para librarme de algo.	☐	☐
10. En alguna ocasión me irrito con la gente que me pide un favor.	☐	☐

b) Estresores y valoración de la situación

Listado de Problemas de Memoria y Conducta Revisado (RMBPC; 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 ahacerle 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
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

Conducta	*Frecuencia*	**Reacción**
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

Índice de Barthel (Mahoney y 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 decomer 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 realizarlotodo 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. Loscomplementos 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 ysupositorios.

(0) Incontinente.

6. MICCIÓN (Valorar la semana previa):

(10) Continente. Ningún episodio de incontinencia. Capaz de usar cualquier dispositivo por sísolo.

(5) Accidente ocasional. Máximo un episodio de incontinencia en 24 horas. Incluye necesitarayuda 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 otrapersona.

(5) Necesita ayuda. Capaz de manejarse con pequeña ayuda: es capaz de usar el cuarto debaño. 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 utilizaprótesis, debe ser capaz de ponérsela y quitársela solo.

(10) Necesita ayuda. Necesita supervisión o una pequeña ayuda física por parte de otrapersona. 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

Escala De Deterioro Global (GDS; Reisberg et al., 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.

c) Recursos

Cuestionario de Apoyo social (PSQ; Reig et al., 1991)

	Nunca	**Alguna vez**	**Frecuente mente**	**Siempre**
1. Tengo amigos o familiares allegados que me visitan en casa.	0	1	2	3
2. Cuando lo necesito hay alguna persona que me expresa afecto y me anima.	0	1	2	3
3. Cuando lo necesito hay alguien que me alienta a que exprese mis ideas y pensamientos	0	1	2	3
4. Cuando lo necesito tengo a alguien que me puede prestar una ayuda económica o material importante.	0	1	2	3
5. Cuando lo necesito tengo a alguien para contarle los problemas que tengo relacionados con el cuidado.	0	1	2	3
6. Cuando lo necesito tengo las fuentes de información adecuadas.	0	1	2	3

Función familiar. Cuestionario Family APGAR (Smilkstein, 1978)

	Casi nunca	A veces	Siempre
¿Está satisfecha(o) con la ayuda que recibe de su familia?	0	1	2
¿Conversan entre ustedes los problemas que tiene en casa?	0	1	2
¿Siente que su familia le quiere?	0	1	2
¿Está satisfecho con el tiempo que su familia y usted pasan juntos?	0	1	2
¿Las decisiones importantes se toman en conjunto en casa?	0	1	2

Frecuencia de actividades de ocio (LTS; Stevens et al., 2004)

Durante el **mes pasado**, ¿con qué frecuencia ha realizado alguna de las siguientesactividades?

	Nada	**Un poco**	**Mucho**
1.Estar tranquilo	0	1	2
2.Ir a la iglesia u otras reuniones de grupos u organizaciones	0	1	2
3.Aficiones u otros intereses	0	1	2
4.Ir a comer o cenar fuera o a otras actividades sociales	0	1	2
5.Pasar buenos ratos con otras personas	0	1	2
6.Visitar a la familia y/o amigos	0	1	2

Evitación Experiencial en el Cuidado (EACQ; Losada et al., 2014)

A continuación,aparecen algunas frases. Por favor, piense hasta qué punto cada una de ellas se aplica austed (le define)

	Nada	**Un poco**	**Moderada-mente**	**Bastante**	**Muchísi-mo**
1.No se deben tener malos pensamientos hacia la persona a la que se cuida	1	2	3	4	5
2.Nunca me he sentido mal con motivo del cuidado de mi familiar	1	2	3	4	5
3.Evito pensar que otros familiares se portan de forma egoísta y tiendo siempre a excusarlos pensando cosas como que “ellos están más ocupados, pobres, tienen sus vidas….”	1	2	3	4	5
4.No soporto enfadarme con mi familiar.	1	2	3	4	5
5.No se debe sentir rechazo u otras emociones desagradables hacia la persona a quien se cuida.	1	2	3	4	5
6.Es normal que un cuidador tenga pensamientos negativos sobre la persona a la que cuida	1	2	3	4	5
7.Cada vez que vienen pensamientos malos sobre mi familiar o mi situación como cuidador, intento escapar de ellos y distraerme.	1	2	3	4	5
8.Es normal sentir estrés y depresión cuando se cuida a un familiar dependiente	1	2	3	4	5
9.Me asustan las emociones y pensamientos que tengo en relación a mi familiar.	1	2	3	4	5
10.Cuando tengo emociones negativas en relación al cuidado procuro entretenerme con otra actividad para que se me pase rápidamente.	1	2	3	4	5
11.Si un cuidador tiene pensamientos negativos hacia su familiar lo mejor es intentar ignorarlos.	1	2	3	4	5
12.Tiendo a “no hacer caso” a los pensamientos negativos que me surgen hacia mi familiar.	1	2	3	4	5
13.Es perjudicial que un cuidador se pare a analizar los sentimientos negativos que tiene con respecto a su familiar enfermo o algún otro familiar.	1	2	3	4	5

	Nada	**Un poco**	**Moderadamente**	**Bastante**	**Muchísimo**
14.Reflexionar sobre lo que un cuidador siente y piensa sobre su situación de cuidado es dañino.	1	2	3	4	5
15.En situaciones difíciles del cuidado, en las que necesitaría algún tipo de apoyo, prefiero no hablarlo con otros familiares si esto puede suponer un conflicto.	1	2	3	4	5

d) Consecuencias del cuidado

Depresión (CES-D; Radloff et al., 2012)

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

Ansiedad (POMS: McNair et al., 1971)

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

	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

Cuestionario de Culpa del Cuidador (CGQ; Losada et al., 2010)

	Nunca	**Rara vez**	**Algunas veces**	**Bastantes veces**	**Casi siempre**
1. Me he sentido mal por haber hecho algún plan o actividad sin contar con mi familiar.	0	1	2	3	4
2. Me he sentido culpable por la forma en que me he comportado en ocasiones con mi familiar.	0	1	2	3	4
3. Me he sentido mal por no atender a mis otros familiares (marido, mujer, hijos…) como debería.	0	1	2	3	4
4. Me he sentido mal por no poder dedicar más tiempo a mi familia (marido, mujer, hijos…).	0	1	2	3	4
5. He pensado que no estoy haciendo las cosas bien con la persona a la que estoy cuidando.	0	1	2	3	4
6. He pensado que, teniendo en cuenta las circunstancias, estoy haciendo bien mi tarea como cuidador/a.	0	1	2	3	4
7. Cuando he salido a hacer alguna actividad agradable (p.ej., ir a cenar a un restaurante), me he sentido culpable y no he dejado de pensar que debería estar cuidando o atendiendo a mi familiar.	0	1	2	3	4
8. Me he sentido mal por cosas que quizá había hecho mal con la persona a la que estoy cuidando.	0	1	2	3	4
9. He pensado que quizá no estoy cuidando bien.	0	1	2	3	4
10. Me he sentido mal por haberme enfadado con la persona a la que estoy cuidando.	0	1	2	3	4
11. Me he sentido mal por haber regañado por alguna razón a la persona a la que estoy cuidando.	0	1	2	3	4
12. Me he enfadado conmigo mismo/a por tener sentimientos negativos hacia la persona a la que cuido.	0	1	2	3	4
13. Me he encontrado pensando que no estoy a la altura de las circunstancias.	0	1	2	3	4
14. Me he sentido mal por no tener más paciencia con la persona a la que estoy cuidando.	0	1	2	3	4
15. Me he sentido mal por dejar a mi familiar al cuidado de otra persona mientras yo hacía mis tareas (ej., trabajo, compra, ir al médico, etc.).	0	1	2	3	4
16. Me he sentido mal por dejar a mi familiar al cuidado de otra persona mientras yo me divertía	0	1	2	3	4

17. Me he sentido culpable por desear que a otros "les toque esta cruz" o sufran lo mismo que yo.	0	1	2	3	4
18. Me he sentido mala persona por odiar y/o envidiar a otros familiares que podrían hacerse cargo y no lo hacen.	0	1	2	3	4
19. Me he sentido mal por tener sentimientos negativos (p.ej., odio, enfado o rencor) hacia algunos familiares.	0	1	2	3	4
20. Me he sentido culpable por el hecho de tener tantas emociones negativas en relación al cuidado.	0	1	2	3	4
21. He pensado que la forma en la que cuido de mi familiar podría no ser adecuada y contribuir a que su problema vaya a peor.	0	1	2	3	4
22. Me he sentido culpable al pensar que mi falta de información y preparación podría hacer que no estuviera manejando el cuidado de mi familiar de la mejor forma posible.	0	1	2	3	4

Anexo 2: Versión impresa del Estudio Uno

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Article

Sociocultural Influences on the Feeling of Loneliness of Family Caregivers of People with Dementia: The Role of Kinship

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Abstract: The extent to which familism, dysfunctional thoughts, and coping variables contribute to explaining feelings of loneliness in caregivers, controlling for kinship, is analyzed. Participants were 273 family caregivers of people with dementia. Sociodemographic variables, familism, dysfunctional thoughts, coping strategies for requesting and receiving help, perceived social support, and leisure activities were assessed. The fit of a theoretical model for explaining the effect of cultural and psychological variables on feelings of loneliness in each kinship group was tested. No significant differences in the distribution of loneliness by kinship were found. Higher levels of familism are associated with more dysfunctional thoughts, that are linked to more maladaptive strategies for coping with caring (e.g., less social support and fewer leisure activities). This in turn is associated with higher scores in the feeling of loneliness. The model bore particular relevance to the group of daughters, husbands, and sons, yet not in the case of wives. Sociocultural and coping factors associated with the caring process seem to play an important role in explaining feelings of loneliness in caregivers. Sociocultural factors associated with the care process seem to play an important role in explaining feelings of loneliness in caregivers.

Keywords: caregivers; dementia; familism; dysfunctional thoughts; kinship; loneliness

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1. Introduction

The progressive aging of the population due to increasing life expectancy is associated with a significant increase in the risk of dementia in Western countries [1] and in the number of people needing care [2]. The care of relatives that have dementia is commonly provided by families and, more specifically, by one person who adopts the role of primary caregiver, usually a woman [3]. Family care of a relative with dementia is associated with significant negative physical and psychological consequences for the caregiver, among which are the presence of anxious and depressive symptoms [4] and loneliness. Loneliness has scarcely been studied in caregiving contexts, despite the presence of studies suggesting its great prevalence among caregivers [5–7]. Such negative consequences associated with caregiving appear to occur to a greater extent among women [8], with studies suggesting that caregiver daughters in particular are at greater risk of suffering emotional problems [9].

Different theoretical models have explained the presence of emotional distress in caregivers, with the stress and coping model proposed by Lazarus and Folkman [10] salient among them. According to this model, apart from the sources of the stress itself, the consequences of caregiving-related stress depend on how the person interacts with the situation based on their evaluation of it and the personal and social resources available to them. Based on the Lazarus and Folkman [11] model, theoretical models adapted to caregiving have been developed, such as the sociocultural stress and coping model, which has significant empirical support [11]. This model offers a conceptual framework of caregiver stress and the different coping processes as influenced by cultural factors [11]. One of the cultural values which has received the most attention in the study of care is familism [11,12]. This variable reflects a cultural value related to solidarity between the different members of the family associated with strong feelings of loyalty and dedication to one another [13]. Thus, while factors such as family solidarity or affection may have a role to play in family caregiving, such care also involves the fulfillment of a duty, so that caring for the family member is combined with obligation. The provision of care in a context where the perception of family obligation is strong is associated with a significant negative impact resulting in emotional distress for caregivers [12].

The effect of cultural variables in caregiving seems to be greater on women due to the traditional attitudes associating care with the female role, so that this activity continues to fall more heavily on them [14]. This distribution of traditional gender roles may be at the root of why women, in contrast to men, become involved to a greater extent in caregiving tasks and therefore deal with more demands for care and spend more time on it [8]. Furthermore, the fact that women habitually have to play multiple roles (worker, wife, daughter, mother, etc.) makes them more likely to experience the adverse consequences of caregiving [15].

These considerations are in line with those posited by the cognitive model adapted to caregiving [16]. This model hypothesizes that culture clearly influences how caregiving is seen and handled (e.g., "Only the closest person to the frail/sick older adult knows how to truly take care of him or her"; "It is selfish for a caregiver to dedicate time to himself/herself when a relative is frail/sick and needs care"). Such thoughts can be linked to behaviors which may have negative physical and psychological consequences for health, such as not asking for help or not engaging in leisure activities. Failure to ask for help can reduce the possibilities of maintaining social relationships (support network), leisure, motivation, and energy, thereby changing the structure of one's social network, which can result in isolation [17] and loneliness [7]. Although scarce, the available literature on loneliness in caregivers seems to suggest that female caregivers report higher levels of loneliness [6] and, according to the results obtained by Stefani, Seidmann, Pano, Acrich, and Pupko [18], daughters show greater loneliness than wives.

Taking into account all of the above, and based on the sociocultural [11] and cognitive [16] models of care-related stress and coping, the present study therefore had the following objectives: (a) to assess the degree to which perceived loneliness is present in caregiving and analyze potential kinship-based differences in the degree of perceived loneliness; (b) to evaluate the fit of a theoretical model analyzing the degree to which, by kinship, cultural values are associated with dysfunctional thoughts and the maladaptive coping strategies of requesting and receiving less help, as well as having less social support and fewer leisure activities, and (c) to analyze how these relationships influence the perception of loneliness in family caregivers of people with dementia (see Figure 1).

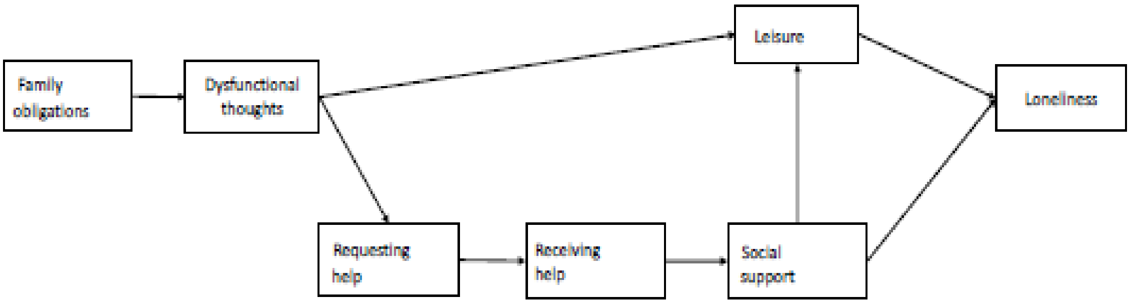

Figure 1. The sociocultural stress and coping model tested.

Along these lines, we expected (1) to find a significant percentage of caregivers, especially women and in particular daughters, reporting feelings of loneliness; (2) that a greater presence of the cultural value of familism would be associated with more dysfunctional thoughts about caregiving, which would be linked to the existence of more maladaptive coping strategies for caregiving, that is, requesting and receiving less help, which would in turn lead to a lower predisposition to social support and a lower frequency of leisure activities; and (3) that a greater implementation of such maladaptive coping strategies would be reflected in higher scores in the feeling of loneliness among caregivers. Given the influence of gender roles, the aforementioned consequences were expected to be especially significant in caregiver daughters as they are subject to greater role conflict.

2. Method

2.1. Participants

The study sample comprised 273 people (women = 68.9%) aged between 28 and 88, all of them caregivers of relatives with dementia residing in the Community of Madrid (Spain). Participants were divided into four kinship-based groups: husbands (n = 56; 20.5%), wives (n = 67; 26.48%), daughters (n = 117; 42.85%), and sons (n = 33; 12.08%). The sociodemographic characteristics of participants by kinship are shown in Table 1.

Table 1. Kinship differences in the assessed variables.

Variables	0. Daughters		1. Wives		2. Husbands		3. Sons		F/χ^2 (sig)	Diff.
	(n = 117)		(n = 67)		(n = 56)		(n = 33)			
	Mean	SD	Mean	SD	Mean	SD	Mean	SD		
Age	54.07	8.22	72.34	8.06	75.21	6.64	52.87	9.94	98.49 (0.00)	1 & 2 > 0 & 3
Loneliness never (%)	43.5		46.2		57		48.5		10.75 (0.29)	n.s.
Loneliness sometimes (%)	30.8		22.3		19.6		24.2			
Loneliness occasionally (%)	17.1		10.4		10.8		15.2			
Loneliness most or all of the time (%)	8.5		20.1		12.5		12.2			
Work outside home (% yes)	51.29		10.5		1.8		60.6		89.64 (0.00)	0 & 3 > 1 & 2
Live with children (% yes)	41.1		17.9		7.2		24.3		25.32 (0.00)	0 > 1, 2 & 3
Care for other relatives (% yes)	35.1		11.9		3.6		9.1		34.87 (0.00)	0 > 1, 2 & 3
Hours of care	11.1	8.46	16.1	7.50	16.59	7.44	8.68	9.16	12.04	0 & 3 < 1 & 2
Frequency of disruptive behaviors	37.21	13.98	32.31	12.23	32.89	11.42	31.93	11.17	2.78 (0.03)	0 > 1, 2 & 3
Functional capacity of person cared for	61.96	27.77	71.65	26.17	7663	23.82	65.61	31.07	3.52 (0.01)	0 < 1 & 2
Family obligations	6.39	3.51	10.00	4.12	9.82	4.55	8.60	3.52	13.02 (0.00)	0 < 1, 2 & 3
Dysfunctional thoughts	19.03	11.12	34.78	15.47	37.98	12.18	25.06	12.29	27.94 (0.00)	1 & 2 > 0 & 3
Requesting help	2.95	0.71	1.83	0.97	2.05	1.02	2.18	0.91	2.52 (0.04)	0 > 1, 2 & 3
Receiving help	2.83	1.17	2.85	1.39	2.98	1.31	2.93	1.15	2.08 (0.08)	n.s
Social support	11.52	3.68	11.13	3.72	10.77	4.57	8.72	3.95	3.34 (0.01)	3 < 0, 1 & 2
Leisure	5.71	2.78	5.43	2.70	6.48	2.80	6.12	2.67	1.26 (0.29)	n.s

Note: SD = Standard Deviation; n.s = non-significant differences.

Participants were recruited through health and social services centers, which facilitated initial contact to confirm criteria for inclusion in the study were met (identifying as the main caregiver of the sick relative, dedicating at least one hour a day to caregiving and having done so for at least the previous 3 months, and being aged over 18). All subjects participated voluntarily and were individually interviewed face-to-face. The study was approved by the Ethics Committee of the Rey Juan Carlos University, and prior to the assessment, informed consent, guaranteeing data confidentiality among other issues, was obtained from each individual.

2.2. Measures

Drawing upon the sociocultural stress and coping model, the following variables were measured.

Sociodemographic variables: age, gender, kinship to the person being cared for, daily hours caring, paid work outside the home, living with children at home, and caring for other relatives.

Care-recipient functional capacity. This was measured through the Barthel Index [19], which showed internal consistency (Cronbach's alpha) of 0.91 in this study.

Frequency of behavioral problems associated with dementia. This was measured through the Revised Memory and Behavior Problems Checklist (RMBPC) [20]. It includes 24 items (e.g., "Asking the same question over and over") which assess the frequency of behavioral problems scored on a 5-point Likert scale ranging from 0 ("Never") to 4 ("Every day"). The internal consistency (Cronbach's alpha) in this study was 0.78.

Familism: family obligations. This was assessed through the family obligations subscale of the Revised Familism Scale (RFS) [21]. It consists of 5 items (e.g., "One should make great sacrifices in order to guarantee a good education for his/her children") with a response range from 0 ("Totally disagree") to 4 ("Totally agree"). The subscale's internal consistency (Cronbach's alpha) for this study was 0.74.

Dysfunctional thoughts. The Dysfunctional Thoughts Questionnaire (CPD) [22] was used to evaluate thoughts, beliefs, and attitudes that hinder adaptive coping related to caregiving. It consists of 16 items (e.g., "Only the person closest to the frail/sick older adult knows how to truly take care of him or her") with a response range from 0 ("Totally disagree") to 4 ("Totally agree"). Internal consistency (Cronbach's alpha) in the present study was 0.91.

Requesting and receiving help. These were assessed by administering two items developed ad hoc for this study ("Do you ask your relatives for help with caring for your sick relative?" and "Do you receive help?"). Both items have a 4-option Likert-type response format ranging from 1 ("Never") to 4 ("Always").

Social support. The Psychosocial Support Questionnaire (PSQ) [23] was used to assess the perception of social support, using 6 items (e.g., "My friends and/or relatives pay me visits at home") in a Likert-type response format with a response range from 0 ("Never") to 3 ("Very often"). Cronbach's alpha in the present study was 0.76.

Frequency of leisure activities. This was measured using the adapted Leisure Time Satisfaction scale (LTS) [24]. Its 6 items (e.g., "Quiet time by yourself", "Taking part in hobbies") measure the extent to which caregivers had participated in leisure activities. Responses are rated on a 5-point Likert-type scale from 0 ("Not at all") to 4 ("A lot"). Cronbach's alpha for this scale in the present study was 0.71.

Feeling of loneliness. Item 14 ("I felt lonely") of the CES-D scale [25] with a response range from 0 ("Rarely or never") to 3 ("All the time") was used to measure how lonely people felt. This item has been used as an indicator of loneliness in previous studies (e.g., [26]) and is the same or similar to that included in different instruments to assess loneliness, such as the OARS scale [27].

2.3. Data Analysis

Statistical Package for the Social Sciences (SPSS statistics 22) (IBM, Chicago, IL, USA) and AMOS 6.0 software (IBM, Chicago, IL, USA) were used to carry out the analyses for this study. Considering the small sample size of the group of sons, the associations that are significant at $p < 0.10$ were highlighted for this group. A p value of 0.05 is considered for the rest of the results. First, descriptive analyses, comparison of means, and independence tests were carried out between the sociodemographic variables assessed and the perception of loneliness. Second, correlation analyses were performed between the different variables for each kinship group (presented as Supplementary Materials). Finally, and following the sociocultural model of stress and coping [11] and the cognitive model adapted to caregiving [12,16], we assessed the fit of the data to the model presented in Figure 1 through path analysis. The cultural variable of family obligations is taken first, followed by dysfunctional thoughts and caregiver resources (asking for help, receiving help, social support and engagement in leisure activities) and, finally, the feeling of loneliness. The associations found in the model for each of the kinship groups were analyzed. The following indices were used to assess the fit of the data from the model: chi-square, incremental fit index (IFI), comparative fit index (CFI), and the root mean square error of approximation (RMSEA).

3. Results

3.1. Sample Characteristics by Kinship

Table 1 shows the descriptive characteristics for each of the variables studied by kinship group. As can be seen, significant differences were found between these groups for almost all the variables assessed, with the exception of receiving help, leisure and loneliness. The percentage of caregivers who reported feeling lonely occasionally or most or all of the time ranged from 25.6% (daughters) to 30.5 (wives).

The data show that more daughters and sons work outside the home than husbands and wives. Daughters and sons also report a smaller number of daily hours devoted to caregiving compared to wives and husbands. Daughters as a group are those who most report living with children and who seem to be caring the most for other family members. Finally, daughters report caring for people with more problem behaviors than the other kinship groups, and they also care for more people with lower functional capacity than wives and husbands.

In turn, it is also daughters who present differences in family obligations compared to the other groups, where significantly lower scores in this variable are found. Regarding dysfunctional thoughts, results show that husbands and wives present more dysfunctional thoughts about caregiving than sons and daughters. In relation to asking for help, the data suggest that sons as a group ask for the most, while wives are the least likely to implement this caregiving coping strategy. However, in terms of social support, significant differences are seen in this variable between sons and the other groups, with sons in this case scoring lower on social support received. The associations between the assessed variables (correlations) are presented in the Supplementary Materials.

3.2. Model Fit and Associations by Kinship Group

The overall model fitted the data very well ($\chi^2 = 67.31$; $p = 0.075$; $\chi^2/df = 1.29$; IFI = 0.956; CFI = 0.946; RMSEA = 0.033). Table 2 shows the unstandardized estimates for each of the kinship groups assessed. The standardized regression weights for each kinship group are shown in Figure 2.

As can be seen in Table 2 and Figure 2, all the associations between the variables shown in the model are significant in the group of daughters. In this group, the perception of family obligation is associated with more dysfunctional thoughts, which in turn are associated with asking for and receiving less help. Receiving less help is associated with less perceived social support. Less social support and more dysfunctional thoughts are associated with less engagement in leisure activities. Finally, less engagement in leisure activities and less social support are associated with a greater perception of loneliness. The relationship between these variables explains 27% of the variance of loneliness in daughters.

Table 2. Standardized and unstandardized regression weights by kinship.

			Daughters		
			Unstandardized Estimates	**S.E.**	**C.R.**
Family obligations	→	Dysfunctional thoughts	1.942 **	0.233	8.339
Dysfunctional thoughts	→	Requesting help	−0.013 *	0.006	−2.269
Requesting help	→	Receiving help	0.614 **	0.147	4.183
Receiving help	→	Social support	0.855 **	0.284	3.008
Dysfunctional thoughts	→	Leisure	−0.060 **	0.021	−2.867
Social support	→	Leisure	0.282 **	0.063	4.492
Leisure	→	Feeling of loneliness	−0.101 **	0.030	−3.358
Social support	→	Feeling of loneliness	−0.089 **	0.023	−3.911
			Sons		
			Unstandardized Estimates	**S.E.**	**C.R.**
Family obligations	→	Dysfunctional thoughts	1.802 **	0.523	3.442
Dysfunctional thoughts	→	Requesting help	0.018	0.013	1.376
Requesting help	→	Receiving help	0.744 **	0.187	3.984
Receiving help	→	Social support	1.093 †	0.572	1.910
Dysfunctional thoughts	→	Leisure	−0.023	0.035	−0.665
Social support	→	Leisure	0.251 *	0.109	2.307
Leisure	→	Feeling of loneliness	−0.214 **	0.066	−3.256
Social support	→	Feeling of loneliness	0.026	0.044	0.587
			Wives		
			Unstandardized Estimates	**S.E.**	**C.R.**
Family obligations	→	Dysfunctional thoughts	1.992 **	0.392	5.076
Dysfunctional thoughts	→	Requesting help	−0.020 **	0.007	−2.722
Requesting help	→	Receiving help	0.842 **	0.147	5.710
Receiving help	→	Social support	0.580 †	0.331	1.751
Dysfunctional thoughts	→	Leisure	−0.065 **	0.020	−3.300
Social support	→	Leisure	0.093	0.082	1.141
Leisure	→	Feeling of loneliness	−0.069	0.054	−1.265
Social support	→	Feeling of loneliness	−0.015	0.039	−0.394
			Husbands		
			Unstandardized Estimates	**S.E.**	**C.R.**
Family obligations	→	Dysfunctional thoughts	1.117 **	0.327	3.413
Dysfunctional thoughts	→	Requesting help	−0.019	0.011	−1.759
Requesting help	→	Receiving help	0.863 **	0.132	6.536
Receiving help	→	Social support	1.194 **	0.448	2.663
Dysfunctional thoughts	→	Leisure	−0.050	0.029	−1.745
Social support	→	Leisure	0.166 *	0.077	2.170
Leisure	→	Feeling of loneliness	−0.119 *	0.050	−2.394
Social support	→	Feeling of loneliness	−0.042	0.030	−1.397

Note: † = $p < 0.10$; * = $p < 0.05$; ** = $p < 0.01$; S.E. = Standard error; C.R. = Critical Ratio.

In the case of wives, results are very similar to those of daughters in terms of the significant relationship between the variables family obligations, dysfunctional thoughts, asking for help, receiving help, and the relationship between receiving help and social support ($p < 0.10$) and dysfunctional thoughts and less leisure. However, contrary to our hypotheses, no significant relationship was found in wives between social support and leisure, and feelings of loneliness (Table 2). The model tested explains only 3% of the variance of loneliness in wives.

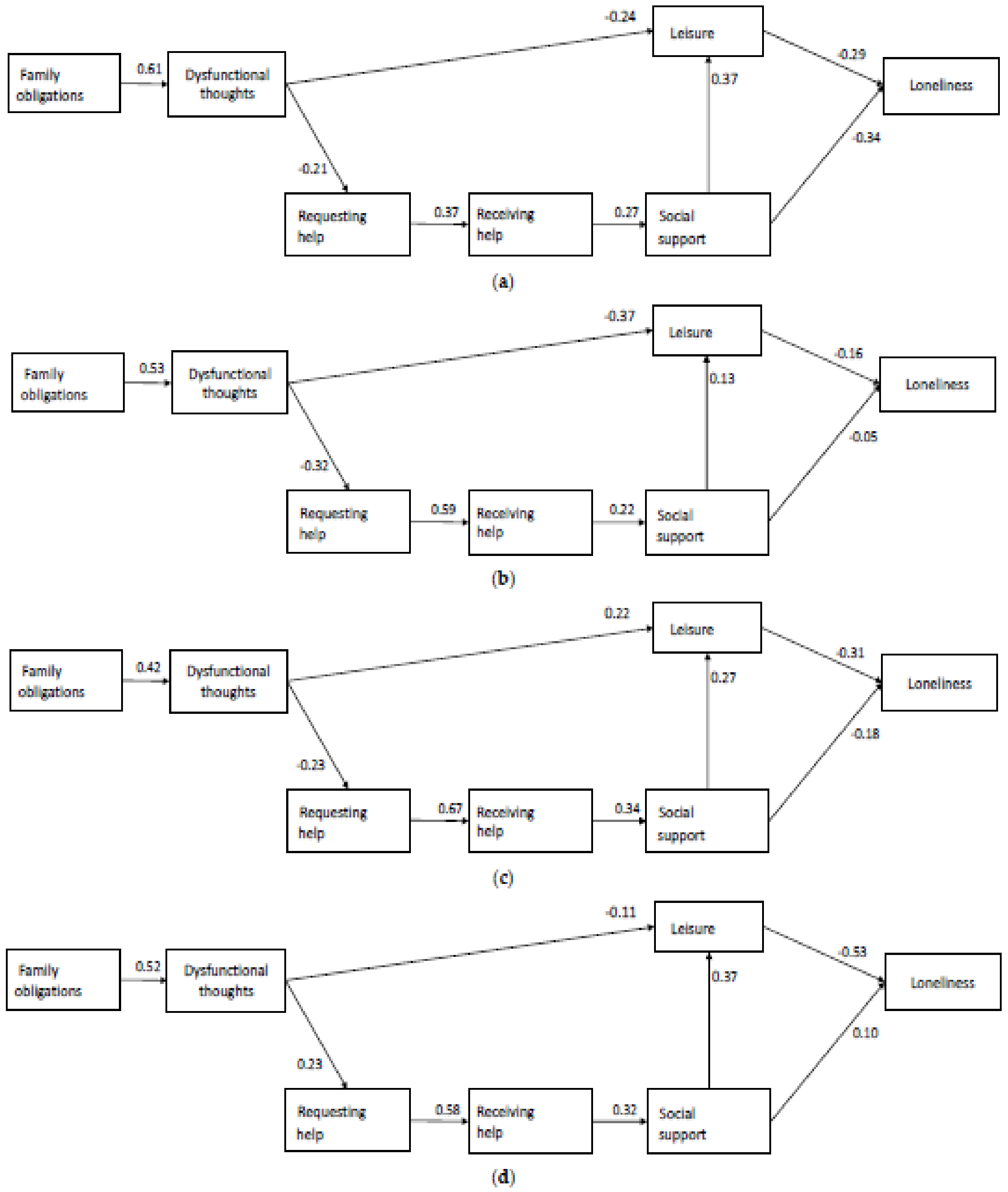

Figure 2. Standardized regression weights for (**a**) daughters, (**b**) wives, (**c**) husbands, and (**d**) sons.

Regarding husbands, practically all the associations observed in daughters and stated in the model are also present (some with a $p < 0.10$), with the exception of the relationship between social support and loneliness, which seems to be mediated by leisure. The model explains 16% of the feeling of loneliness in husbands.

Finally, in the case of caregiver sons, the data obtained are somewhat different from the other groups. In this case, despite finding the significant association observed in all groups between family obligations and dysfunctional thoughts, dysfunctional thoughts were not significantly associated in sons with asking for help or with leisure. As with husbands, the pathway that seems to influence the feeling of loneliness most is that by requesting less help, less help is received, less social support is perceived, there is less engagement in leisure activities, and this influences loneliness. The percentage of variance explained in sons is 25%.

4. Discussion

The main objective of this study was to analyze the degree to which perceived loneliness is present in caregiving and whether there are differences in perceived loneliness based on kinship. The results obtained are consistent with other studies in that they reflect perceived loneliness being present in a significant percentage of caregivers [18]. However, although it was expected that daughters would present the highest levels of loneliness due to their being subjected to greater stress and role conflict, the results of this study suggest that there are no kinship-based differences in the degree of perceived loneliness. Therefore, the first hypothesis posited in this study is partially fulfilled, since the data do suggest a high presence of perceived loneliness among caregivers, but not greater loneliness in the group of daughter caregivers compared to other relatives. These results may be due to the fact that a large percentage of daughters have paid work outside the home, a rare occurrence among older groups (husbands and wives). Work is not only a way of earning a salary or gaining social prestige, but it also allows greater participation in social life and can act as a protective factor against the feeling of loneliness [28]. On the other hand, results also show daughters to be the group which most lives with children, most takes care of other family members, and more frequently deals with the disruptive behaviors and functional deterioration of the person in their care. These data seem to confirm that daughters are subjected to more sources of stress [8], which can lead to role overload and higher levels of stress, and which in turn may favor or be related to less awareness of their levels of loneliness.

With regard to the second objective, assessing the fit to the data of a stress and coping model based on sociocultural [11] and cognitive [16] models, the results appear to confirm the proposed hypotheses, especially in the group of daughters. In relation to daughters, these hypotheses seem to be supported by the data since a greater perception of family obligations is linked to a greater sense of loneliness, given that the influence of such obligations on dysfunctional thoughts regarding caregiving favors the implementation of maladaptive strategies (failure to ask for and receive help) and with it less social support and leisure. In this sense, the data also support the cognitive model adapted to caregiving [16]. In particular, our data support the pathological way through which culture has an influence on the development of maladaptive thoughts in caregivers (e.g., "I should not ask for help, this is something that should be resolved in the family"), which have negative consequences in terms of behavior (no help seeking, no leisure time) and affective consequences (loneliness).

For the groups of male caregivers (husbands and sons), the results obtained are generally similar to those observed in daughters, although some differences were noted. In both husbands and sons, for example, the level of perceived social support does not appear to be of particular relevance in explaining their perception of loneliness. The results suggest that in male groups (husbands and sons) the relationship between social support and loneliness could be indirectly mediated through leisure. Different studies suggest that men, despite requesting help in a similar way to women, receive more social support (e.g., [29]). In the case of caregiver sons, this is the group in our study (data not shown) with most singles, where the majority do not have children and practically all of them (all but 3) care for their mother. It is possible that they took on their role as caregivers because no other possible sources of potential caregivers existed in their environment and that the main route of escape from their loneliness was therefore perceived to be through leisure. Future studies should address these issues in more depth.

The most unexpected results were found in caregiver wives, for whom the proposed model explains only 3% of their perceived feeling of loneliness. Although the data obtained suggest that a significant percentage of caregiving wives report loneliness, the variables measured do not seem to contribute to an explanation of this issue in the group in the same way they do in the other kinship groups. It is possible that variables which were not assessed in this study may play a fundamental role in the explanation of loneliness among wives, such as, for example, the loss of a relationship of intimacy and trust with their partner, as well as maladaptive strategies for the regulation of emotions or coping, such as rumination or escape-avoidance coping strategies. Thus, for example, Vikström, Josephsson, Stigsdotter-Neely, and Nygard [30] reported that many couples attributed their perception of loneliness to the loss of an intimate relationship, since their partner, their confidant, provided them with great emotional support. Regarding rumination, the study by Robinson-Whelen Tada, MacCallum, McGuire, and Kiecolt-Glaser [31], carried out exclusively with spousal caregivers, mostly women, the authors concluded that the variable that contributed most to the emotional distress of the caregivers was intrusive and avoidant thoughts about caregiving. Robinson-Whelen et al. [31] also stated that social support received during the caregiving years was not so much related to negative outcomes as social support after the loss of the spouse. Social support during caregiving may not be so relevant for female spouse caregivers because caring for the husband is coherent with the gender-role script. Finally, as reviewed by Yee and Schulz [32], compared with men, women reported using more escape-avoidance coping strategies, suggesting the usefulness of training them in seeking-support strategies (e.g., assertive communication).

Therefore, although loneliness seems to be a pervasive problem among caregivers, there appear to be different explanations for it depending on the kinship of the caregiver with the person in their care. In terms of the influence of familism and the dimension of family obligations in particular, the data indicate a lower presence of familism (family obligations) in the group of daughters and less perceived social support in the group of sons. In relation to familism in daughters, the reduced presence of this variable may be explained by the conflict that this value can trigger in them with respect to the situation in which they find themselves. Daughters may be aware of how the sense of family obligation falls mainly upon them and, therefore, they question it more than other groups since the consequences are much greater for them [32]. Montgomery [33] argues that women, especially those who work outside the home, have greater difficulty in combining work and family, and experience greater social limitations than men, something that contributes to their sense of distress. Regarding perceived social support, the fact that sons show lower levels of this may be explained by taking into account that when sons take on the role of caregiver in a society where the traditional family values prevail and caring seems to be fundamentally associated with the daughters, it may be because there is no one else who can do it, indicating that they are more alone in the caregiving situation. In fact, authors such as Hanlon [34] identify two types of male caregivers: those who have no other option, that is, who are forced into caregiving, with the result that their participation in the labor market decreases, and those who have nothing to lose. Therefore, although the literature supports the argument that men receive more help with caregiving than women, this may not be enough to generate high levels of perceived social support since they are usually in a vulnerable situation, without their own family or children and without a job or career, and caring for their mother because her spouse can no longer do so.

The present investigation has a series of limitations. First, the design was cross-sectional in nature, and longitudinal studies are necessary to confirm or rule out the relationships found. Second, participation in the study was voluntary, so the general population of caregivers may not be properly represented. Furthermore, as noted above, variables which may be of particular relevance to understanding the feeling of loneliness in caregivers were not included in the study. Future research with larger samples may allow a more detailed inquiry into the relationships studied.

Despite such limitations, the present study provides interesting information on an area that generates significant distress among caregivers: loneliness. First, the data confirm that a significant percentage of caregivers perceives loneliness. Second, data from the present study provide additional support to theoretical models of stress and coping adapted to caregiving which highlight the importance of sociocultural aspects in the explanation of caregiver distress [11,12], in this case aimed at explaining the loneliness of caregivers. They also support the cognitive model adapted to caregiving [16] since in the case of daughters in particular, they suggest that cultural variables play an important role in the perception of loneliness. These cultural variables include familism (family obligations) and the dysfunctional thoughts of caregivers, which give rise to maladaptive coping with caring, thereby reducing the chances of obtaining help, social support and engagement in leisure activities. Caregiving daughters seem to be particularly vulnerable to this process since the variables measured explain a large percentage of the loneliness they feel.

Finally, the data from this study confirm that loneliness is a pervasive problem in caregiving and suggest an approach to understanding the issue which can be useful in developing interventions. Such interventions could help caregivers towards a more flexible view of the cultural impositions associated with family obligations in caregiving and maladaptive thinking styles, perhaps through culturally sensitive interventions [35].

Supplementary Materials: The following are available online at https://www.mdpi.com/article/10.3390/ijerph18094700/s1, Table S1: Correlation matrix for husbands, Table S2: Correlation matrix for wives, Table S3: Correlation matrix for daughters, Table S4: Correlation matrix for sons.

Author Contributions: C.H.-D. leaded the data analysis and writing of the initial draft of the manuscript and worked in the assessment of the sample. M.M.-G. collaborated in the design of the study and writing of the manuscript. I.C. collaborated in data collection, data analysis and writing of the manuscript. R.R.-M. collaborated in the design of the study, data collection and writing of the manuscript. M.d.S.P.-C. collaborated in the assessment of the sample and writing of the manuscript. S.B.-C. collaborated in the assessment of the sample, data analysis and writing of the manuscript. A.L.-B. worked in the design of the study and its supervision and the writing of the paper. All authors have read and agreed to the published version of the manuscript.

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Data Availability Statement: The study materials, analytic methods and data are available upon request from the corresponding author on reasonable request.

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Anexo 3: Versión impresa del Estudio Dos

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Sociocultural factors, guilt and depression in family caregivers of people with dementia. Kinship differences

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ABSTRACT

Objectives: This study aims to analyze the role that family obligations and social desirability have for understanding guilt and depressive symptoms in family caregivers. A theoretical model is proposed to analyze this significance based on the kinship with the person cared for.

Methods: Participants are 284 family caregivers of people with dementia divided into four kinship groups (husbands, wives, daughters and sons). Face-to-face interviews were conducted assessing sociodemographic variables, familism (family obligations), dysfunctional thoughts, social desirability, frequency and discomfort associated with problematic behaviors, guilt and depressive symptoms. Path analyses are performed to analyze the fit of the proposed model and multigroup analysis to study potential differences between kinship groups.

Results: The proposed model fits the data well and explains significant percentages of variance of guilt feelings and depressive symptomatology for each group. The multigroup analysis suggests that, for daughters, higher family obligations were associated with depressive symptomatology through a report of higher dysfunctional thoughts. For daughters and wives, an indirect association between social desirability and guilt was observed through reaction to problematic behaviors.

Conclusion: The results support the need to consider the significance of sociocultural aspects such as family obligations and the desirability bias in the design and implementation of interventions for caregivers, especially for daughters. Considering that the variables that contribute to explaining caregivers' distress vary depending on the relationship with the person cared for, individualized interventions may be warranted depending on the kinship group.

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Introduction

People who care for a family member with dementia must face multiple highly demanding, unpredictable, and variable tasks during many hours a day and for a long time (Alzheimer's Association, 2019). This may have important negative psychological consequences in caregivers (Gilhooly et al., 2016; Jütten et al., 2019; Walter & Pinquart, 2020), especially for women (Erol et al., 2016; Wang et al., 2011).

Depressive symptomatology, which refers to a group of symptoms related to negative affect (e.g. sadness and anhedonia), low behavioral activation, and maladaptive cognitions, is the mental health variable that has received the most attention in the scientific literature on care, while other variables, such as guilt, have not received as much attention, even though they generate significant levels of suffering (Losada et al., 2018). Guilt, defined as the negative feeling generated after recognition of the transgression of a value or an important social standard, contributes significantly to explaining the emotional distress of many caregivers (Gonyea et al., 2008; Losada et al., 2018).

Different theoretical models describe factors that contribute to caregivers' emotional distress. One of the models that has received strong empirical support is the sociocultural stress and coping model adapted to caregiving (Knight & Sayegh, 2010). Besides highlighting the importance that behavioral and psychological symptoms associated with dementia have in explaining the emotional symptomatology of caregivers, this model reinforces the influence that cultural variables such as familism have in understanding the care process (Walker et al., 2020). The value of familism is related to the belief that individuals must remain loyal and supportive to the family, sacrificing, if the situation requires it, individual interest for the well-being of the family (Martí & Cid, 2015; Mendez-Luck et al., 2016). Within the European context, this value is more present in some cultures than in others, being predominant in Mediterranean societies, such as Spain, compared to northern European countries (Uccheddu et al., 2019).

One of the main dimensions of familism is family obligations, which refers to the perceived obligation by members of a family to provide emotional and material support and help to each other (Gaugler et al., 2009). Although there are few studies that have analyzed the differences based on sex or kinship in this variable, some studies have obtained results that suggest a greater perception of family obligations in women (Goodman et al., 1994; Van der Lippe & Lippényi, 2020). Due to the traditional attribution of the task of care to the female sex, women appear to further internalize the need to care for dependent relatives as a moral obligation (Bartlett et al., 2018; Meira et al., 2017). The internalization of this obligation occurs through cultural and

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social processes and seems to have a negative effect on the mental health of caregivers (Sayegh & Knight, 2011) because it is related to the appearance of dysfunctional thoughts linked to the task of care (Losada et al., 2010). For example, family caregivers may have thoughts related to the family or cultural norms and be aware that the conflicts or negative feelings that they may experience in relation to the task of caring should not be expressed (e.g. 'No matter how bad they feel, a caregiver should never vent to other people' or 'caregivers should avoid discussing their problems with others'). These dysfunctional thoughts can cause negative emotions and lead caregivers to engage in less adaptive behaviors such as not resting or not asking others for help, which has an impact on their emotional distress and could be associated with the presence of depressive symptoms (Kwon et al., 2017; Losada et al., 2006). That is, the presence of dysfunctional thoughts leads caregivers to establish patterns of maladaptive behaviors (Marquez-Gonzalez et al., 2007), influencing their well-being through the implementation of maladaptive coping strategies, which has been related to the presence of emotional discomfort (Losada et al., 2006). In fact, different studies show that the intervention and modification of these dysfunctional thoughts (for example through cognitive restructuring and training caregivers in identifying and modifying them) can reduce caregivers' discomfort since these thoughts act as barriers to adequate coping with care (Burgio et al., 2003; Gallagher-Thompson et al., 2002; Losada et al., 2011, 2015). Therefore, the internationalization of family obligations could be involved in obstructing the expression or open communication of discomfort or positive emotions associated with care by caregivers. This potential implication of familism has not yet been studied.

A variable that could be related to this potential interference of familism in emotional expression is the social desirability bias, defined as the tendency of the evaluated subjects to deny socially undesirable aspects and admit those that are desirable (Dunn & Shome, 2009; Furnham, 1986; Tyson, 1992). This bias leads to the choice of socially expected responses, rather than those that report their true feelings (Holtgraves, 2004), due to the need to be seen as a subject more oriented towards the values of society and more altruistic than they are (Tyson, 1992). This may influence study results by concealing, moderating, or erroneously generating relationships between relevant variables (Randall et al., 1993). The presence of such a care bias has been scarcely studied in the care literature, although it might be related to the dimension of family obligations discussed as part of the cultural norm of familism; Specifically, caregivers with a greater internalization of the norm of cultural obligations could have a greater tendency towards social desirability, as a reflection of their greater need to adjust more faithfully to what is socially expected from them and to behave according to the family norms. For its part, social desirability could interfere with the caregivers' report, facilitating the tendency to minimize the expression of their discomfort with caring or the frequency or discomfort associated with the behaviors of the care-receiving relative.

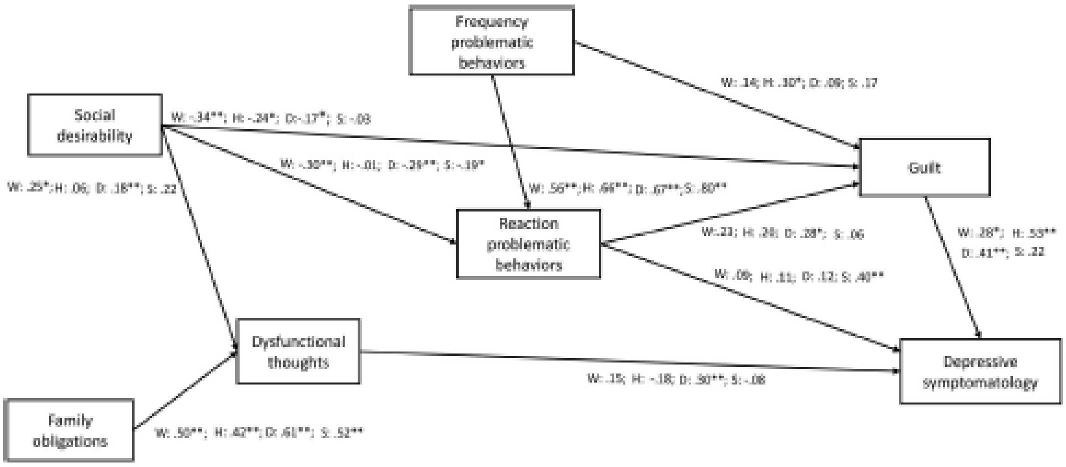
Finally, another variable to mention in the study of caregiving and its relationship with emotional distress is the relationship with the person being cared for. Previous research has found that kinship with the person cared for has a considerable impact on the stress and well-being of caregivers (Biegel & Schulz, 1999; Bourgeois et al., 1996; Kim et al., 2012; Sörensen et al., 2002). It appears that husbands and wives show lower levels of caregiving distress compared to sons and daughters (Conde-Sala et al., 2010) and higher levels of satisfaction with life (Anderson et al., 2013). Additionally, spouses report a higher perceived quality of life for their dementia family member compared to adult child caregivers. However, wives and husbands seem to report more grief than daughters and sons caregivers when the person cared for is transferred to a nursing homes. (Rigby et al., 2019). Furthermore, studies such as Tavero et al. (2018) show that women have a worse self-assessment both in terms of physical, psychological and social health, which affects their quality of life. Especially daughter caregivers have a higher risk of presenting mental health problems due to the stress to which they are subjected by the care task (Romero-Moreno et al. 2014; Stephens et al., 2001) combined with the multiplicity of roles that they face (professional life, raising children, etc.). The conflict experienced by the multiplicity of roles may lead daughters to perform more potentially harmful behaviors towards their relatives with dementia compared to spouse caregivers. In turn, this leads them to present higher levels of feelings of guilt than spouses. (Gonyea et al., 2008; Losada et al., 2010). In fact, the results obtained by Barber and Pasley (1995) showed that, even though daughters and wives provided care in a similar way, the daughters manifested higher levels of strain with the relative they cared for and with other family members.

Taking everything into consideration, and drawing upon the sociocultural model of stress and coping (Knight & Sayegh, 2010), the general objective was to analyze the role that the sociocultural variables familism (family obligations) and the desirability bias have in the explanation of guilt and depressive symptomatology in family caregivers of people with dementia. Figure 1 presents the conceptual model analyzed in the study. Specifically, it was hypothesized that (1) higher scores in perception of family obligations and higher levels of social desirability would be associated with a greater presence of rigid beliefs associated with care (dysfunctional thoughts), and that (2) higher scores in social desirability would be associated with a lower report of discomfort associated with care (discomfort associated with problematic behaviors shown by people with dementia, feelings of guilt and depressive symptomatology). Furthermore, (3) differences based on kinship in the relationships were expected, with wives and daughters showing a greater significance of such sociocultural variables (i.e. family obligations and social desirability) in the care process compared to husbands and sons. Considering that previous studies reported indirect effects of familism on outcomes such as depression (e.g. Losada et al., 2010), indirect effects were expected to exist between the tested sociocultural variables of the model and the levels of guilt and/or depressive symptoms.

Methods

Participants and procedure

A total of 284 caregivers of relatives with dementia living in Madrid, Spain, aged between 28 and 88 years (Mean = 62.94; SD = 12.81) participated in this research. The recruitment of the sample took place through various health and social care centers. The centers facilitated a first contact with the participants in which compliance with the inclusion criteria was confirmed: (1) identifying themselves as the main caregiver of the family member diagnosed with dementia; (2) spending at least one hour of care per day per week or a total of 7 h per week; and (3) having been caring for the sick family member for at least the last three consecutive months. These criteria are similar to those used in studies carried out with family caregivers (e.g. Sutter et al., 2014; Yu et al., 2016), and coherent with the general characteristics of the caregiving population (Alzheimer's Association, 2022).



Note: W: Wives, H: Husbands, D: Daughters, S: Sons; ** p < .01; * p < .05.

Figure 1. Tested sociocultural stress and coping model by kinship group (1a: Wives, 1b: Husbands, 1c: Daughters, 1d: Sons).
Note: ** *p* < .01; * *p* < .05

The evaluation of the participants was carried out between January 2015 and March 2020 through face-to-face interviews conducted by psychologists trained for this task. The evaluations lasted approximately 1 h (approximate range: 45 min – 1 h 50 min) and were carried out in Madrid, Spain. The study was approved by the Ethics Committee of the Rey Juan Carlos University and all subjects signed an informed consent for their participation in the study prior to evaluation.

Measures

Sociodemographic variables

Data were collected on age, gender, relationship with the person cared for, co-residence, time spent caring, daily hours dedicated to care, paid work outside the home and living with children. Regarding the person cared for, data were collected on age and gender, the type of dementia diagnosed and the patient's cognitive assessment. Specifically, for the assessment of the care-recipients' cognitive status the Global Deterioration Scale (GDS; Reisberg et al., 1988) was used.

Familism

The subscale corresponding to the 'family obligations' dimension of the revised familism scale (RFS; Losada et al., 2020, Spanish version) was used. This is made up of 6 items (e.g. 'most of what a son or daughter does should be done to please their parents') with a response range from 0 'totally disagree' to 4 'totally agree'. Higher scores on the subscale thus correspond to a greater perception of family obligations. The internal consistency (Cronbach's alpha) of this dimension in this study is 0.75.

Dysfunctional thoughts

The Dysfunctional Thoughts about Caregiving Questionnaire (DTCQ; Losada, 2005), developed in Spanish, was used. This questionnaire is made up of 16 items (e.g. 'Only the closest person knows how to really take good care of their sick family member') with a response range oscillating between 0 and 4 to evaluate the presence of attitudes, thoughts and beliefs associated with caring that could interfere with adaptive coping with care. A higher score corresponds to a greater presence of dysfunctional thoughts. The internal consistency (Cronbach's alpha) of the scale for the present study is 0.91.

Social desirability

Social desirability is the tendency of evaluated subjects to report behaviors that are culturally acceptable. It was measured in this study as an indicator of the potential need of the participants to respond to culturally accepted behaviors such as providing care for a relative with dementia. The Spanish brief 10-item version (Ávila & Tomé, 1989) of the Marlowe-Crowne Social Desirability Scale (MCSDS; Crowne & Marlowe, 1960) was used. The response range is between 1 (items that the person considers true) and 0 (items that the person considers false), (e.g. 'I have never disliked anyone' or 'I am always polite'). Higher scores on this scale are equivalent to a greater presence of social desirability. Cronbach's alpha for the study sample is 0.61.

Frequency and discomfort associated with problematic behaviors

The Revised List of Memory and Behavior Problems (RMBPC) was administered (Teri et al., 1992; Spanish version by Nogales-González et al., 2015). This questionnaire consists of 24 items (e.g. 'Please indicate if, during the past week, your relative has destroyed property') indicating the frequency of problematic behaviors during the previous week in a response range between 0 'never occurs' and 4 'occurs daily'. In addition, the extent to which the same behavior has generated discomfort for the caregiver is also indicated, from 0 'it did not stress me at all' to 4 'it stressed me extremely'. For the current sample, Cronbach's alpha values are 0.77 and 0.85 for the frequency and discomfort subscales, respectively.

Feelings of guilt

The Caregiver Guilt Questionnaire (CGQ) (Losada et al., 2010; developed in Spanish) was used, which measures the feeling of guilt in caregivers. It consists of 22 items (e.g. 'I have felt guilty for the way I have behaved at times with my family member'), evaluated on a Likert-type scale from 0 'never' to 4 'always or almost always'. The total scale presents a Cronbach's alpha of 0.88 in the present study.

Depressive symptomatology

The Center for Epidemiological Studies - Depression Scale (CES-D; Radloff, 1977; Spanish version by Losada et al., 2012) was used to evaluate this. It is made up of 20 items (e.g. 'I felt that I could not get rid of sadness even with the help of my family or friends') with a response range for each item between 0 'rarely or never' and 3 'all the time' to describe depressive symptoms that the subjects could have experienced during the past week. The internal consistency of this scale (Cronbach's Alpha) has a value of 0.87 for the present study.

Data analysis

Sample characteristics and differences in the assessed variables based on kinship were analyzed through chi-square tests and one-factor ANOVAs, while the model described in Figure 1 (1a for wives, 1b for husbands, 1c for daughters, 1d for sons) was analyzed to study the associations between the variables evaluated, following the sociocultural model of stress and coping (Knight & Sayegh, 2010). The associations between the variables observed in the model were studied through path analysis. Caution should be taken when interpreting the results as the sample size for husbands and sons is small, and so the findings of this study should be considered as preliminary and descriptive, with a need for future studies that may replicate the findings. Only those associations that were found to be significant for at least one kinship group are shown in the figures. Those associations that were not significant for any group (e.g. between family obligations and depressive symptoms) were deleted from the tested model. The fit of the data to the model was based on the values obtained in different goodness-of-fit indices: chi-square (CMIN), chi-square/df (CMIN/df), incremental fit index (IFI), comparative fit index (CFI), and root mean square error of approximation (RMSEA). Data with a well-adjusted fit are those values for CMIN with $p > 0.05$; between 1 and 3 for the CMIN/gl index; values greater than 0.95 for the IFI, CFI indices and for RMSEA values less than 0.08 (Browne & Cudeck, 1993; Hu & Bentler, 1999). Considering that previous studies have reported indirect associations between cultural variables and outcomes such as depressive symptoms (e.g. Losada et al., 2010), all possible indirect effects of the analyzed variables on guilt and depressive symptoms were tested. First, we tested whether social desirability had an impact on guilt and depression symptoms through reaction to problem behaviors or through dysfunctional thoughts. Secondly, we tested whether familism had a significant impact on guilt and depression symptoms through dysfunctional thoughts. Finally, we tested whether the frequency of problematic behaviors of the person with dementia had a significant impact on guilt and depression symptoms through the reaction to such behaviors. Indirect effects were analyzed using bootstrapping, with 2000 bootstrap samples and a bias-correlated confidence interval of 95%. Finally, multigroup analysis was performed to study the differences in the direct and indirect effects reflected in the model between the kinship groups (wives, husbands, daughters, and sons). A freely estimated model (with parameter computed freely across groups) was compared with a restricted model (invariance -equality constraints- was imposed on the structural weights). Differences between the models (with and without restrictions) were computed using chi-square tests. All analyses were carried out with the Statistical Package for the Social Sciences (SPSS Statistics 22) program and the AMOS 6.0 Software.

Results

Descriptive characteristics of the sample

As shown in Table 1, there was a greater participation of women ($n = 194$; 68.4%) and the largest kinship group was daughters ($n = 122$; 43%), followed by wives ($n = 72$; 25.4%), husbands ($n = 58$; 20.4%) and sons ($n = 32$; 11.3%). In addition, it was observed that the type of dementia predominating in the person cared for in the total sample was Alzheimer's disease ($n = 162$; 56.9%), that the average daily hours dedicated to the task of caring was 13 and that the average value of the patient's cognitive assessment (GDS) for the total sample was 4.6, corresponding to moderate-severe cognitive impairment. The mean scores for each kinship group in each of the variables evaluated in the study can also be seen in Table 1.

The results suggest that there are no significant differences between kinship groups in the type of disease of the relative cared for, with Alzheimer's disease predominant in all of them. Regarding the patient's cognitive assessment, no significant differences were observed between kinship groups. Daughter caregivers was the group reporting more working outside the home and living with children. Wives and husbands devoted more daily hours to the task of care compared to the sons and daughters.

Concerning dysfunctional thoughts and social desirability, as shown in Table 1, wives and husbands reported higher mean scores than sons and daughters. There were no significant differences between husbands and wives nor between sons and daughters. Regarding family obligations, the results suggest that daughters report lower mean levels compared to other kinship groups.

In relation to the frequency and reaction to problematic behaviors, significant differences were observed between the daughters and the other kinship groups, with daughters reporting higher mean scores in both variables (Table 1). Finally, in relation to guilt and depressive symptomatology, the data show that daughters and sons reported higher mean scores in feelings of guilt than wives and husbands (with no significant differences between wives and husbands, nor between daughters and sons), and that husbands was the one reporting lower mean levels of depressive symptomatology.

Path analysis for the explanation of guilt feelings and depressive symptomatology

The results of the path analysis performed by kinship group are shown in Figure 1 (1a for wives, 1b for husbands, 1c for daughters, 1d for sons). The fit indices suggest an excellent fit of the model to the data: chi-square = 45.11 ($p = 0.43$), chi-square/df = 1.03, IFI = 0.99, CFI = 0.99 and RMSEA = 0.01. In spite of this, and as already mentioned, caution is needed when interpreting the results, mainly for husbands and sons, due to the small sample size of the groups.

For wives, the model explained 27% of the variance of guilt and 12% of the variance of depressive symptomatology. For husbands, the model explained 27% of the variance of guilt and

Table 1. Characteristics of the sample and differences by kinship.

	0- WIVES (25.4%)		1- HUSBANDS (20.4%)		2- DAUGHTERS (43.0%)		3- SONS (11.3%)			
Variables	Mean	SD	Mean	SD	Mean	SD	Mean	S.D	F/χ^2 (sig)	Differences between kinship groups ($p<0.05$)
Caregivers' Age	72.51	7.90	75.19	6.85	54.02	8.30	53.25	9.88	141.68 (< .001)	0 & 1 > 2 & 3
Care-recipients' age	77.96	7.04	75.10	7.34	83.54	7.21	82.00	12.70	17.35 (<.001)	2 & 3 > 0 > 1
Care-recipients' gender (% female)	0.00		100		82.00		93.80		195.03 (<0.001)	0 < 1, 2y & 3
Alzheimer (% Yes)	48.6		68.4		57.5		59.4		5.16 (0.16)	No differences
Work outside home (% Yes)	6.9		0		52.1		59.4		93.38 (<.001)	2 & 3 > 0 & 1
Living with children (% Yes)	16,7		8.6		39.7		25.0		24..25 (<.001)	2 > 0, 1 y 3
Living with the care-recipient (% Yes)	98.6		100		50.8		50.0		84.23 (<.001)	0 y 1 > 2 y 3
Family obligations	10.00	4.02	9.88	4.70	6.45	3.52	8.75	3.48	16.90 (<.001)	2 < 0, 1 & 3
Dysfunctional thoughts	34.63	15.06	38.50	12.58	18.91	11.08	25.28	12.42	41.35 (<.001)	0 & 1 > 2 & 3
Social desirability	8.21	1.52	7.95	1.65	6.75	2.07	6.06	2.15	16.25 (<.001)	0 & 1 > 2 & 3
FrequencyBPSD.	31.76	12.10	32.76	12.09	37.73	14.30	32.81	10.15	4.15 (0.01)	2 > 0, 1 & 3
Reaction BPSD	15.69	11.91	15.43	15.57	22.13	16.36	17.72	15.54	4.01 (0.01)	2 > 0, 1 & 3
Guilt	14.46	9.87	16.26	10.61	25.50	13.07	25.47	14.14	17.38 (<.001)	2 & 3 > 0 & 1
Depressive symptomatology	18.18	10.84	13.02	8.44	18.97	11.36	18.31	11.14	4.34 (0.01)	1 < 0, 2 & 3
Time since caregiving (months)	59.38	61.88	47.66	32.20	48.14	36.40	48..50	31.77	1.23 (0.30)	No differences
Daily hours of care	16.49	7.17	16.51	6.80	10.70	7.39	7.55	6.00	20.86 (<.001)	0 & 1 > 2 > 3
Care-recipients' GDS	4.58	1.21	4.42	1.21	4.80	1.26	4.41	1.21	1.54 (0.21)	No differenfes

Note: BPSD = Behavioral and Psychological Symptoms of Dementia; GDS = Global Deterioration Scale; Range of the potential scores for each of the measured variables: Family obligations: 0–24; Dysfunctional thoughts: 0–64; Social desirability: 0–10; Frequency and Reaction problematic behaviors: 0–96; Guilt: 0–88; Depressive symptomatology: 0–60.

37% of the variance of depressive symptomatology. In the case of daughters, the model explained 18% of the variance of guilt and 29% of the variance of depressive symptoms and, in sons, the model explained 5% of the variance of guilt and 25% of the variance of depressive symptoms. Figure 1 shows the standardized coefficients of the direct relationships between the evaluated variables (the non-standardized coefficients can be consulted in supplemental online material, as well as the standard errors and the critical ratios). The multigroup analysis suggests that the relationships between the variables observed in Figure 1 are different depending on each kinship group, given that a significant decrease in the fit of the evaluated model was observed when moving from the model without restrictions ($p = 0.18$; chi-square/df = 1.19) to the restricted model of structural weights ($p = 0.01$; chi-square/df = 1.43).

The results shown in Figure 1a and 1c suggest that, for wives and daughters, higher scores in social desirability and family obligations are associated with more dysfunctional thoughts. In husbands and sons (Figure 1b and 1d), the only significant association found was between family obligations and dysfunctional thoughts. The relationship between social desirability and dysfunctional thoughts in men did not reach significance.

Although an association between family obligations and dysfunctional thoughts was found in all kinship groups, a significant relationship between these variables and depressive symptomatology was observed only for daughters. Specifically, the results showed the existence in daughters of a significant indirect association between family obligations and depressive symptomatology through dysfunctional thoughts (standardized indirect effect = .18; $p < .01$; SE = .05; CI = .10 – .28). That is, in daughters, a higher score in the perception of family obligations was associated with a higher report of dysfunctional thoughts, and this association helps to explain their levels of depressive symptomatology. According to the multigroup analysis, the relationship observed in daughters between family obligations and depressive symptomatology via dysfunctional thoughts) was statistically different to the relationship between such variables in husbands (the associations observed for daughters are different to those observed for husbands; estimate = .72; CI = .40 – 1.13; $p = .001$) and sons (the associations observed for daughters are different to those observed for sons; estimate = .72; CI = .01 – 1.29; $p = .046$). In summary, familism (family obligations) seems to affect daughters in a particularly negative way with respect to the other groups as it is associated with a greater presence of dysfunctional thoughts and with more depressive symptomatology.

The data shown in Figure 1 reflects that social desirability was directly and significantly associated with a lower report of discomfort associated with problematic behaviors in all kinship groups except in husbands. In addition, it was found that both in wives (standardized indirect effect = –.07; $p < .05$; SE = .05; CI = –.20—.01) and in daughters (standardized indirect effect = -.08; $p < .05$; SE = .04; CI = –.17—.02) there was an indirect relationship between social desirability and guilt, via reaction to problem behaviors. According to the multigroup analysis, the association found in daughters was significantly different to that found in husbands (the associations observed for daughters are different to those observed for husbands; estimate = –.51; CI = –1.21—.03; $p = .04$). That is, the results suggest that social desirability in women is associated with a lower report of discomfort associated with problematic behaviors, and this association in turn influences women (and, especially, daughters) to report fewer symptoms of guilt.

A significant direct association between social desirability and a lower report of guilt was also found in all groups except sons. In the case of husbands, an indirect relationship was also found between social desirability and depressive symptomatology, via feelings of guilt (standardized indirect effect = –.14; $p < .05$; SE = .08; CI = –.33 – .01). That is, husbands who reported high social desirability reported fewer guilt symptoms, and this ultimately explains lower levels of the variance of depressive symptomatology. In summary, significant negative associations were observed for all kinship groups between social desirability and indicators of discomfort in caregivers (second hypothesis).

Finally, an indirect relationship was found between the frequency of problematic behaviors and depressive symptomatology via reaction to problematic behaviors and guilt for wives (standardized indirect effect = .07; $p < .05$; SE = .05; CI = .00 – .20), husbands (standardized indirect effect = .30; $p < .01$; SE = .10; CI = .11 – .50) and daughters (standardized indirect effect = .19; $p < .01$; SE = .06; CI = .08 – .31). That is, the effect of the frequency of problem behaviors and the distress associated with them on depressive symptomatology was not direct in the case of wives, husbands, and daughters. In other words, for these kinship groups, a higher frequency of problematic behaviors was related to higher levels of discomfort associated with problematic behaviors and guilt symptoms, and this relationship implied a greater report of depressive symptoms.

In the case of sons, the relationship between discomfort associated with problematic behaviors and depressive symptomatology was significant and direct, without the indirect effect of guilt, something that was not observed in the other kinship groups.

Discussion

The objective of this research was to study the impact of the sociocultural variables of familism (family obligations) and the bias of social desirability in the stress process of family care of people with dementia. In particular, it was intended to analyze the relationship of the mentioned variables with the dysfunctional thoughts of caregivers and their reports of discomfort associated with care, through indicators of discomfort associated with problematic behaviors of dementias, feelings of guilt and depressive symptomatology. The above relationships were studied considering the kinship relationship of the caregivers with the person cared for (wives, husbands, daughters and sons).

The results suggest that daughters are subjected to higher stress than the other groups. In addition to being the group (along with sons) that most worked outside the home, they are the ones that reported more living with children and the greatest frequency of problematic behaviors and discomfort associated with these behaviors. Although in the study sample no significant differences were observed between the groups in cognitive status, some studies show that female caregivers seem to report a greater impact of problematic behaviors (Bédard et al., 2005). In addition, the results obtained by Neal et al. (1997) reflect that female caregivers who have a job (more likely in the case of daughter caregivers) have greater difficulties with problematic behaviors than men. Specifically, daughter caregivers who work outside the home do not reduce the hours dedicated to providing assistance to their family member with dementia, something that does happen when care is provided by sons (Bédard et al., 2005). This is in relation to the results obtained in the present study, since as can be seen in Table 1, although daughters spend on average fewer hours caring than spouses, they are the group that manifest higher levels of frequency and reaction to problematic behaviors. This shows the greater impact that problem behaviors have on them. Additionally, the presence of problematic behaviors is strongly associated with higher stress levels in caregivers, and a greater feeling of being trapped in the caregiver role (Bertrand et al., 2006).

Moreover, daughters reported fewer feelings of familism (family obligations) than the other kinship groups, something that could be related to being subjected to greater stress and the awareness of the clash between the different roles they must fulfill (Steiner & Fletcher, 2017). Although future studies should try to analyze this hypothesis, we believe that this higher exposure to stress during a long caregiving process may facilitate daughter caregivers' awareness of the objective difficulty and unfair imposition of responding to perceived pressures or demands derived from family values (Meira et al., 2017), which could lead them to a greater questioning of it. In addition, being a caregiver for a family member with dementia, which is a very demanding task, can lead to the appearance of discrepancies between the role of caregiver and other roles that the caregiver may have (e.g. mother, worker, etc.). When the standards or expectations of their relational identities are exceeded, this has been associated with higher levels of burden for caregivers (Savundranayagam & Montgomery, 2010). This may also be a reason for daughter caregivers reporting fewer feelings of family obligations. When daughters report caregiving behaviors that exceed personal expectations for the caregiver role, daughters may further question their perceived family obligations, adjusting their behaviors to identity standards associated with the role of being caregivers, in order to reduce the discrepancies between the caregiver role and their other roles. This discrepancy in roles and its association with the family obligations perceived by daughters is something that future interventions should consider to reduce the burden levels of daughter caregivers. Regarding the specific study hypotheses, the results obtained partially support the first hypothesis because, although significant associations were found for all kinship groups between family obligations and levels of dysfunctional thoughts, the relationship between social desirability and higher levels of dysfunctional thoughts was observed exclusively in the wives and daughters. It is possible that the relationship observed in women between social desirability and greater report of dysfunctional thoughts of care may be influenced by cultural values not evaluated, related to gender stereotypes or related attitudes such as machismo. The social and cultural consideration that care tasks should be assumed mainly by women (Toepfer et al., 2014) may influence the increased pressure on them to express socially desirable ways of acting in the face of care (e.g. 'help should not be asked for', 'care should be carry out by the person who best knows the person being cared for', etc.).

On the other hand, the results of the multigroup analysis suggest that, exclusively in daughters, levels of familism (family obligations) are indirectly associated with depressive symptomatology, through their influence on dysfunctional thoughts. Although daughters reported a lower perception of family obligation for care, it seems that, perhaps because they are subjected to a multiplicity of roles (Vaquiro & Stiepovich Bertoni, 2010), the difficulty of responding to family values when dealing with care leads them to face it in a more restrictive and maladaptive way, which ends up generating depressive feelings (Losada et al., 2010). That is, family obligations may lead daughter caregivers in particular to present dysfunctional thoughts associated with care (e.g. 'it is selfish for caregivers to spend time on themselves' or 'a caregiver should only ask other people for help in extreme situations') that may involve the use of dysfunctional coping strategies (for example, fewer self-care actions, less asking for help, etc., which in turn affects their levels of depressive symptomatology. Therefore, although daughter caregivers seem to express lower levels of feelings of familism (family obligations), they seem particularly vulnerable to the effects of familism and their consequences on depression symptoms. As mentioned above, dealing with multiple roles and responsibilities, together with difficulties in fulfilling expectations and family values may be key to understanding this seemingly paradoxical finding. Because of all this, it is very difficult for daughter caregivers to find a balance between caring for their relative and their own families and satisfying their own needs, such as spending time doing things of their interest or taking better care of their physical and mental health (McCabe et al., 2016; Tatangelo et al., 2018). Thus, future interventions focused on daughter caregivers should also include treatment components aimed at questioning feelings of family obligations, dealing with the multiplicity of roles, and providing daughter caregivers with resources and strategies for successful coping such as asking others for help.

However, the awareness of the difficulty to respond to family values would not prevent the emergence of feelings of guilt. It is precisely this distancing from a socially desirable value such as familism that may lead them, in turn, to report more feelings of guilt than wives and husbands, due to the internal conflict generated by the impossibility of responding to the family value of care. In the case of wives and husbands, caring for a spouse can be perceived as a duty that, in addition to not conflicting with other responsibilities (childcare and work), is expected as part of their marital commitment (Greenwood & Smith, 2019). However, no significant association was found between low values of familism and higher levels of guilt in daughter caregivers. This could be explained in that, although daughters may have lower levels of familism due to the great stress to which they are subjected and the awareness of the difficulty of responding to the demands and perceived pressures derived from familism, their approach to caregiving can conflict with the high familistic approach to caregiving of other relatives. This may generate in daughter caregivers what has been labelled as induced guilt: the comments, complaints, and criticisms of other relatives about the way in which the daughters deal with care can also be a source of guilt (Gallego-Alberto et al., 2022).

Regarding the second hypothesis of the study, which suggested that social desirability would be associated with a lower report of discomfort by caregivers, it is supported for the husbands, wives and daughters: higher social desirability was associated with a lower report of reaction to problem behaviors in wives and daughters, and a lower report of feelings of guilt in husbands, wives and daughters. The results of the multigroup analysis suggest that, in the case of daughters, the indirect relationship between social desirability and a lower report of guilt, through its influence on a lower report of reaction to problematic behaviors, is statistically higher than that observed in husbands. This is in accordance with the social context of the study, that is, given that care has traditionally been linked to the family and specifically to women, showing complaints or reactions to the problematic behavior of the family member or carrying out activities not linked to care (going out, letting off steam, etc.) would go against what is socially expected. For this reason, in order to fulfill their role as caregiver and not feel guilty for not reaching the norm or the ideal standard, caregivers (especially daughters) with high levels of social desirability could present difficulties when it comes to recognizing negative emotions and carrying out pleasant activities without the cared relative. In this way, the report of lower levels of guilt may reflect rigid behavior patterns developed to avoid feeling bad. Future studies should delve into this analysis and explore the possible mechanisms involved in the relationships between social desirability, guilt, adaptive coping with caregiving and depression.

Given the known relationship between feelings of guilt and depressive symptomatology, the results of this study suggest that psychosocial aspects such as social desirability may lead people to report being less affected by care (less discomfort associated with problem behaviors) and discomfort (less guilt and depressive symptomatology), which would limit the possibility of identifying vulnerable profiles in socially desirable caregivers. Specifically, the results of mean differences in the variables of problematic behaviors, guilt and depressive symptomatology suggest that daughters report more stress and guilt than the other groups, and similar levels of depressive symptomatology. However, the results of this study suggest that these levels could be higher than those reported, given that social desirability could be softening actual levels of discomfort, so that husbands, wives and daughters with high levels of social desirability could in fact have higher levels of discomfort than reported. This highlights the importance of using alternative assessment methods to self-report in certain profiles such as implicit information processing tasks. These, unlike self-report scales, are not subject to cultural bias, so they prevent the subject from having time to reflect before responding (Cabrera et al., 2021; Márquez-Gónzalez et al. 2018).

Additionally, cultural values such as familism and the influence on it of the social desirability bias, could affect the judgment and thoughts of caregivers of family members with dementia, and thus their behaviors (Losada et al., 2010; Toepfer et al., 2014). This influence seems to occur unconsciously and automatically (Cabrera et al., 2021), which is why, with a view to the intervention with caregivers of people with dementia, the identification and discussion of dysfunctional thoughts is recommended (Losada et al., 2011; Toepfer et al., 2014). To this end, the use of well-established techniques that have empirical support, known as 'cognitive restructuring', is suggested. Therefore, as authors such as Márquez-González et al. (2007) and Toepfer et al. (2014) recommend, it is proposed in the first place to train caregivers in strategies that may help them to become aware of those dysfunctional thought patterns that take place automatically. Secondly, those dysfunctional thoughts that, after being evaluated, are concluded to be rigid or inflexible, and to be related to maladaptive coping strategies, will be modified in order to facilitate a more adaptive coping with the caregiving demands .

Regarding the last hypothesis of the study, related to differences in the kinship relationships studied, the results seem to confirm that there are differences depending on the kinship group in the care process. Although significant levels of depressive symptomatology and guilt seem to be found in all groups, the results suggest that daughters may be especially vulnerable to the process of care stress. They are the group that reported living more with children and working more outside the home. Although working outside the home may be felt as a relief by some caregivers (Segel-Karpas et al., 2018), the findings of the study show that daughter caregivers are subject to higher levels of behavioral and psychological symptoms of dementias and discomfort associated with them than the other kinship groups, and they reported more feelings of guilt than wives and husbands. Daughter caregivers are more likely to belong to what is known as the *sandwich generation*, a concept that refers to women between 40 and 60 who care for both their children and their parents (Miller, 1981; Sinha, 2013), and who also have to cope with the demands of a job. This multiplicity of roles leaves them with little time and energy to be able to meet the demands successfully, thus leading them to experience high levels of tension (Pierret, 2006). At the same time, it is in daughters that a clear negative/harmful relationship was observed in the influence of the familism value on their depressive symptomatology.

In daughters, the internalization of the cultural value of familism (family obligations) and their difficulty in reaching the socially established standard may be implicated in a greater presence of depressive symptoms. At this point, it is important to highlight that the variable family obligations measured in this study is taken from the revised familism scale (RFS; Losada et al., 2020). This scale is composed of items that were originally part of the 'familial obligations' and 'family as referents' subscales of the Sabogal et al. (1987) familism scale. Similar to findings in this study, these two subscales were found to be indirectly associated with depressive symptomatology through their effect on dysfunctional thoughts (Losada et al., 2010). Although in the Sociocultural Stress and Coping Model (Aranda & Knight, 1997) it was originally hypothesized that familism would be associated with positive effects, the findings of the current study are in agreement with Knight and Sayegh (2010), who developed the Updated Sociocultural Stress and Coping Model and concluded that familism did not have 'the consistently positive effects that we had originally hypothesized' (p. 7).

In terms of the evaluated model, relevant percentages of explained variance were obtained for guilt and depressive symptoms for all study groups (ranging between 18% and 37%) except for depressive symptoms in wives (12%), and feelings of guilt in sons (5%). Given that wives showed similar levels of depressive symptomatology to daughters, and sons similar levels of guilt symptomatology to daughters, the low percentage variance in depressive symptomatology for wives and the low percentage for guilt in sons seems to suggest that variables explaining these dimensions in them may be different from those evaluated in this study. For example, variables such as leisure activities or the presence of feelings of ambivalence are variables observed in the previous literature that can also influence the levels of these symptoms of informal caregivers (Losada et al., 2018; Schüz et al., 2015).

The results of this study provide additional support for the assumptions made by Knight and Sayegh (2010) in the sociocultural stress and coping model. Thus, support is provided for the impact that the core model, formed by the frequency of problematic behaviors and reaction to them, has on the discomfort of caregivers of relatives with dementia. As suggested in Losada et al. (2018), the impact of problematic behaviors associated with dementia on depressive symptomatology is largely explained through guilt. In addition to confirming the core model, the results of this study confirm the relevant role of sociocultural variables such as familism (specifically, family obligations), social desirability and dysfunctional thoughts, in explaining caregivers' discomfort. Furthermore, this study adds to the sociocultural model the importance of considering kinship profiles.

This study has a number of limitations that should be noted. First, although the sample size is similar to that of other studies carried out with caregivers, the sample is not representative of the population of caregivers as it is made up of voluntary participants, and the sample size of some of the groups may be considered small, something that might have influenced the results. This might be the case especially for husbands and sons. Caution is recommended when interpreting the results as the number of participants in these groups is small, and all the more so considering the number of assessed variables. Therefore, future studies with larger samples of male caregivers are needed in order to confirm the findings of this study. Secondly, it is a cross-sectional study, so the results cannot determine the existence of a causal relationship between the selected variables. Also, the relationships shown in the model, although based on the sociocultural stress and coping model, must be taken with caution since the possibility that other models may also be relevant cannot be disregarded. Longitudinal and experimental studies are needed to confirm the obtained findings. Thirdly, the present study is framed within the European context, specifically in a Mediterranean society, that may have cultural characteristics different to other regions (e.g. the north of Europe; Uccheddu et al., 2019). Thus, future studies are needed in different cultural contexts in order to confirm the generalizability of the findings. In addition, regarding the social desirability measure, given that Cronbach's alpha levels are lower than recommended, the results that suggest a tendency of caregivers to give socially desirable answers should be interpreted with caution. The variables that make up the proposed model are based on self-report responses from caregivers. Thus, these may be influenced by this tendency to appear desirable. It would be recommended that future research includes information from a second source to control for the effects of social desirability. Finally, because in this investigation only the dimension of family obligations was analyzed, it would be interesting if future studies could analyze other dimensions of familism and their effect on desirability and feelings of guilt and depression. In addition, given that some of the items of the family obligations scale refer to the obligations that adult children could have to their parents, these could be interpreted differently by the child caregivers than by spousal caregivers.

Despite the aforementioned limitations, the present study is the first to analyze the joint influence of the variables social desirability and familism (family obligations) in the process of care stress, taking into account the kinship relationship of the caregivers with the people cared for. The results suggest that the levels of discomfort of caregivers who report high social desirability could be higher than those already indicated and show that daughters may be in a situation of special vulnerability to the stress of care, perhaps due to being subjected to more sources of stress and being more affected by the negative effects of culturally accepted values such as familism. These results support the need to take into account the influence of sociocultural aspects in the evaluation and in the design and implementation of interventions for caregivers (Cheng et al., 2019). In cultural contexts influenced by values such as familism, it would be convenient for the interventions to include treatment components aimed at reducing the pressure exerted by this cultural value and the norms associated with it on the dysfunctional thoughts associated with care and the consequences that this could have in the presence of feelings of guilt and depression of family caregivers.

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Disclosure statement

No potential conflict of interest was reported by the authors.

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Anexo 4: Supplementary material for Study One.

This section provides information regarding the correlation analyses done for each group of kinship between the selected variables in the study one.

Supplementary Table 1.1. *Correlation matrix for husbands*

VARIABLES	1	2	3	4	5	6	7	8	9	10	11	12	13
1 .Age													
2. Feeling of loneliness	-0.03												
3. Work outside home	0.26*	-0.10											
4. Live with children	-0.18	-0.01	-0.04										
5. Care for others	-0.27*	0.13	-0.03	-0.05									
6. Frequency disruptive behaviors	-0.14	0.35**	-0.11	0.04	-0.07								
7. Functional capacity	-0.23	-0.09	-0.15	0.06	0.01	-0.08							
8. Hours of care	-0.01	-0.09	-0.13	0.15	-0.12	0.15	0.20						
9.Family obligations	0.23	0.02	-0.20	0.04	-0.18	0.13	0.10	0.09					
10.Dysfunctional Thoughts	0.37**	-0.11	0.16	0.12	-0.03	-0.10	-0.07	0.31*	0.42**				
11. Requesting help	0.01	-0.07	0.13	0.19	-0.01	-0.11	-0.12	0.06	-0.34*	-0.23			
12. Receiving help	-0.10	-0.17	0.00	0.23	0.00	-0.26	-0.05	-0.02	-0.21	-0.18	0.67**		
13. Social Support	0.01	-0.27*	-0.02	0.20	-0.27	-0.16	-0.08	0.07	-0.23	-0.14	0.36**	0.35*	
14. Leisure	-0.37**	-0.36**	-0.17	-0.02	0.07	-0.21	0.21	-0.17	-0.04	-0.26	0.07	0.11	0.30*

* = $p < .0$; ** = $p < .01$

Supplementary Table 1.2. *Correlation matrix for wives*

VARIABLES	1	2	3	4	5	6	7	8	9	10	11	12	13
1 .Age													
2. Feeling of loneliness	0.06												
3. Work outside home	-0.24*	-0.06											
4. Live with children	-0.25*	-0.06	-0.03										
5. Care for others	-0.15	-0.16	0.03	0.07									
6. Frequency disruptive behaviors	-0.01	-0.08	-0.19	-0.17	-0.11								
7. Functional capacity	-0.16	-0.13	-0.10	-0.12	0.19	0.14							
8. Hours of care	0.08	-0.05	-0.04	-0.08	-0.19	0.14	-0.03						
9.Family obligations	0.48**	-0.01	-0.16	-0.12	-0.09	-0.06	-0.04	0.10					
10.Dysfunctional Thoughts	0.47**	0.13	-0.19	-0.07	-0.04	-0.01	-0.23	0.02	0.53**				
11. Requesting help	0.01	-0.15	0.01	0.12	0.16	-0.14	0.02	-0.01	-0.23	-0.32**			
12. Receiving help	0.15	-0.26*	-0.04	0.02	-0.07	-0.02	-0.17	0.05	-0.01	-0.15	0.59**		
13. Social Support	-0.07	-0.07	0.05	-0.15	-0.07	-0.05	0.15	-0.20	-0.07	-0.09	0.15	0.22	
14. Leisure	-0.33**	-0.16	0.13	-0.02	-0.01	0.09	0.44*	0.22	-0.25*	-0.38**	0.25*	0.03	0.16

* = $p < .0$; ** = $p < .01$

Supplementary Table 1.3. *Correlation matrix for daughters*

VARIABLES	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
1 .Age													
2. Feeling of loneliness	-0.04												
3. Work outside home	-0.30**	-0.13											
4. Live with children	-0.23*	0.07	0.00										
5. Care for others	0.00	-0.21*	-0.14	0.01									
6. Frequency disruptive behaviors	-0.23*	0.16	0.19*	0.01	0.15								
7. Functional capacity	-0.24**	-0.02	-0.04	0.127	-0.09	0.16							
8. Hours of care	0.11	0.11	-0.25**	-0.08	-0.10	-0.07	-0.08						
9.Family obligations	0.08	0.02	-0.07	0.00	0.01	0.01	0.01	-0.01					
10.Dysfunctional Thoughts	0.27**	0.25**	-0.13	-0.02	-0.14	-0.13	-0.05	0.07	0.61**				
11. Requesting help	-0.19*	-0.11	0.02	0.09	0.07	-0.02	-0.00	-0.05	-0.14	-0.21*			
12. Receiving help	0.07	-0.31*	0.22*	-0.01	-0.02	-0.13	-0.09	-0.07	-0.04	-0.05	0.36*		
13. Social Support	-0.04	-0.45**	0.10	-0.03	-0.14	-0.28**	0.12	-0.03	0.12	-0.06	0.14	0.27**	
14. Leisure	-0.04	-0.42**	0.05	0.02	-0.05	-0.14	0.09	-0.05	-0.17	-0.26**	0.10	0.23*	0.39**

* = $p < .0$; ** = $p < .01$

Supplementary Table 1.4. *Correlation matrix for sons*

+ = p. < .10; * = p < .0; ** = p < .01

VARIABLES	1	2	3	4	5	6	7	8	9	10	11	12	13
1 .Age													
2. Feeling of loneliness	-0.10												
3. Work outside home	-0.50*	0.17											
4. Live with children	-0.06	-0.09	0.02										
5. Care for others	0.17	0.03	0.26	0.31+									
6. Frequency disruptive behaviors	-0.15	0.48	0.07	0.06	0.03								
7. Functional capacity	-0.17	-0.22	0.18	0.08	-0.02	0.00							
8. Hours of care	0.22	-0.14	-0.25	-0.14	0.09	0.02	0.08						
9.Family obligations	0.17	0.14	-0.13	-0.49**	-0.20	-0.04	0.08	0.12					
10.Dysfunctional Thoughts	0.29	-0.29	-0.37*	-0.27	0.04	-0.22	0.11	0.44**	0.51**				
11. Requesting help	-0.22	-0.21	-0.04	-0.04	-0.18	-0.17	0.42*	0.17	0.14	0.24			
12. Receiving help	-0.19	-0.30*	0.213	-0.11	-0.10	-0.32+	0.36*	0.04	0.08	0.19	0.58**		
13. Social Support	-0.20	-0.11	0.04	0.02	-0.19	-0.13	0.12	-0.20	0.15	-0.12	0.49**	0.30+	
14. Leisure	0.08	-0.50**	0.01	0.24	-0.13	-0.06	0.28	-0.18	-0.09	-0.15	0.19	0.23	0.38**

Anexo 5: Supplementary material for Study two

This section provides information regarding the correlation analyses done for each group of kinship between the selected variables in the study two.

Supplementary Table 1. (part 1). Standardized and non-standardized estimators and errors by kinship group.

			WIVES				HUSBANDS			
			Standarized Estim.	Non standarized estim	S.E	C.R	Standarized Estim.	Non standarized estim	S.E	C.R
Family obligations	→	Dysfunctional thoughts	.47	1.70**	.35	4.83	.40	1.09**	.32	3.40
Social Desirability	→	Dysfunctional thoughts	.30	2.73*	.90	3.05	.07	.51	.091	.55
Social Desirability	→	Reaction problematic B.	-.34	-2.51**	.67	-3.71	-.01	-.010	.93	-.11
Social Desirability	→	Guilt	-.28	-1.66*	.67	-2.49	-.23	-1.47*	.71	-2.06
Frequency problematic B	→	eaction problematic B.	.52	.51**	.09	5.74	.67	.86**	.12	6.90
Frequency problematic B	→	Guilt	.15	.12	.10	1.23	.32	.28*	.13	2.14
Reaction problematic B.	→	Guilt	.25	.20	.11	1.92 ten	.20	.14	.10	1.38
Reaction problematic B.	→	Depressive symptomatology	.09	.09	.11	.77	.12	.06	.06	1.06
Guilt	→	Depressive symptomatology	.26	.29*	.14	2.13	.53	.42**	.09	4.74
Dysfunctional thoughts	→	Depressive symptomatology	.12	.09	.08	1.06	-.17	-.11	.07	-1.62

Supplementary Table 1. (part 2). Standardized and non-standardized estimators and errors by kinship group.

			DAUGHTERS				SONS			
			Standarized Estim.	Non standarized estim.	S.E	C.R	Standarized Estim.	Non standarized estim.	S.E	C.R
Family obligations	→	Dysfunctional thoughts	.55	1.60**	.22	7.39	.33	1.00*	.47	2.12
Social Desirability	→	Dysfunctional thoughts	.16	.85*	.40	2.11	.25	1.42	.92	.55
Social Desirability	→	Reaction problematic B.	-.31	-2.40**	.50	-4.86	-.22	-1.54*	.73	-2.11
Social Desirability	→	Guilt	-.17	-1.10*	.57	-1.95	-.01	-.09	1.17	-.07
Frequency problematic B.	→	Reaction problematic B.	.63	.66**	.07	9.96	.78	1.07**	.14	7.67
Frequency problematic B.	→	Guilt	.07	.06	.09	.65	.18	.23	.34	.67
Reaction problematic B.	→	Guilt	.30	.25*	.09	2.65	.06	.06	.26	.23
Reaction problematic B.	→	Depressive symptomatology	.07	.06	.06	.93	.44	.32*	.11	2.94
Guilt	→	Depressive symptomatology	.41	.38**	.08	4.97	.19	.15	.12	1.29
Dysfunctional thoughts	→	Depressive symptomatology	.31	.34**	.08	4.05	-.05	-.05	.13	-.36