

Modeling the distress of adult-child caregivers of people with dementia: the mediating role of self-efficacy

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Abstract

Background: The increased tasks and responsibilities involved in supporting a parent with dementia (PWD) can induce distress in adult-child caregivers. Previous studies have shown that distress can be influenced by PWD and caregiver determinants but few studies have considered the associations between these variables.

Objective: This study tested a complex model of adult-child caregiver distress in which PWD and caregiver determinants and their associations are considered.

Methods: 159 adult-child caregivers participated in this online study. PWD and caregiver determinants were assessed using questionnaires and their associations were investigated using the partial least squares path method.

Results: The model showed a significant partial mediation through self-efficacy (confidence in one's ability to organize and manage caregiving situations) between poor self-rated health and distress. Self-efficacy was a significant mediator of the relationship between informal social support and distress, and between preparedness and distress. The direct path between parental overprotection and distress was significant. The association between care and distress was significantly stronger for adult-child caregivers not living with their PWD.

Conclusions: The model revealed the important mediating role of self-efficacy. Clinical interventions should improve the preparedness of adult-child caregivers and the quality of social support. The positive perception of their self-rated health may thus be promoted.

Keywords: Dementia; Adult-child; Caregivers; Model

Introduction

Caring for an elderly parent with dementia (PWD) involves tasks and responsibilities for adult-child caregivers [1]. As the disease evolves (memory, language, recognition and executive disorders, dependence on gestures), adult-child caregivers have to provide increasing emotional, psychological, physical and financial support (i.e. repeating and recalling information, taking on administrative tasks, overseeing treatment, assisting with personal care, mobility, protection, transportation, and housekeeping and managing behavioral problems) to their PWD [2,3]. This gradually leads them to focus on their parent and to put their own life on hold [4], which may lead to distress and declining wellbeing [1,5,6].

Previous studies have identified a variety of factors that may influence the caregiving burden and distress of adult-child caregivers. The impact of the caregiving situation on their health is an important predictor of their distress [6]. The clinical characteristics of PWD (e.g. comorbidities, functional and cognitive impairment, neuropsychiatric symptoms) may affect caregivers' burden. Indeed, PWD gradually disengage from complicated tasks [7], instrumental activities of daily living (IADL) and activities of daily living (ADL) [8–10]. Impaired ADLs and IADLs, as well as higher comorbidities, were significantly related with caregivers' burden [11,12], which makes them more reactive to the problematic behaviors of their PWD [1].

The pre-existing relationship between the adult-child and their parent may partially predict the perception and quality of the current caregiving experience [13]. A positive relationship and emotional attachment, mutual appreciation of being cared for and being able to provide care, as well as the feeling of being able to give back are linked to more positive caregiving outcomes: higher motivation to care for their PWD, better perception of the current relationship as rewarding, better reaction to memory and behavior problems, and more effective communication. However, a poor pre-caregiving relationship is linked to more negative caregiving outcomes, such as strain and depression [14,15].

Adult-child caregivers may feel neglected by family and health/social care services and experience frustration with healthcare organizations which, in their opinion, do not take sufficient responsibility for the diagnosis and care of their loved one [4,16]. The availability of respite, the size of the informal caregiving network, tasks and care shared across the network, and disagreement with the members of the support network were found to predict adult-child caregivers' emotional strain and burden [15,17–19].

Adult-child caregivers are rarely prepared for their parent's dependence in terms of care [20]. They need information about the disease and the treatments to be able feel a part of the process and competent to manage the behavior and needs of their parent [4].

Deep et al. [21] showed that confidence in one's ability to organize and manage caregiving situations (i.e. sense of self-efficacy) was negatively correlated with depression. Previous studies showed that self-efficacy is an important mediator between physical health and depressive symptoms in caregivers [22], between the behavioral and psychological symptoms (BPSD) of PWD as well as the neuropsychiatric symptoms and caregivers' burden [23–25], and between social support and caregivers' mental health and burden [23,26].

To provide an integrative view of distress, Van der Lee et al. [3] and Kim et al. [27] highlighted the importance of including different types of PWD determinants (i.e. behavioral and cognitive disorders and need of support) and caregiver determinants (i.e. social functioning, social support, physical health, competence and self-efficacy) in a complex model of distress. Several intermediate pathways and associations between these determinants should be considered. In the review of multivariate models by Van der Lee et al. [3], complex models including both patient and caregiver determinants concerned either all kinship caregivers such as spouses, children and friends or only spouse caregivers. To our knowledge, there is no model dedicated to the experience of adult-child caregivers. Such a complex model would provide useful insights into the implications of the adult-child caregiver's role. Since it focuses on the

variables that play an important role in caregivers' distress, this model highlights major targets for psychosocial interventions in adult-child caregivers of PWD.

Aim of study

Based on the conceptual framework of Van der Lee et al. [3], the present study investigates a complex model assessing the effects of PWD and caregiver determinants and their associations on adult-child caregivers' distress. This framework guided the choice of variables investigated in this study. We examined PWD determinants: the severity of PWD symptoms perceived by caregivers and caregiver determinants: their self-rated health, their sense of confidence and preparedness, the quality of their family and social support and the quality of the parental bond. Previous studies have demonstrated that these variables are directly linked to adult-child caregivers' distress and that self-efficacy has an important mediating role [22-26]. We built a model (*Step 1*) in which we hypothesized that adult-child caregivers' self-efficacy is a mediator between: (1) the severity of PWD symptoms and adult-child caregivers' distress, (2) adult-child caregivers' poor self-rated health and adult-child caregivers' distress, (3) the quality of informal social support and adult-child caregivers' distress, (4) adult-child caregivers' preparedness and adult-child caregivers' distress, (5) the quality of the parental bond and adult-child caregiver's distress. Second, the model compared caregivers living with their PWD and those not living with them (*Step 2*). The literature shows that cohabitation plays an important role in how adult-child caregivers' burden is experienced. When they live with their PWD, they are more likely to be unmarried, to be the unique caregiver and to use few external resources. When they do not live with their PWD, they are more likely to be married, to work outside the home and to have children at home [28]. Caregivers living with their PWD experience a high level of burden and distress [12,29]. Those not living with their PWD have other responsibilities (work, young children or teenage dependents) that may interfere with the caregiving situation. They often

have to arrange working hours to accommodate the PWD, including commuting between the latter's home and their own professional and family responsibilities [29–32]. Caregiving becomes an additional task that must be factored into their schedules [6]. They experience more guilt [29] and higher depressive symptoms, even more so when they live far away [33]. Comparisons like these are needed to consider the appropriate support required by adult-child caregivers [34] and improve its efficiency [35,36].

Materials and Methods

Procedure

The present study was conducted online using a survey creation software (Limesurvey). Participants were recruited via Internet forums for caregivers and through Facebook. The inclusion criteria were the following: caregivers had to be 18 or older, the main caregiver and the child of a person with Alzheimer's disease or a related type of dementia. The PWD had to be living at home (either with their caregiver or not) and not in residential care. E-mails were sent to social networks and forums inviting people to participate in a survey about their caregiving experience. They were free to participate and could withdraw from the survey at any time. If they agreed to participate, they could click on a link directing them to the study home page and informed consent page.

Participants

In total, 560 people started filling in the online questionnaires and 173 completed them. The average time to fill in questionnaires was 45 minutes. Participants who took less than 20 minutes to respond were removed from our final sample, as a short response time suggested insufficient involvement. In the end, 159 adult-child caregivers were selected for the study (final group). Out of the 387 cases who not completed the study, 261 did not fill in any information, and 126

filled in all or part of the socio-demographic information (nonrespondent group). Comparisons between the participants in the final group and the nonrespondents showed no differences in gender, status, gainfully employed, adult-child caregivers' age, PWDs' age, caregiving time, diagnosis, delay between the diagnosis and the proposed interview, and delay between the first signs of dementia and the proposed interview.

The “children living with the person with dementia” (CL) group consisted of 59 caregivers and the “children not living with the person with dementia” (CNL) group consisted of 100 caregivers.

Table 1 shows that the participants were mostly female (85.53%), single (47.17%), with a monthly home income lower than 2,700 euros (64.15%), a high education level (59.12%) and were mainly employees (54.72%). They took care of a PWD with Alzheimer’s disease mainly (57.86%), having been diagnosed for an average of 4.30 years (SD: 4.27), aged 81.22 years (SD: 8.62), for an average of 6.55 hours per day (SD: 6.78).

-----[Insert Table 1 about here]-----

Ethical issues

The survey was approved by the university’s ethics committee and complied with the tenets of the Declaration of Helsinki of 1975.

Measures

First, the adult-child caregivers responded to questions addressing their sociodemographic status (i.e., gender, age, status, employment, and education level). Several measures then assessed the characteristics of the caregiving situation, including the severity of the PWD symptoms perceived by the adult-child caregivers, their sense of confidence and preparedness, their self-rated health, the quality of their social support, the quality of the parental bond and their level of distress.

Severity of PWD symptoms perceived by adult-child caregivers

Adult-child caregivers assessed the functional autonomy of their PWD focusing on activities of daily living (ADLs) with a 9-item scale [37]. Each item was rated using a 5-point Likert scale from 1 (entirely able to perform the ADL) to 5 (not at all able). The overall score ranged from 9 to 45. The internal consistency reliability (Cronbach's alpha) was 0.94 in the study sample. Instrumental activities of daily living (IADLs) were measured using a 4-item questionnaire [8]. Each item was rated using a 4-point Likert scale from 1 (entirely able) to 4 (entirely unable). The score ranged from 4 to 16. The internal consistency reliability (Cronbach's alpha) was 0.71 in our sample. The severity of the cognitive impairment of the PWD was assessed using the 8-item Cognitive Status Scale [38]. The responses ranged from 0 (not difficult, able to do) to 4 (very difficult, not able to do). The score ranged from 0 to 32. The internal consistency reliability (Cronbach's alpha) was 0.90 in this study. For these scales, the higher the score, the greater the disturbances.

Sense of confidence and preparedness

The 8-item Preparedness for Caregiving Scale [39] assessed the degree of caregivers' preparedness to provide care. Preparedness was defined as the perceived readiness for multiple aspects of caregiving, such as providing physical care, emotional support, establishing in-home support services, and coping with the stress of caregiving. The responses ranged from 1 (not prepared at all) to 5 (very well prepared). The internal consistency reliability (Cronbach's alpha) was 0.91 in this study. A higher score meant that the caregiver felt well prepared to provide care.

Planning for future care needs and knowledge of formal services were evaluated using two questionnaires developed by Sörensen and Pinquart [40]. The Planning for Future Care

Needs Scale assesses the decisions that caregivers make to address their relative's future care needs (6 items). The caregivers' familiarity with formal services was assessed using the 7-item Knowledge of Services Scale. Response scales ranged from 1 (not true at all for me) to 5 (completely true for me). In our study, the internal consistency reliability coefficients (Cronbach's alpha) were 0.83 for the Planning for Future Care Needs Scale and 0.90 for the Knowledge of Services Scale. A higher score meant that the caregiver felt well prepared for future care needs.

The 15-item Self-Efficacy Scale [41] assessed the level of confidence of the caregiver regarding coping with the caregiving situation. Each item was rated on a 5-point response scale ranging from 1 (not confident at all) to 5 (extremely confident). The internal consistency reliability (Cronbach's alpha) was 0.91 in our sample. A higher score indicated that the caregiver felt confident regarding coping with caregiving.

The Revised Scale for Caregiving Self-Efficacy Scale [42] comprises three subscales that specifically measure a caregiver's ability to obtain respite from family and friends (5 items), to control disturbing thoughts about the caregiving role (5 items) and to respond to a relative's disruptive behaviors (5 items). Each item is rated on a scale ranging from 0 (absolutely incapable) to 100 (fully capable). The internal consistency reliability (Cronbach's alpha) was 0.90 (respite care), 0.92 (control of disturbing thoughts) and 0.96 (response to relative's behaviors) in this study. A higher score indicated that the caregiver felt confident with this type of management.

Self-rated health

Based on the SF-36 [43], subjective health was assessed using two questions: "*Would you say that your health is...*" for general health [43] and "*When you compare yourself with other people your age, would you say your health is...*" for health compared with people of the

same age. The responses ranged from 1 (very good) to 5 (very bad). The internal consistency reliability (Cronbach's alpha) was 0.89 in this study. A higher score indicated that the caregiver considered his/her health to be poor.

Quality of social support

The Inventory of Socially Supportive Behaviors [44] was used to determine the frequency of informal social support: emotional support (11 items), informational support (7 items), and instrumental support (9 items). The items are rated on a 4-point scale ranging from 1 (never/almost never) to 4 (very often/always). The internal consistency reliabilities (Cronbach's alpha) were 0.81 for informational support, 0.85 for instrumental support and 0.92 for emotional support. A higher score meant that the caregiver frequently received this type of informal support.

Quality of parental bond

The Parental Bonding Instrument (PBI) [45] retrospectively assesses the behaviors and attitudes of participants' parents towards them, from birth to 16 years of age. It comprises 12 questions on the "care" dimension and 13 on the "protection" dimension. The care dimension ranges from rejection or coldness (low score) to warmth and affection (high score), while the protection dimension ranges from allowance of autonomy (low score) to overprotection and controlling behaviors (high score). The internal consistency reliability coefficients obtained in our study were 0.77 for "overprotection" and 0.79 for "care". The higher the score, the more cared for or overprotected the parent with dementia felt.

Caregivers' distress

The Hospital Anxiety and Depression Scale (HADS) [46] is composed of 14 items rated with a 4-point scale ranging from 0 to 3. Seven questions are related to anxiety (total A), and seven are related to depression (total D). The internal consistency reliability coefficients in our study were 0.86 for the depression dimension and 0.81 for the anxiety dimension. The higher the score, the more anxious or depressed the caregiver felt.

The 14-item Psychological Distress Index is an adapted version of the Psychiatric Symptom Index [47]. The respondents rated how often they felt distressed over the past week, from 1 (never/almost never) to 4 (very often/always). The internal consistency reliability (Cronbach's alpha) was 0.93 in this study. The higher the score, the more distressed the caregiver felt.

Statistical analyses

Means, SDs, percentages and Pearson's correlation coefficients were calculated. Analyses were performed using the Statistical Package for the Social Sciences (SPSS; IBM, Armonk, NY). T-tests and chi-square tests were performed to compare the CNL and CL groups, depending on whether the variables were continuous or categorical, respectively. Statistical significance was set at $p < 0.05$.

We used partial least squares path modeling (PLS-PM) to test our hypotheses. PLS-PM is a method for studying complex multivariate relationships between manifest variables (MVs) and latent variables (LVs). PLS-PM is a variance-based structural equation modeling (SEM) technique that does not rely on distributional assumptions and is able to deal with small sample sizes and non-normality [48]. Since each causal subsystem sequence of paths is estimated separately in the PLS-PM approach, Tenenhaus et al. [49] suggested that the sample size should be equal to the larger of the following: 10 times the number of indicators of the scale with the

largest number of manifest indicators. The sample size should be larger than 40 participants in the current study, suggesting that the PLS-PM analyses were feasible with the present analytical sample. A full path model is comprised of two sub-models: the inner model describes associations between the LVs and the outer model describes associations between each LV and respective MV. The outer model was developed in such a way that PLS-PM could incorporate reflective and formative latent variables [50]. Formative latent variables are considered as formative constructs because their indicators are not interchangeable and determine a specific aspect of the construct's domain, while reflective latent variables are defined as reflective constructs because the indicators are related to each other and present a high overlap [50]. The results are shown as path coefficients (β) and their bootstrap (4000 resamples) 95% confidence interval (CI). PLS-PM analyses were conducted with SmartPLS version 3.2.1 [51].

Results

Descriptive data and preliminary analyses

Table 1 shows that CNL participants were mainly women (CNL: 90% vs CL: 77.97%), married (CNL: 44% married vs CL: 61.02% single), with a higher education level (CNL: 70% vs CL: 40.69%) and working as employees (CNL: 66% vs CL: 35.39%). CL participants took care of older PWD ($M_{CL}= 84.54$, $SD: 8.25$; $M_{CNL}= 79.26$, $SD: 8.26$) and for a greater number of hours per day ($M_{CNL}= 10.73$, $SD: 7.43$; $M_{CL}= 4.08$, $SD: 4.94$). The two groups were comparable in terms of age of participants, monthly home income, diagnosis, delay between first signs and interview, and delay between diagnosis and interview.

Supplemental Table 1 shows the descriptive statistics (mean, SD) for both CL and CNL participants and Supplemental Table 2 shows the intercorrelations between the variables.

Reflective-formative measurement model

Outer model

The outer model describes the relationship between each LV and its respective MV. It is composed of *two formative latent variables* and *six reflective latent variables*. The reflective latent variables include: *Adult-child caregiver's preparedness, Informal social support, Adult-child caregiver's poor self-rated health, Care recipient's impairments, Adult-child caregiver's self-efficacy, and Adult-child caregiver's distress*. The two formative latent variables are: *Overprotection* and *Care*. The model included 19 MV loadings on 8 LVs (Table 2). The quality of this outer model was acceptable regarding unidimensionality (DG-rho > 0.70), internal consistency reliability (Cronbach's alpha > 0.70), convergent validity (AVE > 0.50) and multicollinearity (VIF < 5) for the LVs. The standardized root mean square residual indicated a good fit (SRMR= 0.05) [52]. The adjustment of MVs to their respective LVs was examined. If MVs did not contribute to the unidimensionality criterion of the LVs, they were discarded. In this model, no MV was discarded.

-----INSERT Table 2-----

Inner Model

The proportion of explained variance (R^2) for the LVs of *Adult-child caregiver's self-efficacy* and *Adult-child caregiver's distress* was 0.50 and 0.49 respectively. The direct and indirect bootstrapped path coefficients are given in Table 3 and Table 4. Figure 1 shows the path coefficients (β) between LVs for the inner model.

-----INSERT Table 3-----

-----INSERT Table 4-----

Concerning hypothesis (1), results show a significant direct path between *Severity of the PWD symptoms* and *Adult-child caregiver's distress* ($\beta = 0.19$). The bootstrap method for testing indirect effects indicates that the indirect effect from *Severity of the PWD symptoms* through *Adult-child caregiver's self-efficacy* to *Adult-child caregiver's distress* is non-significant.

Concerning hypothesis (2), the results reveal a significant direct path between *Adult-child caregiver's poor self-rated health* and *Adult-child caregiver's distress* ($\beta = 0.39$) and a significant indirect effect is observed from *Adult-child caregiver's poor self-rated health* through *Adult-child caregiver's self-efficacy* to *Adult-child caregiver's distress* ($\beta = 0.10$).

Concerning hypothesis (3), the direct path between *Informal social support* and *Adult-child caregiver's distress* is non-significant ($\beta = 0.07$), while a significant indirect effect is observed from *Informal social support* through *Adult-child caregiver's self-efficacy* to *Adult-child caregiver's distress* ($\beta = -0.06$).

Concerning hypothesis (4), the direct path between *Adult-child caregiver's preparedness* and *Adult-child caregiver's distress* is non-significant ($\beta = -0.04$), while a significant indirect effect is observed from *Adult-child caregiver's preparedness* through *Adult-child caregiver's self-efficacy* to *Adult-child caregiver's distress* ($\beta = -0.16$).

Concerning hypothesis (5), the direct path is significant between *Overprotection* and *Adult-child caregiver's distress* ($\beta = 0.19$), while the direct path between *Care* and *Adult-child caregiver's distress* is non-significant ($\beta = 0.07$). The indirect paths from *Care* through *Adult-child caregiver's self-efficacy* to *Adult-child caregiver's distress* ($\beta = -0.03$) and from *Overprotection* through *Adult-child caregiver's self-efficacy* to *Adult-child caregiver's distress* ($\beta = 0.04$) are non-significant.

-----INSERT Figure 1-----

Comparison

A nonparametric multi-group analysis was conducted to investigate possible differences between CL and CNL, using the PLS-MGA method (Table 3). Direct path comparisons showed that the association between *Care* and *Adult-child caregiver's distress* was significantly stronger for CNL than for CL ($\beta = 0.20$ vs $\beta = -0.11$ respectively).

Discussion

Based on the recommendations of Van der Lee et al. [3], this is the first complex model to assess the effects of PWD determinants, caregivers' determinants and their associations on adult-child caregivers' distress. It provided a good data fit and accounted for 49 % of the variance in adult-child caregivers' distress. The results are of major interest as they emphasize important targets for psychosocial interventions among adult-child caregivers of PWD.

The mediating role of self-efficacy

The protective role of self-efficacy, i.e. the belief that personal control over caregiving problems is possible [22], regarding adult-child caregivers' distress is confirmed. The results show that the more confident they feel in managing the caregiving situation, the less distress they experience. Previous studies have already shown that caregivers with low self-efficacy experience greater anxiety or depression [21,22,53]. Our study underlines the importance of supporting and increasing adult-child caregivers' self-efficacy and confidence in managing the caregiving situation, by increasing their ability to obtain respite from family and friends, to control disturbing thoughts about the caregiving role and to respond to PWDs' disruptive behaviors.

The important mediating role of self-efficacy is also confirmed [22–26]. Although it has already been demonstrated in previous studies, examining this mediation in a complex model helps identify factors that influence and promote confidence in caregivers to empower them. In this perspective, we underline the important role of adult-child caregivers' preparedness and self-rated health, as well as the moderate impact of the quality of informal social support that they receive. The indirect path with *Severity of the PWD symptoms* is not significant and the quality of the childhood bond with the parent with dementia directly impacts the adult-child caregiver's distress.

Our results highlight the important influence of informal support and preparedness on adult-child caregivers' distress with two sequenced mediations through self-efficacy. While previous studies have shown their direct link with caregivers' distress [15,17–19,54,55], we showed that, when self-efficacy variables were introduced in the model, these direct associations disappeared and mediating effects were observed through self-efficacy. The more prepared and supported by their informal social network adult-child caregivers felt, the less distressed and the more confident they were in managing the caregiving situation. Caregivers with no social support stated that they were less likely to feel confident in asking for help owing to the lower number of opportunities for positive feedback from others about the caregiving tasks that they were performing [21]. Moreover, according to Vellone et al. [56], when adult-child caregivers perceive themselves as able to provide care, able to plan for the future needs of their parent, and aware of available services, they feel more confident in dealing with caregiving situations. These results suggest that improving adult-child caregivers' preparedness and the quality of their informal support boosts their confidence in their ability to manage the caregiving situation and protects them from distress.

A partial sequential mediation was observed between adult-child caregivers' poor self-rated health and adult-child caregiver's distress. The worse they perceived their health to be,

the less confident they felt about managing the caregiving situation, the more distressed they are. This result is consistent with previous studies [6] and makes health a priority target in supporting caregivers. With the increase in tasks and responsibilities that comes in addition to their responsibilities at home and at work, they tend to neglect their own health [57].

The impact of the childhood parental bond

The direct association between care and adult-child caregivers' distress was not significant across all participants. However, a significant difference was observed between the CL group and the CNL group, with a stronger association for the latter. This association is the opposite of what is usually found in the literature, i.e. the more care adult-child caregivers received from their parent during childhood, the less distress they feel in their primary caregiver role [58]. Our model shows that for adult-child caregivers who do not live with their PWD, the more emotionally warm, empathetic and close the childhood bond was, the more distress they feel in the caregiving situation. This result might be explained by the fact that adult-child caregivers may perceive the caregiving situation as reciprocity for their parent's love, support, care and devotion during their childhood [30,59] and they may see it as the opportunity to give it back to them [60–62]. However, those who do not live with their PWD and have to manage competing demands from the parent they care for, their nuclear families, their job, their friends and their own health, cannot be as available as they would like to be and experience more guilt and a feeling of burden [29,63].

Moreover, contrary to the surprising results of Daire et al. [64], our model confirms the hypothesis that the more control, overprotection, intrusion, excessive contact, infantilization, and prevention of independent behavior in the childhood bond they experienced with their parent with dementia, the more adult-child caregivers feel distress. This result is consistent with previous studies showing that a poor pre-caregiving relationship is related to more negative

caregiving outcomes, such as strain and depression [14,15]. To conclude, the quality of the childhood parental bond may play a role in predicting the level of distress in the current caregiving situation.

Limitations

This research should be considered in light of the following limitations. First, concerning the sample, if the size is sufficient to use the PLS-PM approach [49], a larger sample would facilitate the use of SEM (structural equation modeling) as a confirmatory analysis, thus examining more complex and less unidirectional associations between the variables and would also increase the scope and generalizability of the results. Moreover, participants were mainly women. Nevertheless, it is the case in the majority of studies of dementia caregivers [65–67]. Second, the online data collection method constitutes a selection bias of our sample because it leads to sampling a specific group of individuals who have access to a computer and are confident in such technology. Third, we examined a large set of variables to propose a complex model of adult-child caregivers' distress. The protocol was therefore long, which might have led to several participants dropping out or botching the completion of the questionnaires. Very few used the possibility of taking a break and resuming later. It would also be interesting to randomize the order in which the questionnaires are presented.

Conclusion

The results of this study allow us to consider several clinical implications for adult-child caregivers. First, an assessment of preparedness, of the quality of informal support, of the quality of the childhood parental bond and of self-rated health is recommended to identify the adult-child caregivers who are at highest risk of distress. Specific attention and support should

therefore be provided to adult-child caregivers with poor preparedness, poor informal support, poor quality of childhood parental bond and poor self-rated health.

Second, self-efficacy varies over time for each individual according to mood and experience and can be modified through therapeutic support [22,68,69]. Previous studies have already established that self-efficacy is an important target to decrease the feeling of burden and depression in caregivers of persons with Alzheimer's disease [24]. Our findings suggest that interventions to decrease distress can target self-efficacy either directly or through the improvement of caregivers' sense of preparedness, quality of social support and self-rated health. Psychoeducational interventions have shown promising results in enhancing self-efficacy and preparedness and in reducing psychological burden and distress [22,26]. These interventions are based on the acquisition of caregiving skills and techniques, information about the caregiving situation, about the behavioral and psychological symptoms of dementia (BPSD), about support and management of daily and leisure activities (particularly interesting for CNLs having received more care in their childhood), on case management and on emotion management, i.e. mindfulness [70–72]. Moreover, it is essential to monitor and promote a positive perception of adult-child caregivers' physical health and help them organize their own care according to their schedule (particularly interesting for CNLs having received more care in their childhood). The quality of informal support can be improved with a better identification of their resources. Family meetings may be organized to inform them about the disease and evaluate how other family members may potentially help.

Finally, the quality of the parental bond seems essential in the success of such interventions. Indeed, Chen and Bailey [73] showed that adult-child caregivers may misinterpret the behavior of their PWD according to their prior relationship. If the adult-child caregiver felt aggressiveness and intolerance during his/her childhood, anger from the PWD may be perceived as manipulative and intentionally hostile behavior. Caregivers may also not

know how to provide care and interact with their PWD without increase the PWD's anxiety or distress. When the parental bond is weak, psychoeducation about the nature of dementia seems necessary to help caregivers reach a better understanding of the behavior of their PWD and reconsider their unrealistic assumptions about the control their PWD may have over symptoms and their meaning. Psychotherapy may be suggested to address the unconscious relationship scripts that lead to problematic relationship patterns and shift attachment patterns to find internal security may be suggested [74,75]. These suggestions would help to improve the relationship between caregivers and their PWD, reinforce their confidence and decrease distress.

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Disclosure statement

The authors have no conflict of interest to report.

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Table 1. Sociodemographic data

Variables	All participants (N=159)				CL (N=59)				CNL (N=100)				t-test	Chi ²
	M	SD	N	%	M	SD	N	%	M	SD	N	%		
Adult-child caregivers characteristics														
Age of participant, years	51.48	10.41			52.54	10.46			50.85	10.38			-0.99	
Gender														4.34*
Male			23	14.47			13	22.03			10	10		
Female			136	85.53			46	77.97			90	90		
Status														10.11*
Married			57	35.85			13	22.03			44	44		
In a civil partnership			7	4.10			3	5.08			4	4		
Living in common-law relationship			18	11.32			7	11.86			11	11		
Single			75	47.17			36	61.02			39	39		
Widowed			2	1.26			0	0			2	2		
Monthly home income (euros)														9.43
< 1,500			52	32.70			25	42.37			27	27		
Between 1,500 and 2,700			50	31.45			20	33.90			30	30		
Between 2,700 and 3,900			28	17.61			7	11.86			21	21		
> 3,900			30	18.87			7	11.86			22	22		
Education														21.89*
< High education level			65	40.88			35	59.32			30	30		
> High education level			94	59.12			24	40.67			70	70		
Gainfully employed			87	54.72			21	35.59			66	66		13.84*
Caregiving time, average hours per day	6.55	6.78					10.73	7.43			4.08	4.94	-6.77*	
Characteristics of parent with dementia														
Age, years	81.22	8.62			84.54	8.25			79.26	8.26			-3.90*	
Delay between diagnosis and interview, years	4.30	4.27			4.41	3.06			4.23	4.86			-0.25	
Delay between first signs and interview, years	6.46	5.35			6.71	3.69			6.31	6.13			-0.46	
Diagnosis														0.85
Alzheimer's disease			92	57.86			36	61.02			56	56		
DFT			9	5.66			3	5.08			6	6		
Lewy			18	11.32			7	11.86			11	11		
Vascular dementia			8	5.03			2	3.39			6	6		
Others			32	20.13			11	18.64			21	21		

Abbreviations: M, mean; SD, standard deviation

Table 2. Outer model and unidimensionality of each latent variable

Latent Variables (LVs)	Manifest Variables (MVs)	Weights	Unidimensionality
ACCG's preparedness	Preparedness for Caregiving Scale	0.59	$\alpha = 0.74$ DG-rho = 0.83 Composite = 0.84 AVE=0.64
	Planning for Future Care Needs Scale	0.28	
	Knowledge of Services Scale	0.36	
ACCG's self-efficacy	Request respite care	0.25	$\alpha = 0.81$ DG-rho = 0.83 Composite = 0.88 AVE=0.64
	Cope with behaviors	0.34	
	Control disturbing thoughts	0.33	
	Self-Efficacy Scale	0.33	
ACCG's distress	Anxiety dimension of HADS	0.34	$\alpha = 0.88$ DG-rho = 0.89 Composite = 0.93 AVE=0.81
	Depression dimension of HADS	0.39	
	Psychological Distress Index	0.37	
Overprotection	Overprotection dimension of PBI	1.00	
Care	Care dimension of PBI	1.00	
Informal social support	ISSB Informational support	0.29	$\alpha = 0.82$ DG-rho = 0.85 Composite = 0.89 AVE=0.72
	ISSB Emotional support	0.47	
	ISSB Instrumental support	0.40	
ACCG's poor self-rated health	Health in general	0.50	$\alpha = 0.90$ DG-rho = 0.90 Composite = 0.95 AVE=0.90
	Health compared with people of same age	0.55	
Severity of PWD symptoms	ADL	0.32	$\alpha = 0.82$ DG-rho = 0.86 Composite = 0.89 AVE=0.73
	IADL	0.49	
	Cognitive Status Scale	0.36	

Note: DG-rho, Dillon-Goldstein's rho; Composite, Composite reliability; AVE, Average variance extracted; adult-child caregiver, ACCG

Table 3. Direct bootstrapped path coefficients for all participants and comparison between groups

Variables	All participants		CNL		CL		Mean difference
	β Mean (SD)	95% bootstrap CI	β Mean (SD)	95% bootstrap CI	β Mean (SD)	95% bootstrap CI	
ACCG's preparedness to ACCG's self-efficacy	0.49 (0.05)	[0.39;0.60]*	0.53 (0.07)	[0.38;0.64]*	0.46 (0.11)	[0.22;0.65]*	0.07
ACCG's preparedness to ACCG's distress	-0.04 (0.09)	[-0.20;0.13]	-0.04 (0.11)	[-0.26;0.16]	-0.07 (0.15)	[-0.33;0.24]	0.03
ACCG's self-efficacy to ACCG's distress	-0.32 (0.09)	[-0.51;-0.14]*	-0.30 (0.13)	[-0.56;-0.06]*	-0.30 (0.14)	[-0.57;-0.02]*	0.00
Overprotection to ACCG's self-efficacy	-0.11 (0.07)	[-0.25;0.03]	-0.10 (0.08)	[-0.26;0.06]	-0.13 (0.16)	[-0.46;0.17]	0.03
Overprotection to ACCG's distress	0.19 (0.08)	[0.05;0.34]*	0.15 (0.09)	[-0.01;0.32]	0.19 (0.12)	[-0.07;0.41]	0.04
Care to ACCG's self-efficacy	0.08 (0.08)	[-0.08;0.25]	0.02 (0.08)	[-0.15;0.18]	0.15 (0.17)	[-0.18;0.48]	0.13
Care to ACCG's distress	0.07 (0.07)	[-0.06;0.23]	0.20 (0.09)	[0.04;0.37]*	-0.11 (0.13)	[-0.37;0.16]	0.31*
Informal social support to ACCG's self-efficacy	0.19 (0.06)	[0.08;0.30]*	0.22 (0.08)	[0.07;0.37]*	0.10 (0.10)	[-0.16;0.26]	0.12
Informal social support to ACCG's distress	0.07 (0.07)	[-0.07;0.20]	-0.02 (0.09)	[-0.17;0.17]	0.16 (0.11)	[-0.08;0.37]	0.18
ACCG's poor self-rated health to ACCG's self-efficacy	-0.31 (0.07)	[-0.44;-0.18]*	-0.36 (0.09)	[-0.53;-0.19]*	-0.21 (0.11)	[-0.44;-0.02]*	0.15
ACCG's poor self-rated health to ACCG's distress	0.39 (0.07)	[0.25;0.54]*	0.36 (0.10)	[0.15;0.55]*	0.41 (0.10)	[0.23;0.06]*	0.05
Severity of PWD symptoms to ACCG's self-efficacy	0.13 (0.06)	[0.01;0.24]*	0.11 (0.08)	[-0.04;0.26]	0.19 (0.12)	[-0.04;0.42]	0.08
Severity of PWD symptoms to ACCG's distress	0.19 (0.07)	[0.04;0.32]*	0.21 (0.08)	[0.03;0.36]*	0.14 (0.13)	[-0.12;0.38]	0.07

Note: CI: Confidence Interval; *: $p < 0.05$; SD: standard deviation; adult-child caregiver, ACCG

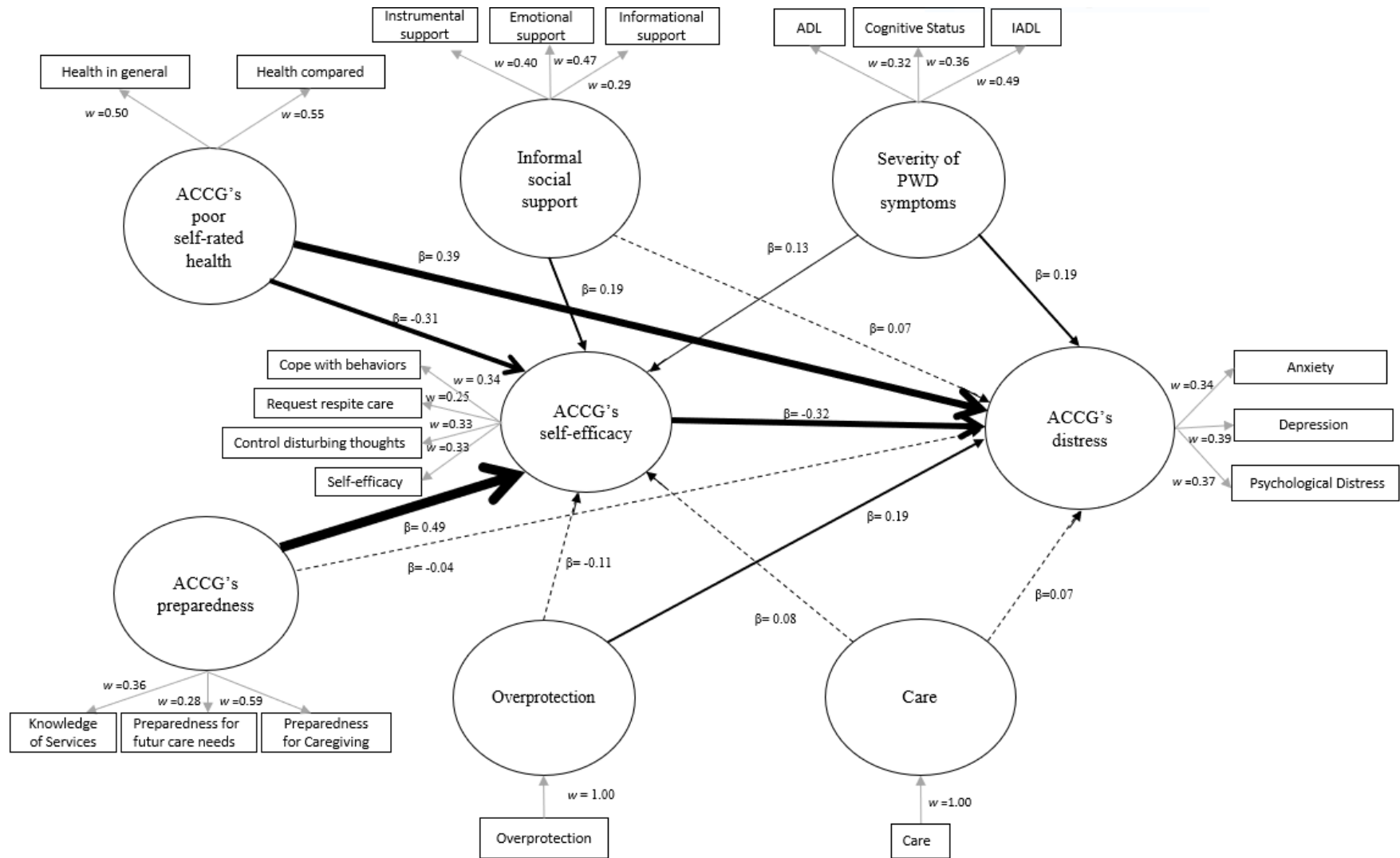
Table 4. Indirect bootstrapped path coefficients for all participants

Variables	All participants	
	β Mean (SD)	95% bootstrap CI
ACCG's preparedness to ACCG's self-efficacy to ACCG's distress	-0.16 (0.05)	[-0.27;-0.07]*
Overprotection to ACCG's self-efficacy to ACCG's distress	0.04 (0.03)	[-0.01;0.09]
Care to ACCG's self-efficacy to ACCG's distress	-0.03 (0.03)	[-0.10;0.02]
Informal social support to ACCG's self-efficacy to ACCG's distress	-0.06 (0.03)	[-0.12;-0.02]*
ACCG's poor self-rated health to ACCG's self-efficacy to ACCG's distress	0.10 (0.04)	[0.04;0.18]*
Severity of PWD symptoms to ACCG's self-efficacy to ACCG's distress	-0.04 (0.02)	[-0.09;-0.00]

Note: CI: Confidence Interval; * $p < 0.05$; SD: standard deviation; adult-child caregiver, ACCG

Figure 1. PLS-PM graph for all participants.

Note: Bold lines show significant paths, different thicknesses represent low, moderate and high significance. Dotted lines show non-significant links between latent variables; adult-child caregiver, ACCG.



Supplemental Table 1. Descriptive data for MVs

LVs MVs	All participants (N=159)		CNL (N=100)		CL (N=59)	
	M	SD	M	SD	M	SD
Severity of PWD symptoms						
ADL	26.12	11.85	23.84	11.63	29.98	11.29
IADL	13.79	2.21	13.37	2.35	14.51	1.75
Cognitive status	16.50	8.13	14.98	8.05	19.07	7.68
Care						
Care	22.31	7.71	22.11	7.17	22.64	8.60
Overprotection						
Overprotection	16.34	7.68	16.91	7.25	15.37	8.33
ACCG's poor self-rated health						
Health in general	3.37	1.07	3.24	1.13	3.59	0.91
Health compared	3.26	1.18	3.21	1.20	3.34	1.15
ACCG's distress						
Psychological distress	33.47	9.83	33.32	9.77	33.71	10.01
Anxiety	10.87	4.43	11.23	4.49	10.27	4.31
Depression	7.96	4.68	7.71	4.86	8.39	4.37
ACCG's preparedness						
Preparedness for caregiving	25.11	7.91	24.94	8.06	25.39	7.69
Preparedness for future care needs	21.07	5.72	20.95	5.70	21.27	5.79
Knowledge of services	25.40	7.14	25.78	6.89	24.76	7.57
ACCG's self-efficacy						
Self-efficacy	39.97	12.62	38.59	12.95	42.32	11.79
Control disturbing thoughts	57.08	26.40	59.18	25.28	53.53	28.05
Request respite care	55.09	29.52	57.10	29.29	51.69	29.85
Cope with behaviors	66.59	27.04	69.46	25.77	61.73	28.64
Informal social support						
Informational support	1.54	0.50	1.65	0.52	1.35	0.39
Instrumental support	1.38	0.47	1.43	0.52	1.30	0.37
Emotional support	1.78	0.65	1.82	0.68	1.71	0.61

Abbreviations: M, mean; SD, standard deviation; adult-child caregiver, ACCG

Supplemental Table 2. Intercorrelations between the variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	18.	19.	20.	
1. ADL	-	0.58*	0.59*	0.08	-0.08	0.31*	0.29*	0.20*	0.23*	0.27*	0.18*	0.27*	0.03	0.13	-0.09	0.19*	0.01	-0.10	-0.02	-0.13	
2. IADL	-	-	0.63*	0.02	-0.04	0.21*	0.18*	0.15	0.16*	0.13	0.06	0.20*	-0.05	0.08	-0.03	0.11	0.06	-0.20*	-0.07	-0.18*	
3. Cognitive status	-	-	-	0.10	-0.06	0.15	0.19*	0.21*	0.19*	0.14	0.06	0.08	-0.12	0.07	-0.05	0.15	-0.04	-0.20*	-0.04	-0.15	
4. Care	-	-	-	-	-0.44*	-0.04	0.03	-0.04	0.01	-0.09	0.12	0.06	-0.15	0.22*	0.08	0.27*	0.05	0.16*	0.22*	0.17*	
5. Overprotection	-	-	-	-	-	0.13	0.11	0.23*	0.23*	0.27*	-0.10	-0.01	0.02	-0.18*	-0.10	-0.28*	-0.17*	0.04	-0.11	-0.05	
6. Health in general	-	-	-	-	-	-	0.81*	0.46*	0.41*	0.53*	-0.15	0.01	-0.17*	-0.30*	-0.35*	-0.28*	-0.37*	-0.14	-	-0.24*	
7. Health compared	-	-	-	-	-	-	-	0.52*	0.49*	0.62*	-0.11	-0.05	-0.19*	-0.22*	-0.34*	-0.29*	-0.37*	-0.09	-0.12	-0.20*	
8. Psychological distress	-	-	-	-	-	-	-	-	0.78*	0.75*	-0.30*	-0.07	-0.24*	-0.36*	-0.29*	-0.37*	-0.48*	-0.05	0.02	-0.10	
9. Anxiety	-	-	-	-	-	-	-	-	-	0.62*	-0.23*	-0.13	-0.24*	-0.29*	-0.35*	-0.27*	-0.40	0.02	-0.03	-0.07	
10. Depression	-	-	-	-	-	-	-	-	-	-	-0.20*	-0.02	-0.16*	-0.30*	-0.33*	-0.41*	-0.45*	-0.15	-0.07	-0.26*	
11. Preparedness for caregiving	-	-	-	-	-	-	-	-	-	-	-	0.45*	0.42*	0.67*	0.14	0.55*	0.48*	-0.05	0.03	-0.01	
12. Preparedness for future care needs	-	-	-	-	-	-	-	-	-	-	-	-	0.58*	0.31*	0.10	0.33*	0.22*	-0.10	-0.04	-0.05	
13. Knowledge of services	-	-	-	-	-	-	-	-	-	-	-	-	-	0.32*	0.29*	0.22*	0.24*	-0.05	-0.08	0.01	
14. Self-efficacy	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.36*	0.55*	0.61*	0.02	0.09	0.14	
15. Request respite care	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.43*	0.46*	0.24*	0.34*	0.31*	
16. Cope with behaviors	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.67*	0.15	0.21*	0.12	
17. Control disturbing thoughts	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.11	0.15	0.16*	
18. Information support	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.65*	0.53*
19. Instrumental support	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	0.61*
20. Emotional support	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

*p<0.05