

**Predictors of caregiver distress: spouse, adult child living and not living with the person
with dementia**

Wawrziczny Emilie, Mpsy, PhD ^{a*}, Duprez Christelle, Mpsy, PhD ^a, Antoine Pascal, Mpsy,

PhD ^a

^a Laboratory SCALab, UMR CNRS 9193, University of Lille, Villeneuve d'Ascq, France

Short title: Dementia caregiver distress

*corresponding author:

Emilie Wawrziczny, PhD
*University of Lille, Laboratory SCALab, UMR CNRS 9193
Domaine Universitaire du Pont de Bois
BP 149
59653 Villeneuve d'Ascq, FRANCE
+33(0)3 20 41 70 97
emilie.wawrziczny@univ-lille.fr*

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Abstract

Background: The experience of the caregiving situation is different according to the type of relationship and living with the person with dementia is a factor contributing to caregiver distress. This study aimed to identify the predictors of caregiver distress based on the type of caregiver profile: spouse, adult child living with the person with dementia and adult child not living with the person with dementia.

Method : In total, 213 caregivers participated. This study evaluated the positive and negative implications of the caregiving situation and the level of distress using questionnaires. The analyses consisted of univariate and multiple linear regression models using a forward method.

Results: Regarding the standardised beta scores, the variables that are the most significant in predicting spouse caregiver distress are the impact on health and the impact on daily routine. The variable that is the most significant in predicting the distress of adult child caregivers living with the person with dementia is the impact on health. The variables that are the most significant in predicting the distress of adult child caregivers not living with the person with dementia are the impact on health, the impact on daily routine and the impact on finances.

Conclusion: The results make it possible to consider different propositions for support: evaluating the health of all caregivers, giving guidance in accepting help and focusing caregivers' actions on their values for spouse caregivers, family mediation sessions for adult child caregivers living with the person with dementia and information and assistance concerning the available aids for adult child caregivers not living with the person with dementia.

Keywords: dementia, caregiver, distress

Caregivers are an essential support that allow the persons with dementia to remain in their own home for as long as possible. Nevertheless, the caregiving situation leads to changes in caregivers' roles, tasks and responsibilities, which has an impact on their quality of life (1). In Adams' qualitative study (2), the caregivers described that they dedicate time to caring for and supporting the person with dementia and responding to their growing needs caused by the evolution of the troubles (memory, language, gestures, recognition, executive functions). They must repeat things and give reminders in cases of forgetfulness and oversee or offer help with cognitive and physical tasks in day-to-day life. They also take on administrative tasks (mail, paperwork, managing finances), oversee treatments and manage the household and personal care (hygiene and meals). Finally, they cope with the person with dementia's behavioural changes and the presence of certain symptoms, such as depression, apathy or agitation (3).

In Brodaty & Donkin's review (4) and Brodaty, Green, & Koschera's meta-analysis (5), the authors revealed the negative impact that progressively assuming these responsibilities has on the caregivers' social life (sacrificing their activities, restriction of time with friends and family, family conflict, reduction of working hours...), on their physical and psychological health (cardiovascular problems, difficulties sleeping, depression, anxiety...) and on their financial situation (medications, loss of income...), which can lead to a significant feeling of isolation and distress. However, studies show that the caregiving situation is complex and that caregivers' feelings are much more mixed than just one negative feeling. In fact, caregivers also have a feeling of satisfaction or personal benefit from the caregiving situation, such as feeling useful, important and competent (6–10).

Furthermore, in most cases, this support is provided by a family member, usually the spouse and children (4). Previous studies supported that the experience of the caregiving

situation varies depending on these types of relationship with the person with dementia (11-13). In that line, the purpose of this study was to examine the predictors of caregiver distress of these two types of caregiver (spouse and children).

Indeed, the adult child caregivers see dementia as a normal part of aging and focus on the abilities of their parents rather than the difficulties (12). They are motivated by extrinsic motivations such as a feeling of obligation or duty (13), which may aggravate distress. They expressed their feeling of losing personal freedom (12) and guilt based on not living with the person with dementia (11) as they have other responsibilities (their career, young children or teenagers to look after) that can interfere with caregiving situation (13).

Spouses are motivated by intrinsic motivations that form a protective barrier against distress (13). However, they expressed their sadness linked to nostalgia for the past and various losses brought about by the disease and they are more realistic about the future (12). Furthermore, for the spouses who are largely living with the person with dementia, they provide more of the support and find less respite than children and children-in-law (13). They are also older than child caregivers and may suffer from health problems that interfere with caregiving situation (13).

Thus, the literature highlighted that the experiences of caregiving situations are different depending on the type of relationship (spouse or child). Alternately, living with a person with dementia is also an important factor that promotes caregiver distress (11). To date, no known studies address the caregivers' experience depending on their profile. Profile elements include a combination of these two elements: spouse living with the person, child caregiver living with the person with dementia and child caregiver not living with the person with dementia. The

purpose of this study was to examine, depending on the profile of the caregiver, the positive and negative implications of the caregiving situation (impact on schedule, financial situation, family support, health, and self-esteem) contributing to caregiver distress.

Materials and Methods

Participants

Participants were recruited via Internet (forums for caregivers) and Facebook (social networks for caregivers). The inclusion criteria were as follows: caregivers had to be the chief caregiver of a person with Alzheimer's disease or a related type of dementia, they had to be the spouse or the child and the person with dementia had to be either at home (with them or not), but not in residential care. In total, 213 caregivers participated in the study; the spouse group consisted of 71 caregivers, the child living with the person with dementia (CL) group consisted of 59 caregivers and the child not living with the person with dementia (CNL) group consisted of 83 caregivers.

For the spouse group, the persons with dementia were diagnosed with Alzheimer's disease (38%) or a related type of dementia, such as frontotemporal dementia (22.5%), Lewy bodies dementia (15.5%), mixed dementia (2.8%), or other types of dementia (21.1%). For the CL group, the persons with dementia were diagnosed with Alzheimer's disease (62.7%), frontotemporal dementia (15.3%), Lewy bodies dementia (10.2%), or other types of dementia (11.9%). For the CNL group, the persons with dementia were diagnosed with Alzheimer's disease (67.5%), frontotemporal dementia (14.5%), Lewy bodies dementia (4.8%), mixed dementia (2.4%) or other types of dementia (10.8%).

Procedure

The method used to recruit participants included posting information about the study on the forums and Facebook pages of existing groups related to the topic of interest (caregivers of persons with dementia). The initial posted message highlighted that we were recruiting for a research study, and looking for people to complete an online survey, it gave a brief explanation of the study, the inclusion criteria and included the URL address needed to access the information letter, the participation consent form and the questionnaires. The connection to the server does not require any identification on the part of the caregiver.

Ethical Approval

The survey was approved by the university ethics committee and adhered to the tenets of the Helsinki Declaration of 1975.

Informed Consent

The informed statement page had information concerning the aims and protocol of the study, the name, position, institution contact details of the principal researcher, anonymity and confidentiality, and inclusion criteria. This page served as an online consent form. After consenting, participants could access a first question to validate the inclusion criteria and, then the entire study online to complete it.

Measures

First, the caregivers responded to a set of questions that included items addressing their sociodemographic status and that of the person with dementia (i.e., sex, age, mean time spent caregiving situation in a day, diagnosis, date of the diagnosis and date of the first signs).

The effect of the disease on their lives

The Caregiver Reaction Assessment (CRA) (14) specifically assesses the caregivers' experiences. Five negative and positive dimensions of caregiver reactions were identified: negative impact on disrupted schedule, financial problems, lack of family support, health problems, and the positive effect on self-esteem. This questionnaire contained 24 items that employed a 5-point response scale ranging from 1 (strongly disagree) to 5 (extremely agree). The internal reliabilities (Cronbach's alpha) for the five scales were between 0.75 and 0.85 in the French version (15) and 0.77 (impact on disrupted schedule), 0.71 (financial problems), 0.87 (lack of family support), 0.78 (health problems) and 0.87 (the effect on self-esteem) in our study.

Caregiver distress

The Hospital Anxiety and Depression Scale (HADS) (16) is a self-assessment for depression and anxiety. This scale is composed of 14 items (7 for anxiety and 7 for depression) that are rated using a 4-point scale from 0 to 3. Combining the HADS-Anxiety and HADS-Depression subscales makes it possible to create a reliable "Total Distress Score" (HADS-T) from 0 to 42 (no cut-off level to define "cases" vs. "non-cases", high scores are suggestive of more symptoms). A recent 10-year review recommended the use of HADS-T as a measure for mental distress (17). The internal reliabilities (Cronbach's alpha) in the French version for the total scale were 0.89 (18), as in our study.

Statistical analyses

The analyses were performed using the Statistical Package for the Social Sciences (SPSS; IBM, Armonk, NY). In step 1, means, SDs, and percentages were calculated for the sociodemographic data. ANOVA and chi-square tests were performed to compare the three

groups depending on whether the variables were continuous or categorical, respectively. For all analyses, the probability level used to indicate statistical significance was set at $p < 0.05$. In step 2, univariate regression analyses were conducted to identify the contribution of each variable to the HADS-T score, independently from all the other variables. In step 3, by using the steps and analyses conditions of Luchesi et al (19), variables that demonstrated statistical significance in the univariate analyses ($p \leq 0.2$) were entered into a multiple linear regression model using a forward method. Forward stepwise selection is one of the classical and popular methods in statistics for selection and estimation of the parameters in a linear model (20). The effect size for linear regression was measured by Cohen's $f^2 = r^2 / (1 - r^2)$. The normal distribution of residuals in each model was verified using the Shapiro-Wilk test.

Results

Characteristics of caregivers

Table 1 shows that the participants were primarily women. The spouse caregivers were significantly older than the child caregivers: 64.91 years (SD : 9.09) for the spouse caregivers compared with 49.95 years (SD : 12.11) for the CL caregivers and 50.05 years (SD : 11.57) for the CNL caregivers.

The two groups of child caregivers were caring for a person with dementia who was significantly older than the person with dementia cared for by the spouse caregivers: 80.86 years (SD : 9.11) for the CL caregivers and 78.75 years (SD : 8.42) for the CNL caregivers compared with 69.73 years (SD : 7.97) for the spouse caregivers (Table 1).

The mean time spent helping per day was, in order, significantly greater for spouses, then for CL caregivers and then least for CNL caregivers: 15.21 hours per day on average (*SD*: 8.15) for the spouse caregivers, 11.03 (*SD*: 7.17) for the CL caregivers and 3.54 (*SD*: 3.96) for the CNL caregivers.

The three groups were comparable in terms of the delay between diagnosis and interview and the time between the first signs of the disease and the interview (Table 1).

Concerning the mean scores of the HADS-T and CRA scales, the “Impact on daily routine” and “Lack of family support” scores resulted in a statistically significant difference among the different caregiver groups ($p < 0.05$). “Impact on daily routine” scores were significantly higher for the spouse and CL groups compared to the CNL group. The “Lack of family support” score was significantly higher for the CL group, compared to the spouse group.

No differences were observed between the three groups’ scores for distress (HADS-T), caregiver self-esteem, impact on finances, or impact on health.

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

Univariate and multiple regressions

For the spouse caregivers’ model

Univariate analyses indicated that within the set of variables investigated, five variables reached significance as predictors of spouse caregiver distress: caregiver age with a negative beta, impact on finances, impact on daily routine, lack of family support and impact on health with

a positive beta (Table 2). The final multivariate model including these variables explained 42% of the variation in the level of distress for spouse caregivers (Table 2). The effect size was 0.79, which means that it can be considered a large effect size according to guidelines by Cohen (20). Regarding the standardised beta scores, the variables that are the most significant in predicting spouse caregiver distress are, in order of significance, the impact on health ($\beta= 0.45, p<0.05$) and the impact on daily routine ($\beta= 0.38, p<0.05$). Spouse caregivers who felt that the situation had a greater impact on their health and on the organization of their day-to-day life experienced a greater feeling of distress.

For the CL caregivers' model

Univariate analyses indicated that four variables reached significance as predictors of CL caregiver distress: caregiver self-esteem with a negative beta, impact on daily routine, lack of family support and impact on health with a positive beta (Table 2). The final multivariate model including these variables explained 41% of the variation in the level of distress for CL caregivers. The effect size was 0.69, which means that it can be considered a large effect size according to guidelines by Cohen (1988). Regarding the standardised beta scores, the variable that is the most significant in predicting CL caregiver distress is the impact on health ($\beta= 0.64, p<0.05$). The CL caregivers who felt that the situation had a greater impact on their health experienced a greater feeling of distress.

For the CNL caregivers' model

Univariate analyses indicated that five variables reached significance as predictors of CNL caregiver distress: delay between diagnosis and interview, impact on finances, impact on daily routine, lack of family support and impact on health with a positive beta (Table 2). The final multivariate model including these variables explained 50% of the variation in the level of

distress among CNL caregivers. The effect size was 1.00, which means that it can be considered a large effect size according to guidelines by Cohen (1988). Regarding the standardised beta scores, the variables that are the most significant in predicting CNL caregiver distress are, in order of size: the impact on health ($\beta= 0.38, p<0.05$), the impact on daily routine ($\beta= 0.32, p<0.05$) and the impact on finances ($\beta= 0.19, p<0.05$). The CNL caregivers who felt that the caregiving had a greater impact on their health, on the organization of their day-to-day life and their finances experienced a greater feeling of distress.

-----[Insert Table 2 about here]-----

Discussion

The original objective of this study was to identify the predictors of distress depending on whether the caregiver is a spouse living with the person with dementia, a child caregiver living with the person with dementia or a child caregiver not living with the person with dementia. This approach is important for adapting support proposals and responding appropriately to the difficulties for each caregiver profile.

If the impact on health is a common predictor of distress for all groups, the impact on finances, the impact on daily routine and the lack of family support all affect the three groups differently.

Health: essential for evaluation and support for all caregivers

This study shows that the impact of the caregiving situation on the health of caregivers is a significant predictor of their feeling of distress. While the literature implies that only older caregivers are affected because they are more frequently affected by health problems (13,21),

this study demonstrates that the evaluation of health is the most important factor for the three groups. In fact, increasing commitments to the person with dementia may lead to them neglecting their own health and needs (22). This neglect may be explained by their difficulties with delegation and their sense of personal responsibility (23), not leaving the person with dementia alone at home (24) or having other responsibilities (25). This result makes it possible to consider the evaluation of health as a predictor to identify caregivers who may present greater distress. It is essential to consider caregivers' physical state of health by alerting the monitoring professionals, who can then help them to organise their own care, while considering the caregiving situation. This indicator can be a major asset to the support.

Supporting spouses and CNLs in their daily routine

For spouses and CNLs, the impact of the caregiving situation on their daily routine constitutes a deciding factor in their feeling of distress. In fact, caregivers focusing on caregiving situation is what leads to disorganisation in their daily activities (26), giving up their activities (24), social isolation, and a lack of respite (27). This impact on their daily routine can be explained for spouses by the fact that in addition to living with the person with dementia, they are retired and their social network becomes gradually limited as the disease progresses (28). They are then fully focused on the caregiving situation with limited or even non-existent solutions for respite. For CNLs, the difficulties are linked to arranging working hours to accommodate the person with dementia, including travelling between their respective homes and other professional and family responsibilities (13,29). Caregiving also becomes an additional task that must be factored into their schedules. In view of these results, it is a question of providing spouse caregivers with guidance on accepting help, delegating tasks and focusing caregivers' actions on the values that are important to them (30). CNLs could also be helped by identifying their professional and personal networks and their options for intervention. Implementing formal and

informal support would then provide relief to help organize the daily routine. As for CLs, they perceive a significant impact on their daily routine, but this factor is not a predictor of their level of distress. It could be hypothesized that even if they live with the person with dementia and caregiving affects their routine, they have kept other commitments that mean that they cannot be completely focused on supporting the person with dementia, while being there for them. Another hypothesis is that hosting the person with dementia results in a reorganisation that has been anticipated in advance and that this preparation reduces the emotional impact of caregiving situation. These hypotheses could be explored with semi-structured interviews that would be analysed qualitatively.

Providing guidance to CNLs in processes for obtaining financial aid

For CNLs, the impact of the caregiving situation on finances is a significant predictor of their feeling of distress. In fact, caregivers with fewer financial resources are at a higher risk of depression (31), more so if they are the children of the person with dementia (32). This study highlights that this affects in particular children who do not live with the person with dementia, which could be explained by the cost linked to travelling between their homes, the cost of care (respite care, pharmaceuticals, medical consultation, transportation...) (32) combined with the other costs of family life. Therefore, it is a question of implementing a form of assistance in administrative processes in order to provide information on potential financial aid and how to obtain it and, in doing so, alleviating the cost of caregiving situation.

Taking into account the quality of family support for CLs

While the “Lack of family support” score is not a significant predictor of distress for the three groups of caregivers, CL caregivers feel this lack more than spouses. In fact, spouses prefer to distance themselves because they cannot tolerate the family behaving with the person with

dementia as if they do not exist or to prevent them from being involved in care-related decisions (24,33). Furthermore, spouses have difficulty delegating because they feel responsible for care, think that they alone can provide their loved one with the best care and are even more motivated by their duty as a spouse (34). Family mediation sessions may be suggested to families where the primary caregiver is a CL in order to assess potential family support, inform other family members about the disease for a better understanding and to redistribute roles where possible (33).

Limitations

Facebook recruitment tended to result in similarly representative samples with lower cost per participant and more rapid recruitment (35). Considering the sample sizes and the different disease profile of persons with dementia in this study, it would be interesting to assess these variables with a larger sample of each group of caregivers and to make analyses according to disease profile. Caregivers recruited used Internet or Facebook what may explain the younger age of the sample. This study shows that the subjective evaluation of the positive and negative implications of caregiving situation on the health of caregivers is a predictive factor of their distress. Nevertheless, it would be interesting to combine this measure with an objective indicator of health. Furthermore, if this study makes it possible to identify certain predictors of caregiver distress, van der Lee et al. (3) highlight the importance of taking into account different categories of factors (quality of relationship with the person with dementia, the feeling of being prepared for and confident in their new role, the severity of the person with dementia's symptoms, adjustment strategies...). It would therefore be interesting to include these dimensions in the evaluation and provide a more complex model of the factors that influence the feeling of distress for caregivers, according to their profile. In addition, given that the feeling of distress develops with the disease, this evaluation could be carried out at several points across

treatment to identify the development of relationships between these factors depending on the development of the disease.

To conclude, the original goal of this study is to identify the predictors of caregiver distress according to their profile. These results make it possible to consider different approaches for support. It is essential to evaluate the perception of health for all caregivers, which is considered the most significant predictor of their distress, and to support them in their personal care by removing the obstacles that contribute to neglect. Spouse caregivers would be given guidance in accepting assistance and focusing caregivers' actions on their values by using, for example, intervention strategies focused on acceptance (30). Family mediation sessions could be suggested to families where the caregiver is a CL in order to assess potential family support (33). Finally, CNL caregivers would be given information and support on available assistance in order to rebalance various commitments by setting up relief and limiting the financial costs of their responsibility.

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Table 1. Sociodemographic Characteristics of Caregivers and Persons with dementia and variables' means by Group of Caregivers.

Variables	Spouse (N=71)			CL (N=59)			CNL (N=83)			χ^2	F (p)	Post-hoc ^b
	%	M	SD	%	M	SD	%	M	SD			
Caregivers characteristics												
Gender											11.61 ^a	
Female	69.01			86.40			89.20					
Male	30.99			13.60			10.80					
Age, years		64.91	9.09		49.95	12.11		50.05	11.57		43.70(p<0.01)	1>2, 1>3
Time for help, mean in a day		15.21	8.15		11.03	7.17		3.54	3.96		63.77(p<0.01)	1>2;2>3;1>3
Persons with dementia characteristics												
Age, years		69.73	7.97		80.86	9.11		78.75	8.42		33.33(p<0.01)	1<2, 1<3
Delay between diagnosis and interview, years		4.83	4.60		4.69	3.81		3.83	3.38		1.45(0.23)	
Delay between first signs and interview, years		7.66	5.48		6.66	4.64		5.88	4.18		2.67(0.07)	
Variables												
HADS-T		20.97	7.31		21.03	8.37		19.48	8.62		0.88(0.42)	
Caregiver's self-esteem		24.91	5.50		25.19	6.49		25.41	5.39		0.14(0.87)	
Impact on finances		9.0	3.16		10.17	3.15		9.60	2.91		2.36(0.10)	
Impact on daily routine		19.96	2.98		20.39	4.01		17.17	4.42		15.27(p<0.01)	1>3, 2>3
Lack of family support		16.65	5.24		19.13	5.27		17.04	5.39		4.03(0.02)	1<2
Impact on health		13.01	3.26		13.74	3.53		12.71	3.87		1.47(0.23)	

Abbreviation: N, effectif; M, mean; SD, standard deviation; HADS-T: Total Distress Score; CL, child living with the person with dementia; CNL, child not living with the person with dementia

^ap <0.05; ^b Comparison of variables between different groups of caregivers. The column lists the groups of caregivers that have significant differences in variables scores

Predictor variables	Spouse caregivers		Predictor variables	CL caregivers		Predictor variables	CNL caregivers	
	β	p		β	p		β	p
<i>Univariate analyses</i>			<i>Univariate analyses</i>			<i>Univariate analyses</i>		
Caregiver age	-0.24	0.04	Caregiver age	-0.02	0.85	Caregiver age	-0.03	0.76
Person with dementia age	-0.05	0.68	Person with dementia age	0.03	0.83	Person with dementia age	0.04	0.73
Delay between diagnosis and interview	0.02	0.87	Delay between diagnosis and interview	0.05	0.70	Delay between diagnosis and interview	0.23	0.04
Delay between first signs and interview	0.01	0.91	Delay between first signs and interview	-0.01	0.91	Delay between first signs and interview	0.11	0.30
Time for help	0.08	0.49	Time for help	-0.00	0.98	Time for help	0.11	0.31
Caregiver's self-esteem	0.04	0.76	Caregiver's self-esteem	-0.30	0.02	Caregiver's self-esteem	0.04	0.70
Impact on finances	0.46	$p<0.01$	Impact on finances	0.18	0.16	Impact on finances	0.43	$p<0.01$
Impact on daily routine	0.47	$p<0.01$	Impact on daily routine	0.31	0.02	Impact on daily routine	0.58	$p<0.01$
Lack of family support	0.34	$p<0.01$	Lack of family support	0.26	0.05	Lack of family support	0.29	0.01
Impact on health	0.53	$p<0.01$	Impact on health	0.64	$p<0.01$	Impact on health	0.62	$p<0.01$
<i>Final multivariate model</i>	β	p	<i>Final multivariate model</i>	β	p	<i>Final multivariate model</i>	β	p
Impact on daily routine	0.38	$p<0.01$	Impact on health	0.64	$p<0.01$	Impact on daily routine	0.32	$p<0.01$
Impact on health	0.45	$p<0.01$				Impact on finances	0.19	0.03
						Impact on health	0.38	$p<0.01$
ANOVA	F= 24.44 , $p<0.01$		ANOVA	F= 40.45 , $p<0.01$		ANOVA	F= 26.60, $p<0.01$	
Durbin watson	1.85		Durbin watson	1.33		Durbin watson	1.80	
R ²	0.42		R ²	0.41		R ²	0.50	

β = Standardised beta weights, p =Significance level for predictor variables (in bold: $p\leq 0.05$) ; R²=Multiple Regression value squared; CL, child living with the person with dementia; CNL, child not living with the person with dementia

Table 2. Univariate and multivariate regression analyses on person with dementia and caregiver variables for prediction of the Hospital Anxiety and Depression Scale total score (HADS-T) for each caregiver group