

**Distress in Caregivers of Amyotrophic Lateral Sclerosis and
Progressive Muscular Atrophy Patients**

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Date: 07-01-2019

Abstract

The aim of this study was to examine what demand factors place informal caregivers of patients with Amyotrophic lateral sclerosis (ALS) or progressive muscular atrophy (PMA) at risk of becoming overwhelmed by psychological distress. Functional and behavioural impairments have been linked to caregiver distress. Demand factors such as work and parental responsibilities may also add to the caregiver's burden but have been scarcely researched. Karasek's model of demand-control served as a theoretical framework to generate the hypotheses. 148 caregivers of patients with ALS or PMA participated in an online survey on distress, physical- and behavioural problems of the patient and socio-demographic variables. The dependent variable was caregiver psychological distress, measured with the Hospital Anxiety and Depression Scale. Demand variables were the functional and behavioural impairments of the patient, having paid employment and having children under 18. Gender was also expected to influence the association between demands and distress. Results: The hierarchical multiple regression model accounted for 44% of the variance in distress. Both behavioural impairments of the patients and having young children were significantly associated with caregiver distress. Caregiver's employment status, functional impairment and gender showed no significant relation with caregiver distress. No interaction effect for gender was found. Conclusion: Caregivers with patients with behavioural problems or with the care responsibility for young children are indicated to be more at risk of developing psychological distress.

Keywords: Amyotrophic lateral sclerosis (ALS), progressive muscular atrophy (PMA), caregiver distress

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Amyotrophic lateral sclerosis (ALS) and progressive (spinal) muscular atrophy (PMA) are both progressive and fatal neurodegenerative diseases. ALS affects the lower and upper neurons, while PMA affects the lower motor neurons. Patients with ALS or PMA experience a gradual decline of functional abilities due to progressive muscle weakness and respiratory problems. Cognitive and behavioral problems are also common in patients with ALS and PMA (Beeldman et al., 2015; Raaphorst et al., 2010). Prognosis of survival in both illnesses is poor with a median survival rate between three to five years after onset of symptoms (Al-Chalabi & Hardiman, 2013; Visser et al., 2007). Because of the similarities in clinical, pathological and genetical features, PMA is often considered to be a rare phenotypical variant of ALS (Müller et al., 2018; Visser et al., 2007).

In the day-to-day care of the patients with ALS or PMA, spouses and adult children play a crucial part, as most patients remain at home during the course of the disease (Bruletti et al., 2015; Goldstein, Atkins, Landau, Brown, & Leigh, 2006). From extensive literature on ALS caregiving it is well-known that these informal caregivers are at risk for caregiving burden (de Wit et al., 2017). Although there is limited research available specifically on caregivers of patients with PMA, informal caregivers are expected to experience similar problems as caregivers of patients with ALS, considering the overlap between disease course, -symptoms and care duties (Raaphorst et al., 2010; Visser et al., 2007).

The physical and emotional demands on informal caregivers of patients with PMA or ALS are high. The disruption that the disease brings into their daily life routines continues at an irrepressible pace and requires a constant adaption of the caregiver to new care situations and caring responsibilities (Chio et al., 2006). Caregivers of ALS patients report a multitude

of problems related to the caregiving situation, such as feelings of anger and frustration, loss of intimacy, role change from spouse to nurse and restrictions on social activities as factors contributing to feelings of distress. (Aoun, Connors, Priddis, Breen, & Colyer, 2012; Gysels & Higginson, 2009; Oyebode, Smith, & Morrison, 2013). The more severe the impairments of the patient and care needed, the more caregivers run the risk of developing psychological distress, feelings of anxiety, depression and poor quality of life (de Wit et al., 2017; Gysels & Higginson, 2009; Pagnini et al., 2010).

The contributing effect of cognitive and behavioural symptoms, often called neuropsychiatric symptoms, on caregiver's burden has been the topic of extensive research in the last decade (Beeldman et al., 2015), and has been related to caregiver depression, caregivers burden and quality of life (Chiò et al., 2010; Lillo, Mioshi, & Hodges, 2012). Studies on the different aspects of cognitive and behavioural impairment found especially the behavioural component affecting caregiver distress (Lillo et al., 2012). Approximately 30 to 50% of the ALS patients and 17% of the PMA patients developed some kind of neuropsychiatric impairment and 10 to 15% reached the criteria for diagnoses of frontotemporal dementia (Beeldman et al., 2015; Raaphorst et al., 2010). Patients may exhibit apathy, irritability, unconsidered or indifferent behaviour. Caregivers can encounter difficult situations in which patients may refuse essential medical care or act inconsiderate towards the needs of the caregiver (Goldstein & Abrahams, 2013). In these situations demands on the caregiver become high, while feelings of control may be low, adding to a sense of burden.

Informal caregivers who have to deal with these physical and emotional demanding situations may be in need of specialised support. However, caregivers are known to be reluctant in asking for help and tend to see the care of the patient as their first priority (Brulletti et al., 2015; Weisser, Bristowe, & Jackson, 2015). Since these informal caregivers are key figures in the care for the patient, decreased wellbeing of the caregiver may interfere

with the care the patient is dependent on and may ultimately lead to institutionalisation of the patient (Brulletti et al., 2015; Thomas et al., 2018). In order to help caregiver and patient there is a need to unravel the full picture of factors related to the caregiver's distress.

A theoretical model that may be useful in examining factors of, as well as explaining, psychological distress in caregivers is the demand-control model or job strain model of Karasek (Molloy et al., 2005). This model assumes that both the physical and emotional demands of a job and the experienced control over these demands will predict the job strain. In this model demand and control have both a predicting as well as an interacting influence on psychological distress (Karasek & Theorell, 1990; Van der Doef & Maes, 1999). When projected on the caregiver's situation, the model offers a potential framework to understand caregivers' distress. Hence, the control demand model specifies when there are high caregiver demands, the feeling of control over caregiving tasks plays a protective role against increasing psychological distress. Several attempts to predict caregiver's emotional distress based on the changes in demand and control were moderately successful. Previous caregivers studies showed that higher demand or lower control situations were associated with higher levels of reported feelings of anxiety and depression, but did not produce the expected interaction of demand and control (Molloy et al., 2005; Orbell & Gillies, 1993). Although there is some evidence for the influential role of demands and control on caregiving distress, the full picture has not yet been uncovered (Molloy et al., 2005).

One of the possible gaps in the research on caregiving distress may be that the focus has largely been on only patient-related demands. However, the model does not yet accurately mirror the daily demands on caregivers. In reality, caregivers seldom solely act as caregivers. They are also parent, employee, neighbour or friend. The combination of occupying other roles and caregiving has been found to be associated with increased caregiver burden (Olsson Ozanne, Graneheim, Persson, & Strang, 2012; Qutub, Lacomis, Albert, & Feingold, 2014).

Two specific roles that have been investigated in relation to psychological distress and caregiving in general are the parental and employee role.

Both work and parental responsibilities may increase the demand on caregivers' time and energy, but little is known about the relationship between these demand situations and psychological distress of caregivers of patients with ALS or PMA. From studies on cancer in families with young children it is known that children are often foremost on the minds of the parents. One of the few studies on caregiving in ALS found that having young children caused caregivers to worry about their ability to support their children in coping and about not being able to spend enough time with them (Olsson Ozanne et al., 2012). Caregivers have to deal with children's reaction on the disease and changes in family roles in relation to the children. When the disease progresses and limits the active involvement of the patient in family-duties and responsibilities, the caregiver gradually takes over full responsibility of the family household, on top of the caregiving duties. This may increase feelings of distress in caregivers.

Research on the influence of paid employment on caregiver distress found that combining the employee and caregiver roles was associated with increased stress levels and burden (DePasquale et al., 2017; Qutub et al., 2014). Being both a caregiver and an employee can create role conflict, causing a feeling of being sandwiched between those two responsibilities (Hammer & Neal, 2008). Caregiving can come with medical emergencies and doctor visits, trapping the caregiver between work obligations and caregiving duties. At the same time, work can also come with unexpected or time-consuming obligations. In an attempt to deal with both demanding roles, caregivers are known to reduce the amount of working hours, temporarily stop working or take sick leave (Lee & Tang, 2015). Without adjustments or a sense of control over either work, work demand or the care situation, it is expected that the risk of psychological distress will increase.

Another possible influencer of caregiver distress is gender. A meta-analysis on 229 studies on gender and caregiving found differences, although small, in the way female and male caregivers respond to care situations (Pinquart & Sörensen, 2006). Compared with male caregivers female caregivers spent more time caregiving and provided assistance in more tasks, especially in personal care, than male caregivers (Pinquart & Sörensen, 2006). Female caregivers also had more difficulty claiming time for themselves compared to male caregivers (Kesselring et al., 2001; Pinquart & Sörensen, 2006). These factors may contribute to higher levels of physical exhaustion and feelings of distress and may increase the risk of becoming emotionally overwhelmed by care demands. Therefore, it is expected that caregiver's gender moderates the relationship between demand situations and caregiver distress, with female caregivers experience more distress when demands are higher than male caregivers.

The objective of this research paper is to investigate demand factors related to patient and caregiver situations that are expected to be associated with psychological distress of caregivers of patients with ALS or PMA. The study will provide knowledge about which factors place the caregiver at risk and may guide the development of caregiver interventions. Additionally, this information will help social workers to identify caregivers at risk. Academic relevance lies in the uncovering of factors that influence caregivers distress and thus contribute to testing an explanatory model.

The research questions to be investigated are "What demand factors are associated with psychological distress of informal caregivers of patients with ALS and PMA?" and "Does caregiver's gender effect the relationship between demand factors and psychological distress of caregivers of patients with ALS and PMA?". The investigation will focus on four demand variables: (1) the functional impairment of the patient, (2) the behavioural impairment of the patient, (3) having paid work and (4) being a parent of children under 18. Gender is expected to act as a moderator variable within the predicative analysis. Dependent

variable in both hypotheses is the self-reported psychological distress of the caregiver, operationalised as experiencing symptoms of anxiety and depression.

The hypotheses to be tested in this investigation are as follows:

- 1.1 Higher levels of functional- or behavioural impairments of the patient, having paid work or being a parent of children under 18 is related to higher psychological distress of caregivers of patients with ALS or PMA.
- 1.2 The association between the above mentioned demand factors and psychological distress of caregivers of patients with ALS or PMA will be stronger for female caregivers than for male caregivers.

Methods

Design

The data used were the pre-randomization baseline data from a separate randomized controlled trial investigating the effectiveness of an online guided psycho-social support program for caregivers of patients with ALS or PMA (Dutch Trialregister NTR5743, registered 28 March 2016). The protocol of this randomized controlled trial has been reported elsewhere (de Wit et al., 2018). Data were collected through an online self-report questionnaire.

Procedure

Participants were recruited from a Dutch Nationwide ALS/PSMA database, and through an announcement on the website of the Dutch ALS Center between August 2017 and April 2018. After prospective participants signed up for the research they received information about the research and online program and were contacted by a researcher to check the inclusion criteria. Inclusion criteria for the study were: The participant should be 18 or older, a partner of either a person with ALS or PMA, have internet access and be proficient in Dutch. Eligible participants were asked to sign and return an informed consent via postal

mail. After the informed consent was received at the research department, participants were sent an invitation via email to fill out the online baseline questionnaire.

Instruments

The questionnaire contained demographic information about the caregiver and the patient (gender, age, educational background, family-configuration), disease information (disease onset), physical impairment and behavioral problems of the patient, and anxiety and depressive symptoms of the caregiver.

The Hospital Anxiety and Depression Scale (HADS) was used to measure psychological distress. The HADS consists of seven items measuring anxiety symptoms and seven questions measuring depressive symptoms. Each item is scored on a 4-point scale [0 - 3], total range [0 - 42]. An example of a question is "I often feel worried". Based on past research on sensitivity and specificity of the HADS, a total score ≥ 12 was considered as cut-off score in this study (Bjelland, Dahl, Haug, & Neckelmann, 2002). Past reviews on the psychometric qualities of the HADS found good homogeneity, validity and test-retest reliability of the HADS total score (Bjelland et al., 2002; Spinhoven et al., 1997, p. 368). In this study, the internal consistency for the HADS was good, Cronbach's α was .91.

The Amyotrophic Lateral Sclerosis Fronto Temporal Dementia (ALS-FTD-Q) was used to measure behavioural changes. The ALS-FTD-Q contains 13 items comparing present behavior of the patient with his/her behaviour three years ago and 12 items about the patient's behaviour in the past month. An example of an item is "your partner displays more withdrawn behaviour". All 25 items are scored on a 4-point scale [1 - 4], with a total score range from 0 to 100. A score ≥ 22 indicated moderate to severe behavioural changes. Review on ALS-FTD-Q psychometric qualities found good construct and clinical validity as well as good internal consistency and test-retest reliability (Raaphorst et al., 2012). The questionnaire showed good discriminating properties to identify ALS patients with the behavioural variant

of frontotemporal dementia (Raaphorst et al., 2012, p. 1380). The ALS-FTD-Q in this study had good internal consistency and validity, Cronbach's α was .88.

The Amyotrophic Lateral Sclerosis Functional Rating Scale – Revised version (The ALS-FRS-R) was used to assess functional impairment. The scale consists of 12 items on a 5-point scale [0 - 4], measuring the loss of function in four domains; fine motor, gross motor, bulbar and respiratory function. A total score ranging from 0 to 48 where ≤ 25 indicates severe to very severe impairment. Past studies showed good to very good construct validity, internal consistency and test-retest reliability (Cedarbaum et al., 1999). In this study Cronbach's α was .84.

For work-related information the distinction was made between either paid employment (fulltime, part-time, freelance, sick-leave) or no employment (retired, unemployed, fulltime caregiver). For information on parental responsibilities the distinction was made between either having children under 18 or of having no children or children above the age of 18.

Data Analysis

Statistical analysis was conducted using SPSS version 24. For all tests performed, $p < .05$ was considered to be statistically significant. The data used for analysis did not contain missing values. Furthermore, data was checked for outliers and for normality with a Q-Q plot and a Kolmogorov-Smirnov test, after which was concluded that the assumption of normal distribution of sample means was met for the ALS-FRS-R, HADS and ALS-FTD-Q. Multicollinearity between the predictor variables was checked and showed no $r > .7$ between the predictor variables.

To address hypothesis 1, which stated that the functional impairment, the behavioural problems, work and parental responsibilities are associated with the psychological distress of the caregiver a hierarchical multiple regression analysis (MRA, method enter) was performed.

For this purpose predictor variables ‘Work’, ‘Parental responsibilities’ and ‘Gender’ were transformed into dummy variables (work = 1, no work = 0; family with children under 18 = 1, family with no children or children above 18 = 0; Man = 0, Female = 1). Caregiver’s age and educational background were entered in the analysis as control variables as these are known to be associated with caregiver distress, work and parental responsibilities (Molloy et al., 2005; Pinguart & Sörensen, 2006). Educational background was split into three categories (low, intermediate and high), based on the Dutch Standard for Education Classification (Centraal Bureau voor de Statistiek, 2016). Education level low and education level high were both transformed into dummy variables (resp. low=1, intermediate = 0, high = 0; low =0, intermediate = 0, high =1).

To test whether female caregivers experience higher distress in demanding situations than male caregivers a hierarchical multiple regression was performed. Predictor variables of interval level were centered prior to creating the interaction variable. Outcome variable was the HADS total score.

Results

In total 148 participants took part in the study. Most caregiver were female, 96 (65%). The average age was 61.5 ($SD = 10.2$), range [32 – 85] years. All but three were living together with a partner with ALS/PMA. Twenty caregivers (14%) reported having children below the age of 18 and 59 (40%) were currently (self)employed. The patient group mainly consisted of men 96 (65%). Mean age was 62.6 ($SD = 9.9$), range [35 – 80]. The diagnosis was ALS for 106 (72%) patients (see Table 1).

Table 2 shows the results of the hierarchical regression analysis examining whether caregiver distress was associated with demographic variables age, gender and education, with demand factors functional impairments, behavioural impairments, having work and family

responsibility and with the interaction variable of gender and functional impairment, gender and behavioural impairment, gender and work, and gender and family responsibility.

The regression model for caregiver distress showed that in block 1, demographic variables explained 8% of the variance in psychological distress $F(4,143) = 3.22, p = .015$. Gender and education were not associated with caregiver distress while a younger age was associated with more distress ($t = -3.39, p = .001$). One unit decrease in age was associated with 0.21 units increase in psychological distress.

In block 2, behavioural impairment and parental responsibility were significantly related to distress, resp. $t(139)=9.77 p < .001$ and $t(139) = 2.66, p = .009$. One unit increase in behavioural problems was associated with .34 units increase in distress. Having family responsibilities increased distress with 4.23 units. Functional impairment, employment status, and education showed non-significant results. The model added a significant amount of variance ($F(4,139) = 26.03, p < .001$), and explained 44% of the variance in psychological distress. In block 3 no significant associations with caregiver distress were found for the interaction of gender with each demand variable. Male and female caregivers did not report different levels of distress when confronted with functional or behavioural impairments, work or caring for young children. After the inclusion of the interaction variables only the relation of behavioural problems with caregiver distress remained intact. The full model did not show a significant change in variance.

Discussion

This study investigated demand factors related to psychological distress of caregivers of patients with ALS or PMA, based on the demand-control model. Results showed that behavioral changes in the patients and having children under the age of 18 were related to increased feelings of distress. However, no associations were detected for demands due to

functional impairment of the patient and paid employment on distress. Levels of reported distress were also not different for female caregivers compared to male caregivers.

The association between neurobehavioural symptoms of the patient and distress of the caregiver is in line with research outcome in the last decade (Chiò et al., 2010; Lillo et al., 2012). Several studies found especially problems related to apathy and executive dysfunctioning linked to caregiver distress (Chiò et al., 2010; Goldstein & Abrahams, 2013). It can cause a patient's behaviour to become unpredictable, irrational and difficult to manage. The care situation changes into a high demand and low control environment, and as such fits into the framework of the demand-control model. That the neuropsychiatric symptoms were indeed related to caregiver's distress in this study is no proof for, but does add to, the credibility of the model.

Hypothesised was that an increase in demand care due to the physical impairment of the patient would also lead to increased caregiver distress (de Wit et al., 2017; Pagnini et al., 2010). However, in the current study no association between care demands and caregiver distress was found. A possible explanation for this outcome is that all patients in the current study are being supported by multidisciplinary ALS teams, who can assist and advice on specialised care for problems arising due to the functional impairments. This may contribute to keeping demands manageable and thus keep stress levels within a healthy range (Brulletti et al., 2015; Larsson, Fröjd, Nordin, & Nygren, 2015). Support from the ALS team may also increase confidence in handling future medical or physical problems. Studies specific on degree of confidence and caregiver distress did find that a caregiver's confidence in one's ability to deal appropriately with illness related matters was associated with feelings of anxiety and depressive symptoms (Kershaw et al., 2015).

The factor work was not related to caregiver distress. Hypothesized was that the demands from work and caregiving would cause the caregiver to feel sandwiched between

these two roles (DePasquale et al., 2017; Qutub et al., 2014). However, this was not supported by the data. A possible alternative explanation could be that work may act as a buffer against distress, giving the caregiver time off from caring and prevent the building up of stress over time (Chambers, Ryan, & Connor, 2001). The current study did not find evidence for a buffering effect, which may be due to the fact that no distinction was made in the number of hours caregivers spent at work. A study among 11.000 Norwegian caregivers, in which caregivers with a fulltime employment reported less stress than caregivers who worked part-time, supports this need for further meticulous research into the relationship between work and caregiver's distress (Hansen & Slagsvold, 2015).

Having the responsibility for young children was related to higher levels of distress compared to the caregivers who did not have parental responsibilities, as was hypothesized based on the limited research available (Olsson Ozanne et al., 2012). The current study did not look into the distinct aspects of caregiving and parenting that might give rise to distress. Next step would be to identify what is causing the higher levels of distress. Two suggested aspects needing more research are time- and energy depletion and worry. Both aspects are linked to caregiving distress, although not in the parental-caregiving context. Recent studies on the impact of ALS in the family on children found these youngsters at risk of developing anxiety, depressive symptoms and internalizing problems (Calvo et al., 2015). Worrying about the impact of the disease on a child or having a child with emotional problems will undoubtedly affect the parent's state of mind. Larger samples with families with young children are needed to identify the factors that give rise to feelings of distress in these caregivers. Nevertheless, the results do support the importance of screening caregivers with young children for psychological distress.

Data provided no evidence that gender influenced the association between demand factors and caregiver distress in this study, in contrast to observed significances, although

small, in previous studies (Pinquart & Sörensen, 2006). Findings suggest that maybe other caregiver specific factors are responsible for the difference in experienced caregiving distress. A recent study on caregiver distress and gender proposed factors such as premorbid personality, social support and coping style as influencers of caregiver burden (Burke et al., 2017). Both a passive coping style and perceived quality of support have been found to be negatively associated with caregiving distress in previous studies (Gysels & Higginson, 2009; Creemers et al., 2015).

There are a number of limitations to the current study. First of all, the study examined demand-factors of the caregiving situation and not the control-factors. Control is one of the main influencing variables of psychological distress in Karasek's Demand & Control model. Whether or not the caregiver believed he or she was capable of dealing with physical or neuropsychiatric problems of the patient and felt a sense of control may have influenced anxiety or depressive moods. Furthermore, the study is limited in the small sample size of families with young children ($n = 20$) which may have affected the analysis with respect to the parental role. Another limitation is that caregiver distress was measured using the HADS. The HADS screens for the current presence of symptoms of anxiety and depression, but makes no distinction between symptoms present prior to disease onset and those caused by caregiving situation (Julian, 2011). If the caregiver was already experiencing heightened levels of psychological distress prior to disease onset then it may have affected the results. Finally, it should be noted that the study was cross-sectional and therefore a causal relationship between demand factors and distress can only be assumed. A study design over time may produce more information on the impact of patient and caregiver demand factors on caregiving distress.

This study provides supportive evidence that neurobehavioural impairments and having young children are associated with higher levels of distress in informal caregivers of

patients with ALS or PMA. The increased levels of distress for caregivers with parental responsibilities are of particular concern. If the caregiver becomes overwhelmed by caregiving tasks, it is not just the patient that is at risk, but the care and wellbeing of young children as well. Knowledge from studies as these give health worker information to identify the caregivers that are at risk. As caregivers will not readily ask help for themselves, early and pro-active identification of caregivers at risk will be essential in the provision of good care for caregivers. Furthermore, current support for caregivers is largely focussed on dealing with functional impairments and emotional impact, not with handling difficult patient behaviour or dealing with ALS and young children. The associations found in this research emphasize the importance of offering additional support for coping with these demanding care situations.

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Table 1

Characteristics of informal caregivers of patients with Amyotrophic Lateral Sclerosis or Progressive Muscular Atrophy (N = 148)

Characteristic	<i>n</i>	Mean (SD)	[range]
Gender Caregiver			
Women	96		
Men	52		
Age Caregiver (years)		61.5 (\pm 10.2)	32-85
70 - 85	33		
60 - 69	56		
50 - 59	42		
30 - 49	17		
Family compilation			
Children < 18	20		
Children > 18	116		
No children	17		
Employment status			
(Self)employed	59		
Retired	63		
Unemployed	26		
Education level			
Low	63		
Intermediate	35		
High	50		
Gender patient			
Women	52		
Men	96		
Age patient (years)		62.6 (\pm 9.9)	35 - 80
70-80	41		
60-69	58		
50-59	32		
30-49	17		
Diagnosis			
ALS	106		
PMA	42		
First symptoms area			
Bulbar onset	32		
Upper limb onset	56		
Lower limb onset	55		
Trunk onset	5		
Time since diagnosis			
< 1 Year	52		

1 - 2 Years	32		
2 - 3 Years	23		
3 - 4 Years	15		
> 4 Years	26		
ALS-FRS-R (score)		31.4 (\pm 9.6)	5 - 47
48 - 25 (mild to moderate physical disabilities)	113		
24 - 0 (severe to very severe physical disabilities)	35		
ALS FTD-Q (score)		16.8 (\pm 12.9)	0 - 60
\geq 22 moderate to severe symptoms	45		
HADS (score)		11.1 (\pm 7.1)	0 - 31
HADS total score \geq 12	69		

Note. *SD* = Standard Deviation. ALS = Amyotrophic lateral sclerosis. PMA = progressive muscular atrophy. ALS-FRS-R = amyotrophic lateral sclerosis-functional rating scale-revised. ALS-FTD-Q = amyotrophic lateral sclerosis-frontotemporal dementia questionnaire. HADS = Hospital Anxiety and Depression Scale.

Table 2

Hierarchical regression analysis examining the association of demand factors with psychological distress of informal caregivers (N = 148)

Psychological distress				
	<i>b</i>	β	95% CI	Adj. <i>R</i> ²
Block 1				.06*
Age	-0.21**	-0.29	[-0.32, -0.08]	
Gender	-0.61	-0.04	[-3.05, 1.83]	
Education (low)	0.09	0.01	[-2.96, 3.14]	
Education (high)	-0.71	-0.05	[-3.77, 2.36]	
Block 2				.44***
Age	-0.11	-0.15	[-0.24, 0.02]	
Gender	-0.73	-0.05	[-2.63, 1.16]	
Education (low)	0.98	0.07	[-1.39, 3.36]	
Education (high)	-0.22	-0.02	[-2.58, 2.14]	
Functional impairment	0.00	0.05	[-0.09, 0.10]	
Behavioural impairment	0.34***	0.61	[0.27, 0.41]	
Parental responsibility	4.23**	0.20	[1.08, 7.38]	
Work	0.91	0.06	[-1.37, 3.19]	
Block 3				.45
Age	-0.11	-0.16	[-0.25, 0.02]	
Gender	-0.85	-0.06	[-3.22, 1.52]	
Education (low)	1.23	0.09	[-1.15, 3.62]	
Education (high)	0.03	0.00	[-2.34, 2.41]	
Functional impairment	-0.15	-0.20	[-0.33, 0.04]	
Behavioural impairment	0.36***	0.64	[0.24, 0.48]	
Family responsibility	3.41	0.16	[-1.57, 8.39]	
Work	0.84	0.06	[-2.89, 4.56]	
Functional impairment x gender	0.21	0.23	[-0.01, 0.42]	
Behavioural impairment x gender	-0.04	-0.06	[-0.19, 0.12]	
Family responsibility x gender	1.06	0.04	[-4.98, 7.10]	
Work x gender	0.03	0.00	[-4.08, 4.14]	

Note. CI = confidence interval. **p* < 0.05, ***p* < 0.01, ****p* < 0.001