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The mediating role of illness cognitions in the relationship between caregiving demands and  
caregivers' psychological adjustment

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## Abstract

**Objectives:** The present study investigated whether illness cognitions mediated the relationship between caregiving demands and positive and negative indicators of adjustment in partners of patients with chronic pain.

**Methods:** The sample of this cross-sectional study consisted of 151 partners (mean age = 61.4, SD = 13.6 years, 57% male) of patients with chronic pain (e.g. back pain). The study was conducted in the Pain Centre of the University Medical Centre Groningen, The Netherlands during November 2014 to June 2015. Participants completed questionnaires that assessed caregiving demands, illness cognitions, perceived burden, distress, positive affect, and life satisfaction.

**Results:** The findings showed that among illness cognitions, acceptance of the illness mediated the association between caregiving demands and burden ( $b = .16$ , CI: .05 to .28) and positive affect ( $b = -.21$ , CI: -.41 to -.06). Helplessness mediated the association between caregiving demands and burden ( $b = .46$ , CI: .26 to .69) and distress ( $b = .35$ , CI: .19 to .53). Perceived benefits did not mediate any of these associations. The findings indicate that partners who experience more demands tend to appraise the consequences of the patients' pain condition more negatively, which in turn is associated with their emotional adjustment.

**Discussion:** The results suggest that illness cognitions play an important role in the psychological adjustment of partners. Enhancing acceptance of the illness and reducing feelings of helplessness could form the basis of interventions aiming at promoting psychological adjustment in partners, especially when it is difficult to reduce the demands.

**Key words:** Illness cognitions, caregiving demands, partners, chronic pain, psychological adjustment

## Introduction

Chronic pain has a considerable impact on the lives of both patients and partners.<sup>1-3</sup> Partners who have to fulfill the unexpected role of caregiver of a patient with chronic pain are confronted with challenging demands, such as providing assistance with daily tasks and emotional support, that can influence one's well-being (i.e., greater burden and distress).<sup>2,4-</sup>

<sup>8</sup> Evidence suggests that individuals' unique perceptions of the personal meaning of the illness-caregiving situation are more important in explaining physical and mental health of caregivers than the amount of care and tasks provided.<sup>9</sup> For example, our previous findings suggests that caregivers' perception of injustice mediates the association between caregiving demands and burden.<sup>2</sup> This study, based on the same sample, focuses on whether caregiving demands are associated with partners' psychological adjustment as a result of their negative and positive cognitions related to the patients' pain, namely helplessness, acceptance, and perceived benefits. Empirical evidence on the potential mediator role of partners' illness cognitions is relevant for understanding why specific stressors (e.g., caregiving demands) have a negative effect on partners' psychological adjustment. Insight into partners' illness cognitions may offer some prospects for interventions beyond stressors of the caregiving condition, because most of these stressors, such as demands of a caring role, can be changed only to a limited degree.

Partners might shape cognitions regarding the consequences of patients' pain as a result of the prolonged stressful experience of caregiving and associated demands.<sup>10</sup> Particularly, caregiving demands might foster negative illness cognitions in partners, such as the notion that the patient's pain controls their life and positive cognitions such as learning to accept the limitations imposed by the patient's pain.<sup>10</sup> An ability to find meaning through

positive appraisals (e.g., acceptance and perceived benefits) may act as a coping mechanism, where partners feel a sense of pride and purpose in their caregiving roles, which in turn might contribute to better psychological adjustment.

The role of cognitive appraisals and coping in the adjustment process among chronic pain patients is well documented.<sup>11</sup> However, research in the area of stress processing as a coping mechanism among partners of patients with chronic pain is limited. Particularly, it is unknown how partners' illness cognitions (e.g., acceptance of patients' limiting condition) would affect their adjustment. Yet, there is some evidence from studies in other caregiving contexts that partners' illness cognitions are significantly associated with their adjustment. Notably, the partners of patients with cardiac disease who reported more helplessness beliefs experienced higher levels of anxiety and depressive symptoms.<sup>12</sup> Similarly, in parents of children with cancer, beliefs of helplessness and low acceptance were associated with worse psychological adjustment.<sup>13,14</sup> While previous research provides some evidence that there is a link between illness cognitions and caregivers' adjustment, it is not yet clear whether partners' illness cognitions can mediate the association between caregiving demands and negative and positive psychological adjustment in partners of patients with chronic pain.

Therefore, this paper aims to investigate the role of partners' illness cognitions in the relation between caregiving demands and both positive and negative indicators of adjustment in partners of patients with chronic pain. In sum, this study hypothesized that partners with more caregiving demands who tend to assign more negative meanings to patients' pain (i.e., more helplessness and less acceptance and perceived benefit), might experience more burden and distress, and less life satisfaction and positive affect.

## Method

### Procedures

The data used in this study is part of a larger study focusing on family caregivers of patients with chronic pain.<sup>2</sup> The study was approved by the Medical Ethical Committee of the University Medical Center Groningen (code: M14.159557). Participants were recruited between November 2014 and June 2015. The inclusion criteria for participants were as follows: being a family caregiver of a patient with chronic pain, being older than 18 years of age, having adequate literacy to fill out the questionnaires. All participants provided written informed consent. This cross-sectional study was conducted in collaboration with the Pain Centre of the University Medical Centre Groningen. The data used in this study was collected in-person and by mail. In in-person data collection (November 2014 to February 2015), family caregivers who accompanied patients to the Pain Centre were invited personally to participate in the study or patients who arrived at the Pain Centre without their family caregivers were asked to invite their family caregivers to participate in the study. In both situations, the researcher provided an information letter for the family caregiver, a consent form, a questionnaire, and a pre-stamped envelope. To facilitate the data collection, during the period from February 2015 to June 2015, envelopes containing the same materials as described above along with a letter explaining the study were posted to the home addresses of the patients who had an appointment at the Pain Centre. Patients were asked to invite their family caregiver to participate in this study. For the present paper, we selected partners of patients with chronic pain in order to focus on a more homogenous group.

## **Measures**

### **Socio-demographic characteristics**

Participants were asked to provide information on their age, gender, education, marital status, and occupation. Partners also provided some demographic information about the patient, including age, gender, and pain location. In addition, partners were asked to indicate their perception of the patient's and their own current health level (0 = The worst imaginable health condition to 10 = The best imaginable health condition) and the current pain intensity of the patient (0 = No pain at all to 10 = The worst imaginable pain).

### **Caregiving demands**

The 38-item Dutch Objective Burden Inventory<sup>15</sup> was used to measure the partners' care activities in the past three months, including personal care (e.g., helping with eating and drinking), practical care (e.g., buying groceries), motivational care (e.g., motivating to quit or reduce smoking), and emotional care (e.g., showing understanding). A higher average score (1 = Never to 3 = Always) indicates more caregiving demands. In the current study, the Cronbach's alpha for this scale was .89.

### **Illness cognitions**

Cognitions concerning the patient's pain were assessed with the Dutch version of the Illness Cognition Questionnaire (ICQ).<sup>10</sup> The wording of its questions was slightly modified to assess partners' cognitions about pain. This instrument contains 18 statements and three subscales: Helplessness (i.e., focusing on the negative consequences of the pain; e.g., "Because of my partner's condition, I miss the things I like the most."), Acceptance (i.e.,

acknowledging the pain and perceiving the ability to manage the negative consequences of the pain; e.g., “I can handle the problems related to my partner’s condition.” Or “I have learned to accept the limitations imposed by my partner’s pain”), and Disease Benefits (i.e., perceiving positive consequences of the pain; e.g., “My partner’s condition has taught me to enjoy the moment more.”). Participants were asked to what degree they agree with the statements: 1 (not at all), 2 (somewhat), 3 (to a large extent), or 4 (completely). Higher mean scores indicate a higher level of helplessness, acceptance, and perceived benefits. In the present study, the Cronbach’s alphas for the helplessness, acceptance, and perceived benefits subscales of the illness cognition questionnaire were .79, .90, and .87, respectively.

### **Burden**

The 12-item version of the Zarit Burden Interview <sup>16</sup> was used to assess partners’ perceived burden. An example item is “Do you feel that your social life has suffered because you are caring for your relative?” (0 = Never to 4 = Nearly Always). A higher average score indicates a higher level of burden. In the current study, this scale showed good internal consistency (Cronbach’s alpha = .89).

### **Distress**

To assess distress, participants were asked to complete the 21-item version of the Depression, Anxiety, and Stress Scale (DASS-21; Lovibond & Lovibond, 1995). Examples are “I couldn’t seem to experience any positive feeling at all”, “I was worried about situations in which I might panic and make a fool of myself”, and “I found it hard to wind down” (1 = Never to 3 = Always). Higher mean scores indicate a higher level of distress. In the current study, the Cronbach’s alpha for the DASS-21 was .94.

### **Positive Affect**

Positive affect was measured using the positive affect subscale of the PANAS. Positive affect reflects the extent one feels enthusiastic, active, and full of energy. The subscale includes 10 adjectives rated according to the extent that they are felt during the last week.<sup>18</sup> All items were scored using a 5-point scale (1-5). The higher score indicates a more positive affect. In the present study, the Cronbach's alpha for the positive affect subscale of the PANAS was .91.

### **Life satisfaction**

The five-item Satisfaction with Life Scale (SWLS)<sup>19</sup> was used to assess the participant's global judgment of life satisfaction. Items were rated on a seven-point scale (1=strongly disagree to 7=strongly agree). Higher mean scores indicate a greater life satisfaction. This scale showed good internal consistency in the current study (Cronbach's alpha = .86).

### **Statistical analyses**

Analyses were conducted with IBM SPSS version 23. Pearson correlations were used to examine associations between caregiving demands, illness cognitions, and positive and negative psychological adjustment (i.e., burden, distress, life satisfaction, and positive affect). The demographic variables that showed a significant correlation with the main variable in each mediation model were controlled in the analyses.

In order to test whether illness cognitions mediate the relationships between caregiving demands and caregivers' psychological adjustment as hypothesized, a series of multiple parallel mediation analyses were conducted using the PROCESS macro 3.0, model 4.<sup>20</sup> Mediation occurs if the indirect effect (i.e., the relationship between the predictor and

outcome variable via the mediator) is significant. The significance of the indirect effect was examined using bootstrap estimations for 5000 samples and 95% confidence intervals based on Preacher and Hayes recommendations.<sup>21</sup> An indirect effect is significant when the confidence interval does not cross zero. The following variables were used for the parallel mediation analyses, X = caregiver demands, M = illness cognitions (M1 = acceptance, M2 = helplessness, M3 = perceived benefits). See Figures 1 to 2 for a depiction of mediation models.

## Results

### Descriptive information

Among participants who received the questionnaires by mail, the response rate was 45%, and the response rate was 78% among those who were approached at the pain clinic. The sample included 151 romantic partners of patients with chronic pain, of which 88% were married or registered as partners. Most of the partners (98%, n = 148) were living with the patients. All participants were Dutch. The mean age of partners was 61.4 (SD = 13.6) years, 57% of partners were male (n = 86). Most partners were retired (33.1%, n = 50) or had a full time (28.5%, n = 43) or part-time job (16.6 %, n = 25). In terms of education, 54.3% of partners listed secondary or higher vocational education as their highest level of education, while 27.8% reported having a high school degree.

The average health level of partners measured with a visual analogue scale was 7.3 (SD = 1.5). The mean age of patients was 61.88 (SD = 12.39). Based on the reports of partners, 41.7% of the patients were male (n = 63) and 55.6% were female (n = 84). Fifty-four patients (35.8%) had multiple pain locations, 15.2% (n=23) had back pain, 9.3% (n = 14) had pain in knee and legs, 8.6% (n = 13) had pain in shoulder and neck, and 35.8% (n = 54)

had pain in other locations. The average pain intensity and the average health level of patients measured with a visual analogue scale based on partners' reports were respectively 6.12 (SD = 2.09) and 4.94 (SD = 1.55).

### **Correlation analysis**

The analyses revealed a significant correlation between patients' health level and caregiving demands ( $r = -.21^{**}$ ;  $p < 0.01$ ). No significant correlation was found between patients' pain intensity and the main variables in the study. There were also no significant correlations between demographic variables (i.e., patients' and partners' age, patients' and partners' gender) and the main variables in the study. However, the variables measuring positive and negative psychological adjustment (i.e., burden, distress, life satisfaction, and positive affect) were correlated. Therefore, we controlled for these variables in the mediation analysis in which they were not the outcome variable. Table 1 presents the correlation coefficients between the caregiving demands, illness cognitions, and psychological adjustment indicators in the study.

## **Investigating the mediating role of illness cognitions in the link between caregiving demands and caregivers' psychological adjustment**

**Burden as an outcome.** The results of the mediation analysis presented in Table 2 showed that the total effect of caregiving demands on burden was significant (Path c,  $b = 1.38$ ,  $p < .0001$ ). In addition, the direct effect of caregiving demands on burden when controlling for acceptance, helplessness, and perceived benefits was also significant (Path c',  $b = .75$ ,  $p < .0001$ ). The results revealed that the indirect effect (i.e.,  $a*b$ ) was significant for acceptance ( $b = .16$ , 95% BC CI: .05 to .28 with 5000 resamples), and helplessness ( $b = .46$ , 95% BC CI: .26 to .69 with 5000 resamples), which indicates that acceptance and helplessness significantly mediated the link between caregiving demands and burden, while controlling for distress, positive affect, and life satisfaction (see Figure 1).

**Distress as an outcome.** The mediation analysis showed that the total effect of caregiving demands on distress was significant (Path c,  $b = .62$ ,  $p < .0001$ ). However, the direct effect of caregiving demands on distress was not significant while controlling for acceptance, helplessness, and perceived benefits. Results revealed that the relationship between caregiving demands and distress was mediated only by helplessness (Path  $a_2b_2$ ,  $b = .35$ , 95% BC CI: .19 to .53 with 5000 resamples). This model is detailed in Table 2 and Figure 1.

**Positive affect as an outcome.** The mediation analysis showed that the total effect of caregiving demands on positive affect was not significant. In addition, the direct effect of caregiving demands on positive affect when controlling for acceptance, helplessness, and perceived benefits was also not significant. The results revealed that the indirect effect (i.e.,  $a*b$ ) was significant for acceptance ( $b = -.21$ , 95% BC CI: -.41 to -.06 with 5000 resamples),

which indicates that acceptance significantly mediated the link between caregiving demands and positive affect after controlling for burden, distress, and life satisfaction. This model is detailed in Table 3 and Figure 2.

**Life satisfaction as an outcome.** The total effect of caregiving demands on life satisfaction was not significant, and the direct effect did not reach statistical significance. In addition, the indirect effects (i.e.,  $a*b$ ) were also not significant, indicating no significant mediating effect of acceptance, helplessness, and perceived benefits, while controlling for burden, distress, and positive affect. This model is detailed in Table 3 and Figure 2.

## Discussion

This study investigated the relationship between caregiving demands and both positive (i.e., positive affect and life satisfaction) and negative psychological adjustment (i.e., burden and distress) in partners of patients with chronic pain and tested whether illness cognitions (i.e., acceptance, helplessness, and perceived benefits) mediated these relationships.

Consistent with previous research, caregiving demands were positively associated with burden and distress.<sup>2,22,23</sup> This study provides an important extension of previous research by showing that illness cognitions (i.e., acceptance and helplessness) represent a pathway through which caregiving demands are related to burden and distress. That is, partners who report more demands tend to appraise the patient's condition more negatively, and therefore might experience more burden and distress. These findings are in line with the stress-coping model, which indicates that the way individuals perceive and think about patients' pain impacts their psychological adjustment<sup>24</sup>. The findings of the current study also showed that acceptance mediated the relationship between caregiving

demands and positive affect, **while controlling for burden, distress, and life satisfaction**.

Notably, acceptance turned out to be an important construct as it mediated the relationship between caregiving demands and both burden and positive affect. Previous studies also suggest that lower acceptance is associated with more health anxiety in parents of children with cancer.<sup>14</sup> It might be that acceptance involves a reorientation of attention towards positive aspects of life, which enables partners to better adapt to demands associated with caregiving.<sup>25</sup> Yet, this finding is in contrast with findings of Karademas' study,<sup>12</sup> in which acceptance in spouses of patients with cardiovascular disease appeared to be unrelated to spouses' psychological symptoms. Further investigation of the potential impact of acceptance in the context of different illnesses is warranted.

The relationship between caregiving demands and life satisfaction was not mediated by illness cognitions. One possible explanation is that life satisfaction is a more stable and less changeable characteristic than positive affect.<sup>19,28</sup> Therefore, life satisfaction might be better predicted by one's appraisals about the world and the self than situational appraisals such as illness cognitions.

In general, the findings of this study showed that illness cognitions, especially acceptance and helplessness, are important for understanding adaptation in partners of patients with chronic pain. Our findings revealed that perceived benefits were not significantly associated with burden and distress. This lack of correlation has been reported in other studies as well.<sup>13,26</sup> However, caregiving demands were positively associated with perceived benefits, which is in accordance with the study of Pakenham et al.<sup>27</sup> This suggests that even in circumstances when partners experience benefits from the patient's pain, they

may feel burden and distress. Therefore, these findings suggest that when dealing with caregiving demands, perceived benefits might be less related to partners' adjustment compared to acceptance and helplessness. Previous studies have focused on the role of partners' negative coping styles (e.g., catastrophizing)<sup>29</sup> and partners' perceptions of their own condition<sup>2</sup> in explaining partners' adjustment. Particularly, research has indicated the mediating role of caregivers' self-perceptions (e.g., sense of mastery and perceived injustice) in the relationship between caregiving demands and caregiver outcomes<sup>2,23</sup>. Our findings add to the existing literature by suggesting that partners' cognitions about the patients' condition also play a key role in their adjustment. Improving acceptance and reducing helplessness could form the basis of an intervention aiming at promoting well-being in partners of patients with chronic pain. Intervention programs focusing on acceptance in patients with chronic pain have already been developed, and the results of these interventions are promising.<sup>30-32</sup> However, less attention has been paid to the effectiveness of such interventions in partners. That is, the existing couple-based interventions are mainly focused on educating partners to validate patients' pain or improving their way of communication.<sup>33</sup> While the effectiveness of such interventions on both patients and partners' well-being is not negligible, developing cognitive behavioral programs aimed at reducing unhelpful cognitions and enhancing positive cognitions in partners of patients with chronic pain might help partners to effectively cope with demands associated with caregiving and improve their adjustment.

The results of this study should be interpreted in light of its limitations. Given the cross-sectional design of the study, no conclusions can be drawn about causality. While the study examined illness cognitions among partners of patients with chronic pain, it did not examine other potential mediators such as social support and coping strategies<sup>7</sup>. Given that

the current study was focused on partners of patients with chronic pain, it would be of interest to investigate the role of illness cognitions in other types of caregivers.

Unfortunately, we were not able to do so owing to the small number of other types of caregivers in our sample. Also, previous research suggests that there is a flow of information between partners regarding the illness experience, which can affect both partners' adjustment. Particularly, in the context of cardiovascular disease, patients' and partners' illness cognitions were related to their partner's corresponding cognitions that in turn were associated with the partner's psychological symptoms. Furthermore, marital quality moderated the relation of each person's illness cognitions to his or her own psychological adjustment.<sup>12</sup> Therefore, future research might benefit from examining both patients' and partners' illness cognitions and investigate how each partner's understanding of the illness may contribute to developing or reforming the other partner illness cognitions. In the present study, we did not include any measures assessing the quality of relationship between partners and patients (e.g., marital quality). It is likely that partners, who have a better relationship with the patient, have more positive illness cognitions even in the presence of high caregiving demands. Strengths of this study include a relatively large sample size, and being among the first studies representing an important step forward in understanding the relationship between caregiving demands and both positive and negative psychological adjustment in partners of patients with chronic pain. Particularly, the current study is one of the few studies examining how partners' appraisals about patients' condition would affect partners' adjustment in the context of chronic pain. Further research is warranted to clarify the interplay between illness cognitions and other related factors (e.g., coping strategies) and well-being.

## **Conclusions**

Our findings suggest that illness cognitions, mainly acceptance and helplessness, are important variables that mediate the association between caregiving demands and partners' psychological adjustment. On the basis of our findings and previous research,<sup>2</sup> multiple mediator models including different cognitive factors such as perceived injustice and illness cognitions provide a more comprehensive account of the associations between caregiving demands and caregivers' psychological adjustment. That is, apart from appraisals of demands and other internal characteristics of caregivers, namely locus of control and sense of mastery, which were previously suggested in caregiving process models,<sup>7,23,34</sup> other broader appraisals (illness cognitions) should be taken into account to better explain the caregiving experience. The results of our study suggest that future interventions should focus on enhancing benign illness cognitions in partners as this may improve partners' well-being especially when reducing the demands associated with caregiving is not possible.

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Fig1. Parallel mediation model for caregiving demands, illness cognitions, and burden/distress. Note. C = total effect,  $c'$  = Direct effect, \*P < .001.

Fig 2. Parallel mediation model for caregiving demands, illness cognitions, and positive affect/life satisfaction. Note. C = total effect,  $c'$  = Direct effect, \*P < .001.

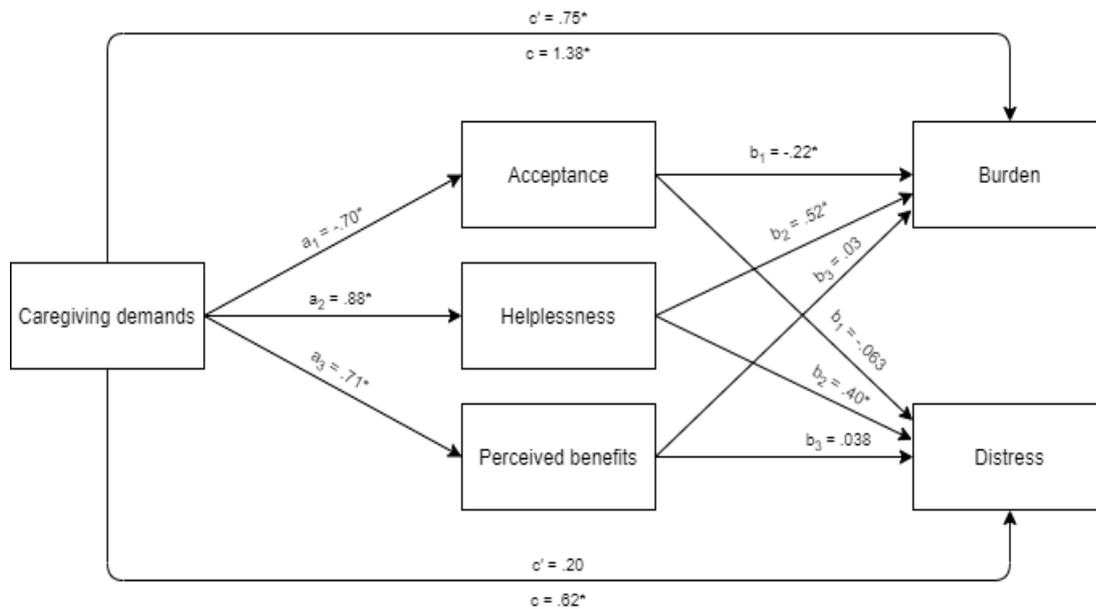


Fig1. Parallel mediation model for caregiving demands, illness cognitions and burden/distress. Note. C = total effect,  $c'$  = Direct effect,  $*P < .001$ .

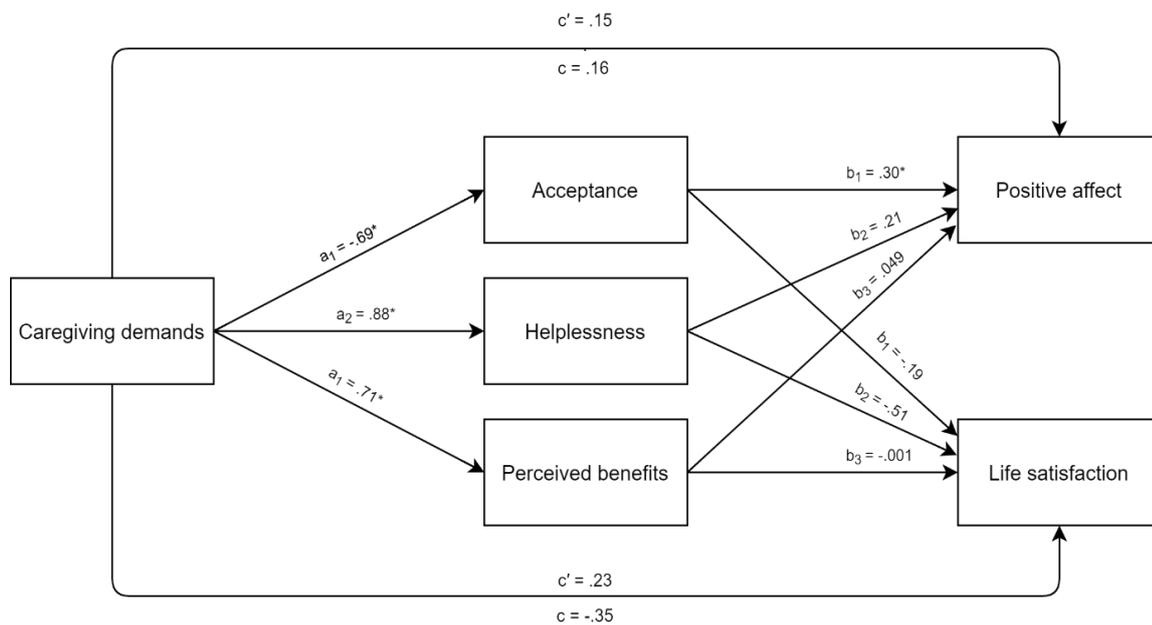


Fig 2. Parallel mediation model for caregiving demands, illness cognitions and positive affect/life satisfaction. Note. C = total effect,  $c'$  = Direct effect,  $*P < .001$ .



Table 2. Path coefficients, indirect effects, and 95% Confidence Intervals (CIs) for illness cognitions mediating the relationship between caregiving demands ~~and~~ burden, ~~and~~ /distress

	<b>Burden</b>				<b>Distress</b>			
	Coefficients	t	P-value	95% C.I.	Coefficients	t	P-value	95% C.I.
<b>Caregiving demands</b>								
<b>Total (c)</b>	1.38	9.14	<.0001	(.62, 1.26)	.62	5.57	<.0001	(.40, .85)
<b>Direct (c')<sup>i</sup></b>	.75	5.26	<.0001	(.47, 1.02)	.20	1.77	.079	(-.02, .43)
<b>Total</b>								
<b>Indirect acceptance (a<sub>1</sub>b<sub>1</sub>)</b>	.16			(.05, .28)	.044			(-.02, .11)
<b>Indirect helplessness (a<sub>2</sub>b<sub>2</sub>)</b>	.46			(.26, .69)	.35			(.19, .53)
<b>Indirect perceived benefits (a<sub>3</sub>b<sub>3</sub>)</b>	.02			(-.06, .01)	.027			(-.02, .09)

Table 3. Path coefficients, indirect effects, and 95% Confidence Intervals (CIs) for illness cognitions mediating the relationship between caregiving demands, and positive affect, and life satisfaction

	<b>Positive affect</b>				<b>Life satisfaction</b>			
	Coefficients	t	P-value	95% C.I.	Coefficients	t	P-value	95% C.I.
<b>Caregiving demands</b>								
<b>Total (c)</b>	.16	.82	.41	(-.23, .56)	-.35	-1.07	.28	(-1, .30)
<b>Direct (c')</b>	.15	.69	.49	(-.29, .61)	.23	.59	.55	(-.52, .98)
<b>Total</b>								
<b>Indirect acceptance (a<sub>1</sub>b<sub>1</sub>)</b>				(-.41, -.06)	.044			(-.02, .11)
<b>Indirect helplessness (a<sub>2</sub>b<sub>2</sub>)</b>	.18			(-.03, .50)	.35			(.19, .53)
<b>Indirect perceived benefits (a<sub>3</sub>b<sub>3</sub>)</b>	.03			(-.09, .19)	.027			(-.02, .09)