

The Impact of Caregiving in Frontotemporal dementia: Key Predictors of Burden and Emotional distress

Cinzia Bussè¹, Leonardo Giora¹, Chiara Cerami², Annachiara Cagnin³, Silvana Morson⁴

¹Padova Neuroscience Centre (PNC), University of Padova, Italy; ²ICoN - Cognitive Neuroscience Center, Scuola Universitaria Superiore IUSS, Pavia, Italy; ³ Department of Neurosciences, University of Padova, Italy; ⁴ Associazione Italiana Malattia Frontotemporale (AIMFT), Brescia, Italy

1 Introduction

This study aims to explore the level of Caregiver Burden among individuals caring for patients with Frontotemporal dementia (FTD) and to identify associated demographic, care-related, and psychological factors. The Caregiver Burden Inventory (CBI) has rarely been investigated in FTD caregivers with limited understanding of specific burden profiles.

2 Methods

Ninety-two FTD caregivers were invited to complete a survey as part of the Elisir Support Project promoted by the Italian Association for Frontotemporal Dementia (AIMFT). The survey included questionnaires assessing sociodemographic characteristics, caregiver-related variables, the Caregiver Burden Inventory (CBI), and the Depression Anxiety Stress Scale (DASS-21).

3 Results

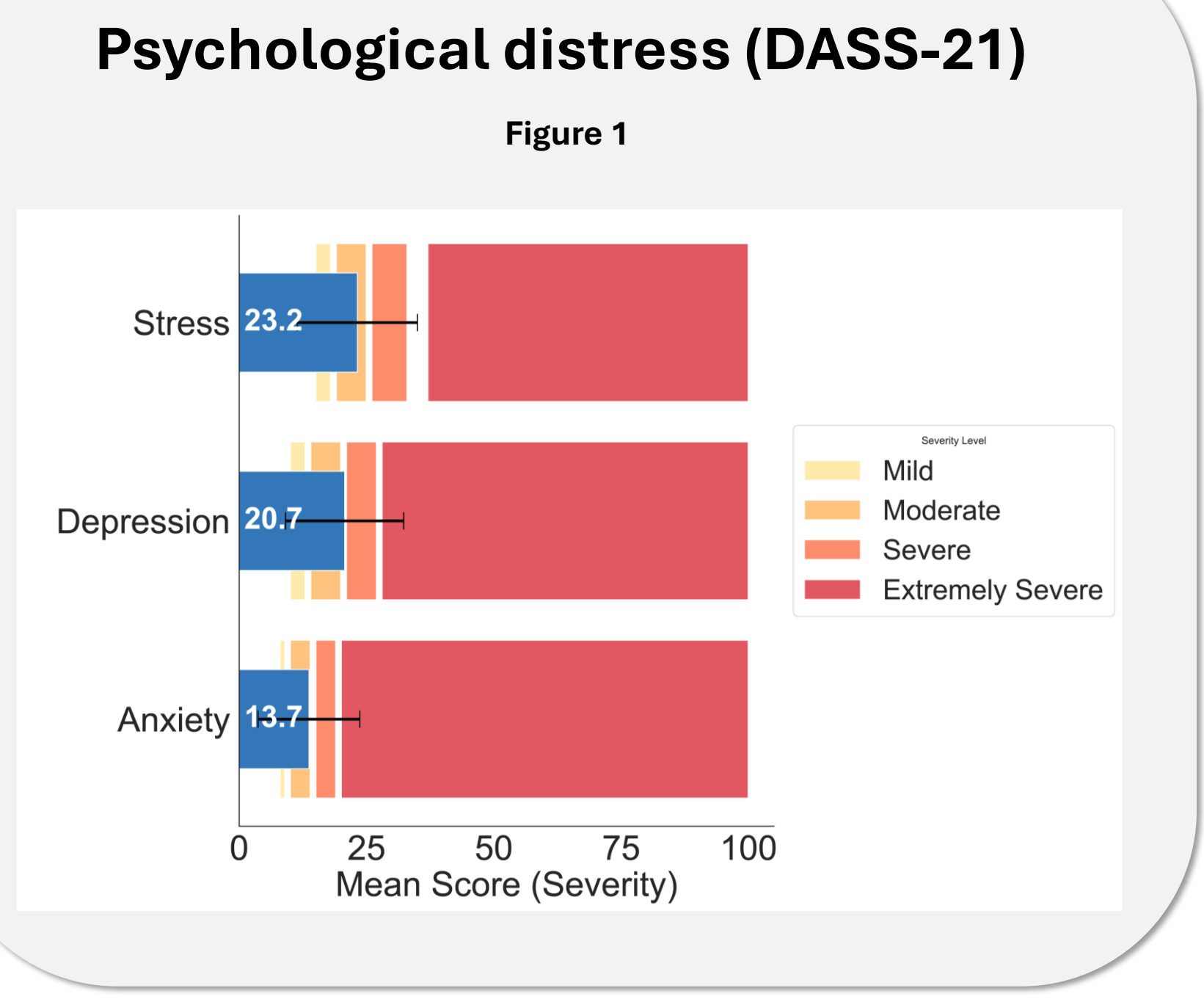
Mean caregiver age was 52.6 ± 14.9 years. Females accounted for 75%. Mean education was 14.6 ± 4.0 years. The caregiver-patient relationship included spouses (54.3%), adult children (35.9%), parents (2.2%), and siblings (3.3%) (Table 1). Regarding patient characteristics, the mean age was 65.1 ± 8.8 years. Most patients had moderate dementia (46.7%). Clinical subtypes were bvFTD (70.6%), PPA (23.9%), and other FTD-related syndromes (5.4%; including PSP, CBD, FTD-MND) (Table 2).

FTD Caregivers characteristics (N=92)
Table 1

Gender F/M (%)	69/23 (75/25)
Age (years)	52.6 ± 14.9
Education (years)	14.6 ± 4.0
Relationship Distribution (caregiver-patient)	
Spouse	54.35%
Adult child	35.87%
Parent	2.17%
Sibling	3.26%

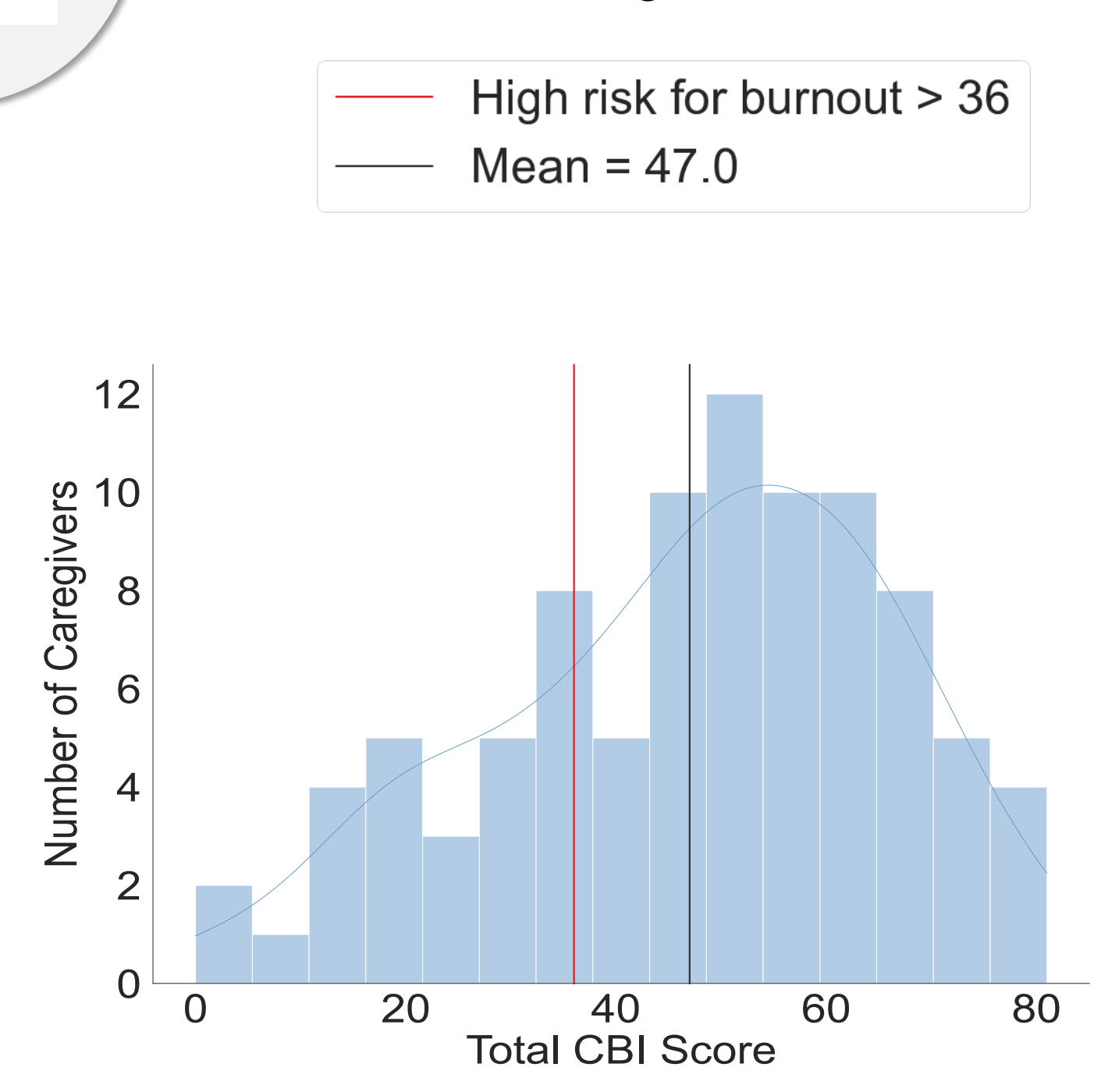
FTD Care-receivers. Demographic and clinical features
Table 2

Age (years)	65.1 ± 8.8
Dementia severity	
Mild	10 (10.9%)
Moderate	43 (46.7%)
Severe	34 (37.0%)
Clinical Subtype	
bvFTD	65 (70.6%)
PPA	22 (23.9%)
FTD-related syndromes	5 (5.4%)

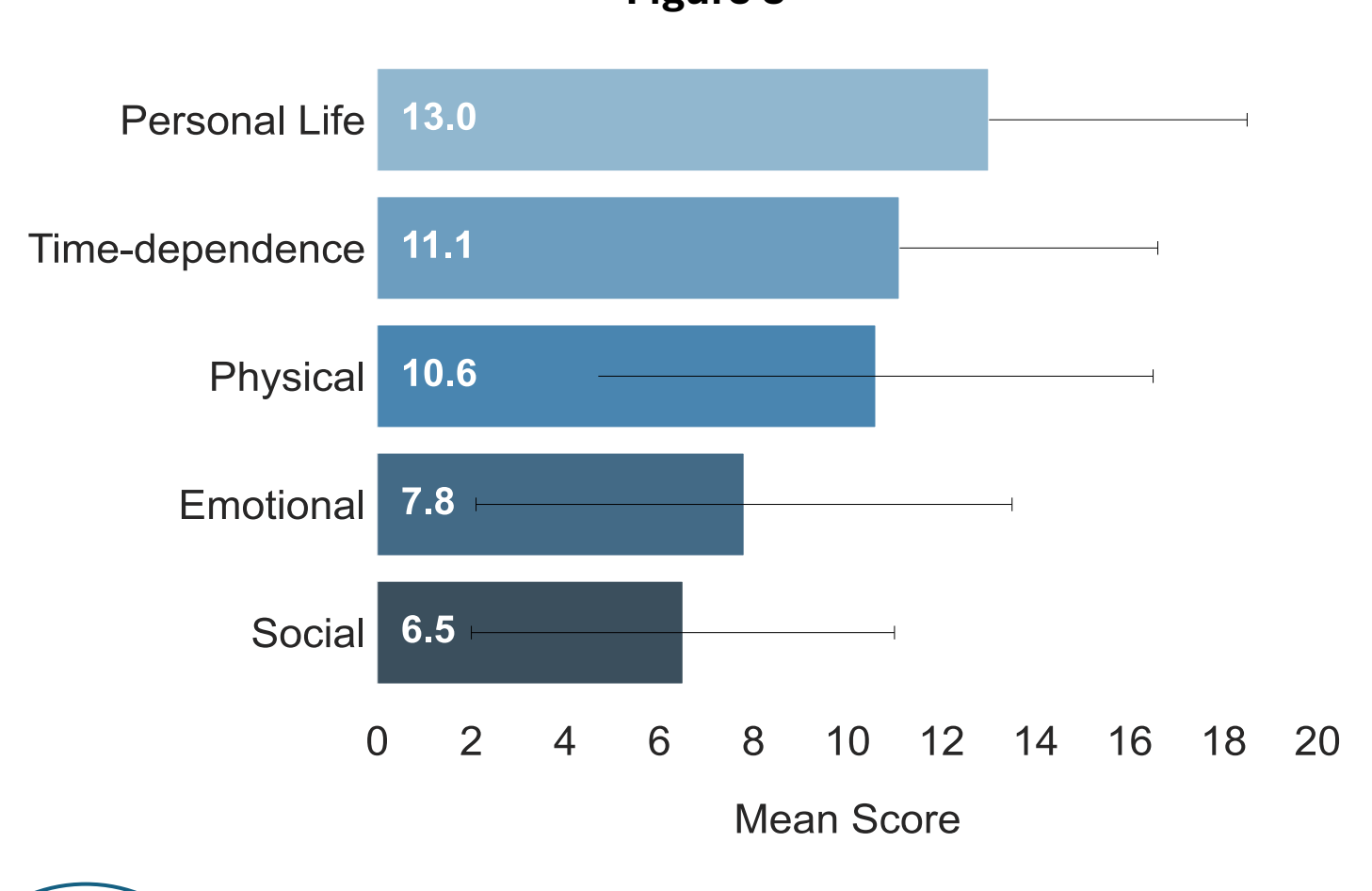


Caregivers showed clinically moderate levels of depression ($M = 20.7 \pm 11.6$), anxiety ($M = 13.7 \pm 10.0$), and stress ($M = 23.2 \pm 11.8$) (Figure 1). The mean CBI score was 47 ± 18.8 (Figure 2), indicating moderate to high burden, with the personal life domain scoring highest (13.0 ± 5.5) (Figure 3). Multiple regression confirmed that depression ($\beta = 0.51, p < 0.001$), longer caregiving time ($\beta = 0.27, p = 0.012$) and poor relationship quality ($\beta = -0.18, p = 0.027$), were the strongest predictors of total burden (Figure 4).

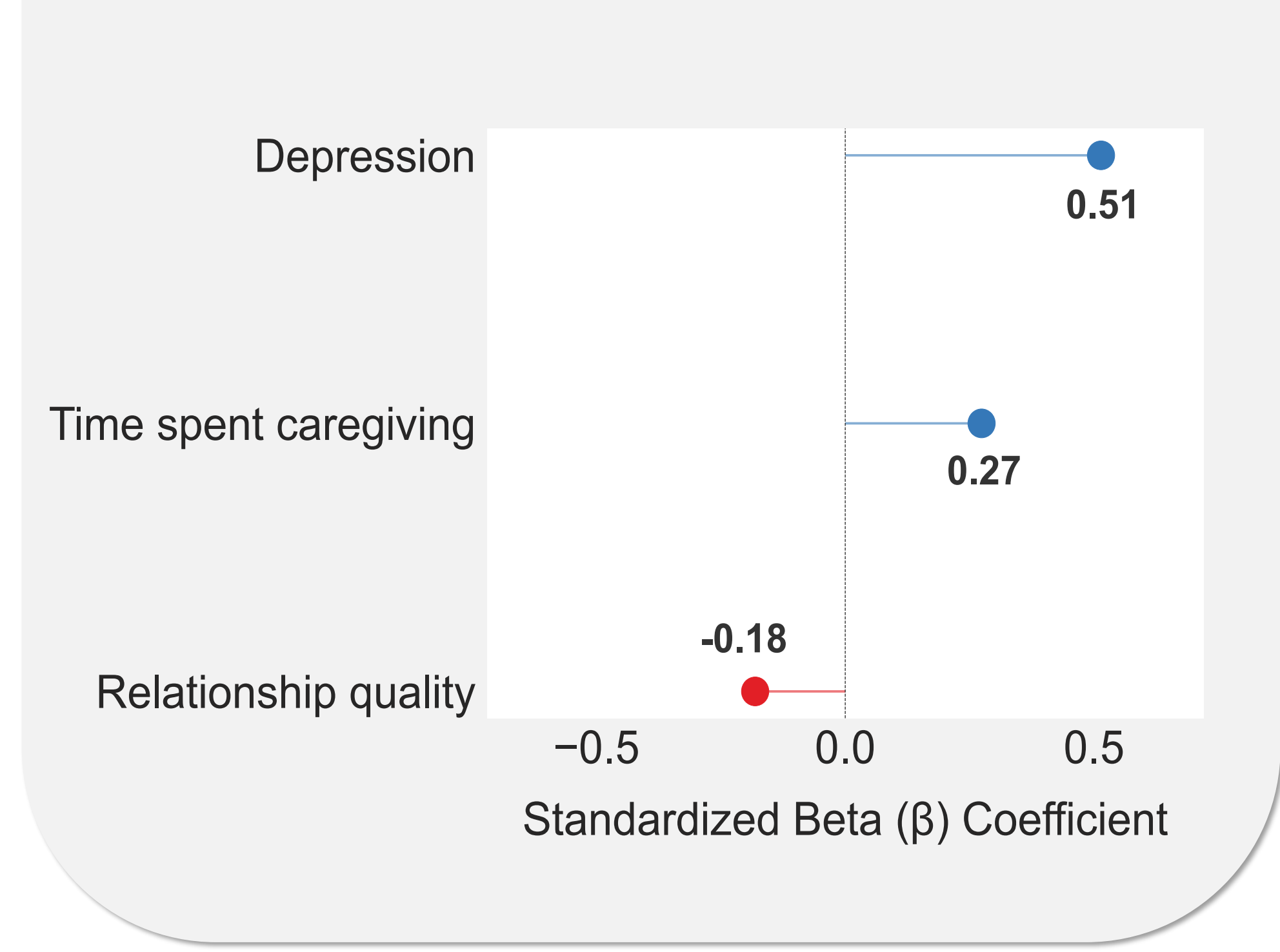
Caregiver Burden Distribution (CBI)
Figure 2



Caregiver Burden Dimensions (CBI subscales)
Figure 3



Caregiver Burden Predictors
Figure 4



4 Discussion

Caregivers of FTD patients experience significant burden, particularly in the personal life domain, reflecting disruption of life trajectory and social roles. Depression, time spent caregiving, and relational factors emerged as key predictors, highlighting the contributions of both objective demands and relationship quality.

5 Conclusion

These findings highlight the need for tailored interventions that address both the practical and emotional challenges of caregiving, with particular emphasis on psychological support for FTD caregivers.