

The burden of Parkinson's disease amongst caregivers over 4 years in Spain

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Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease and its prevalence will continue to grow as the population ages. More than one million people are diagnosed with Parkinson's disease in Europe and up to 5 million worldwide.¹ The prevalence increases with age.¹ Given the growing elderly population in Europe, this number is forecast to double by 2030.² In 2000, a national study estimated the Spanish prevalence at 1.7%.³ Most of patients are looked after by family members or friends, who subsequently experience distress and problems that impact on physical, mental, and socioeconomic aspects of their lives.⁴

Objective

To describe caregivers' Health Related Quality of Life (HRQoL), burden, anxiety and depression and their relation with patients' symptoms in Parkinson's disease (PD).

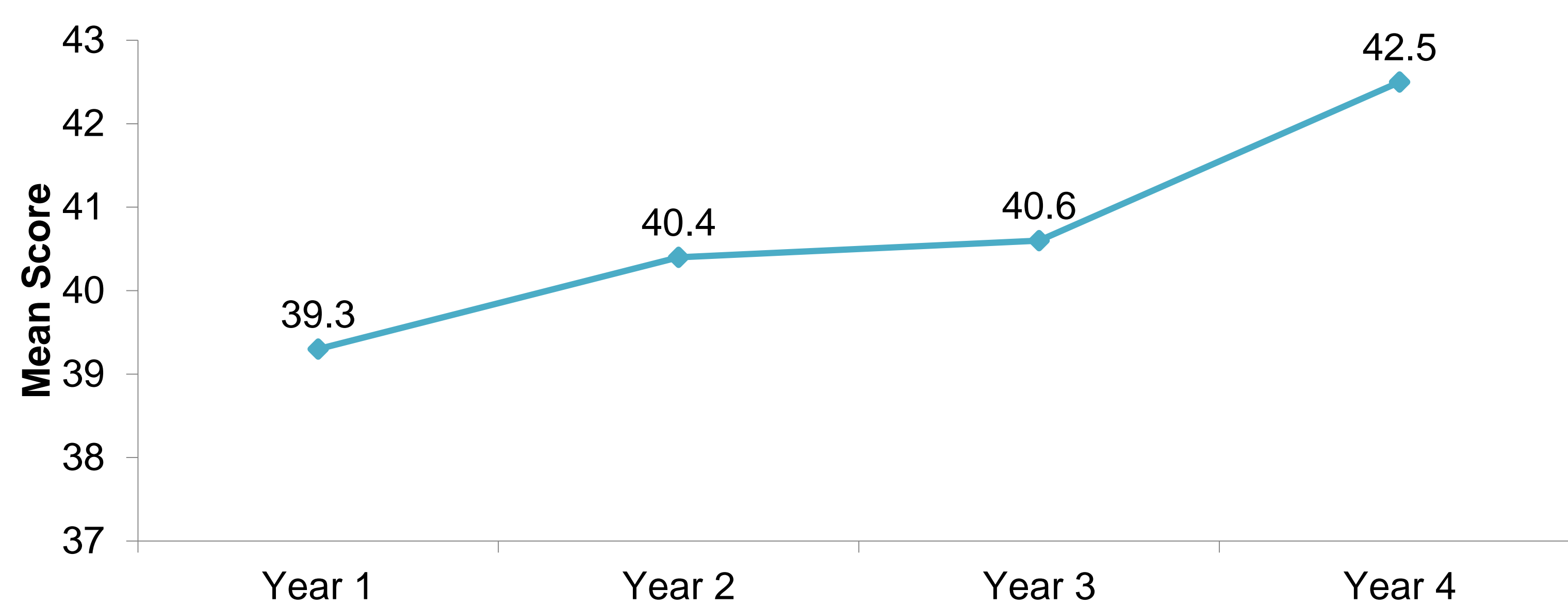
Methods

A descriptive, observational, longitudinal design in PD patients and their caregivers of ELEP study (2006-2010), in Spain. Information collected during 3 months per year for 4 years, included sociodemographic characteristics, motor symptoms (SCOPA-Motor) and HRQoL (EQ-5D: index and VAS) from PD patients and burden (Zarit's CBI), anxiety (HADS-A), depression (HADS-D) and HRQoL from their caregivers. Linear mixed models were performed to assess the relation between caregivers' burden with the patients' motor symptoms and HRQoL.

Results

- 174 PD patients, mean age: 63±11, 50% male, PD duration: 8±6 years; 173 caregivers, 66.5% female, mean number of years taking care of patients: 6±5, were included.
- Patients' SCOPA-Motor increased during follow up time, varying from 39.3±8.4 in year 1 to 42.5±9.5 in year 4 (Figure 1).

Figure 1. Patient's SCOPA-Motor Scores



- Patients' HRQoL decreased over time, demonstrated by EQ-5D index and VAS scores that changed from 0.7±0.3 and 63.7±20.3 to 0.6±0.3 and 60.3±17.9, respectively (Figure 2 and Figure 3).

Figure 2. Patient's EQ-5D Index

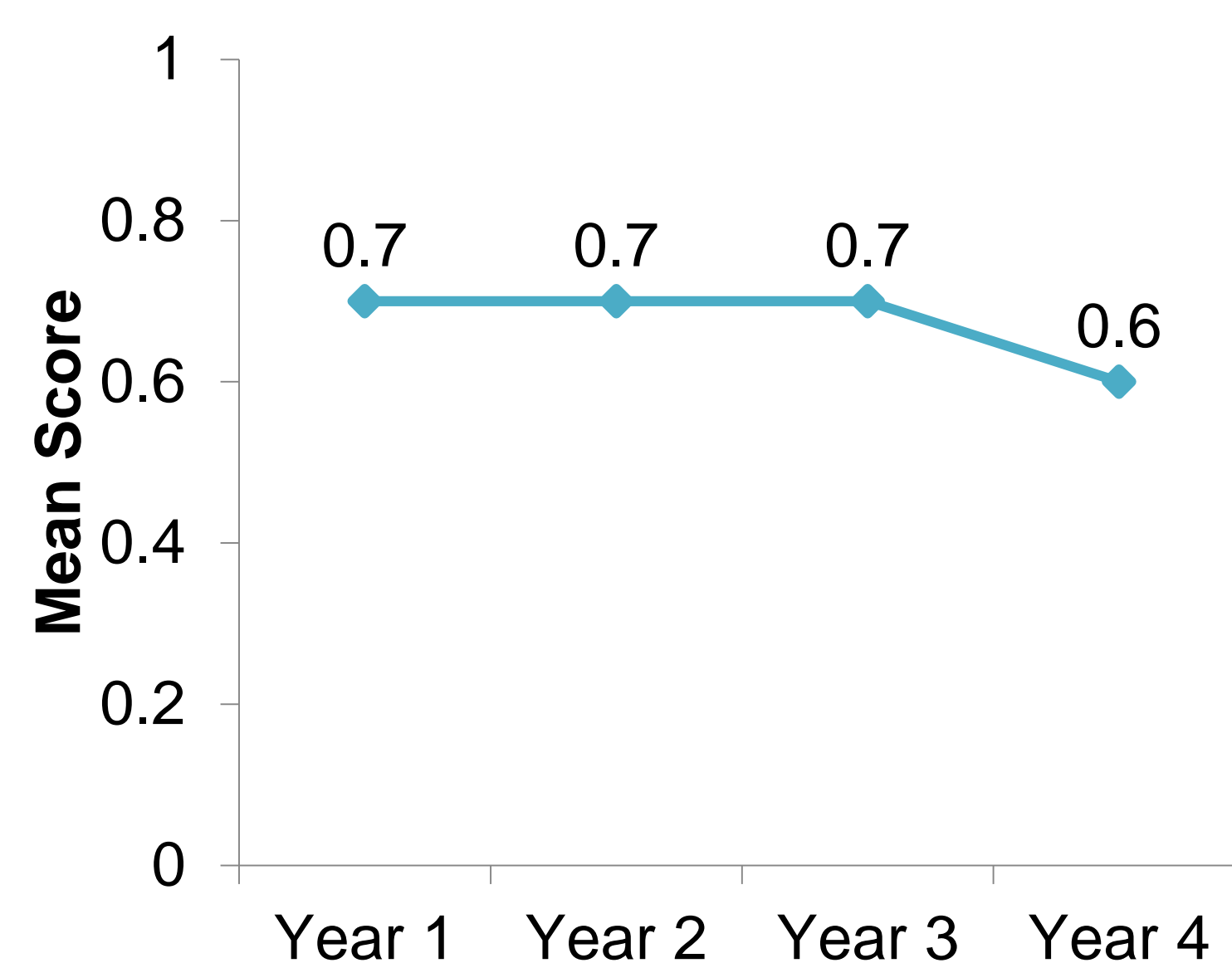
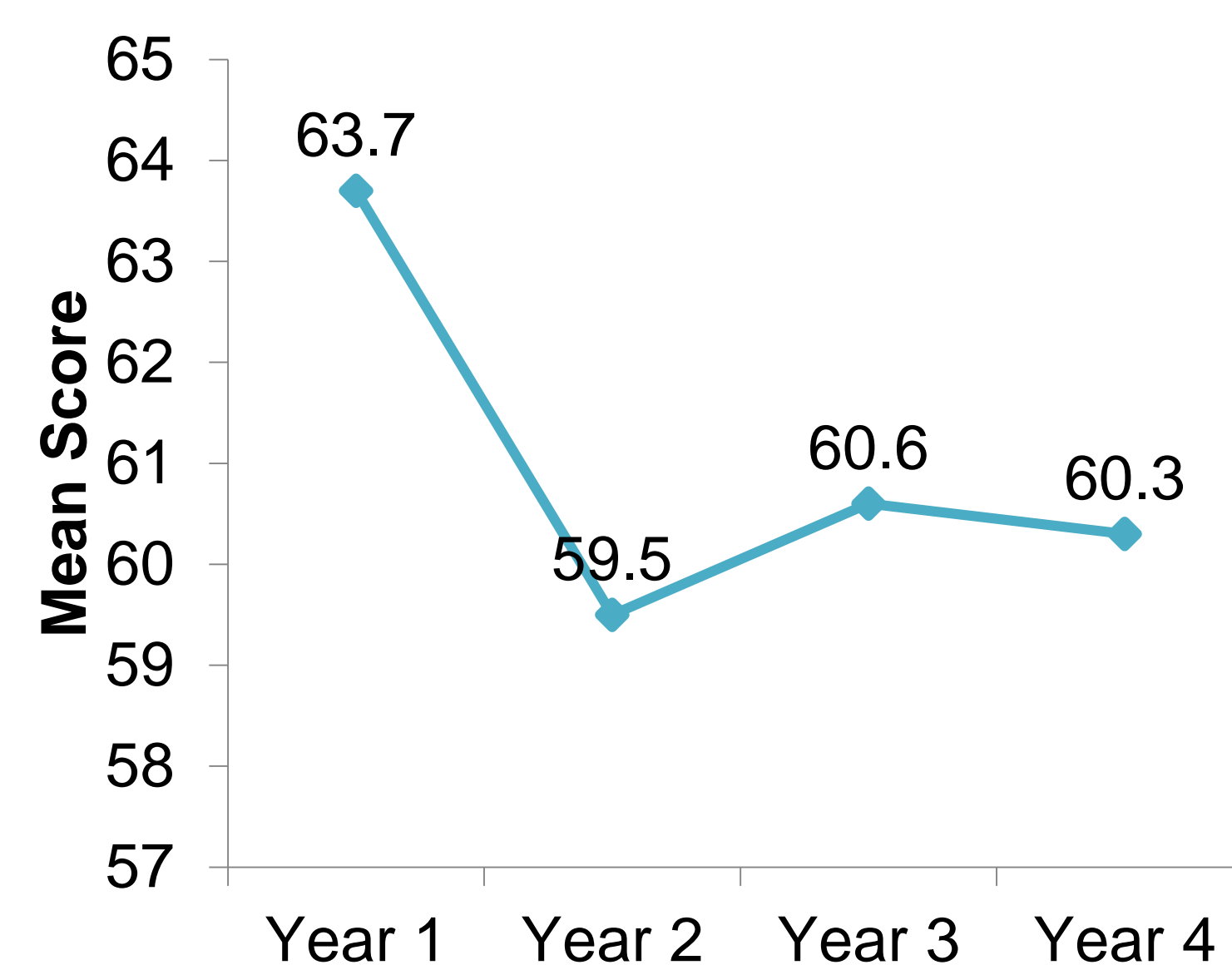
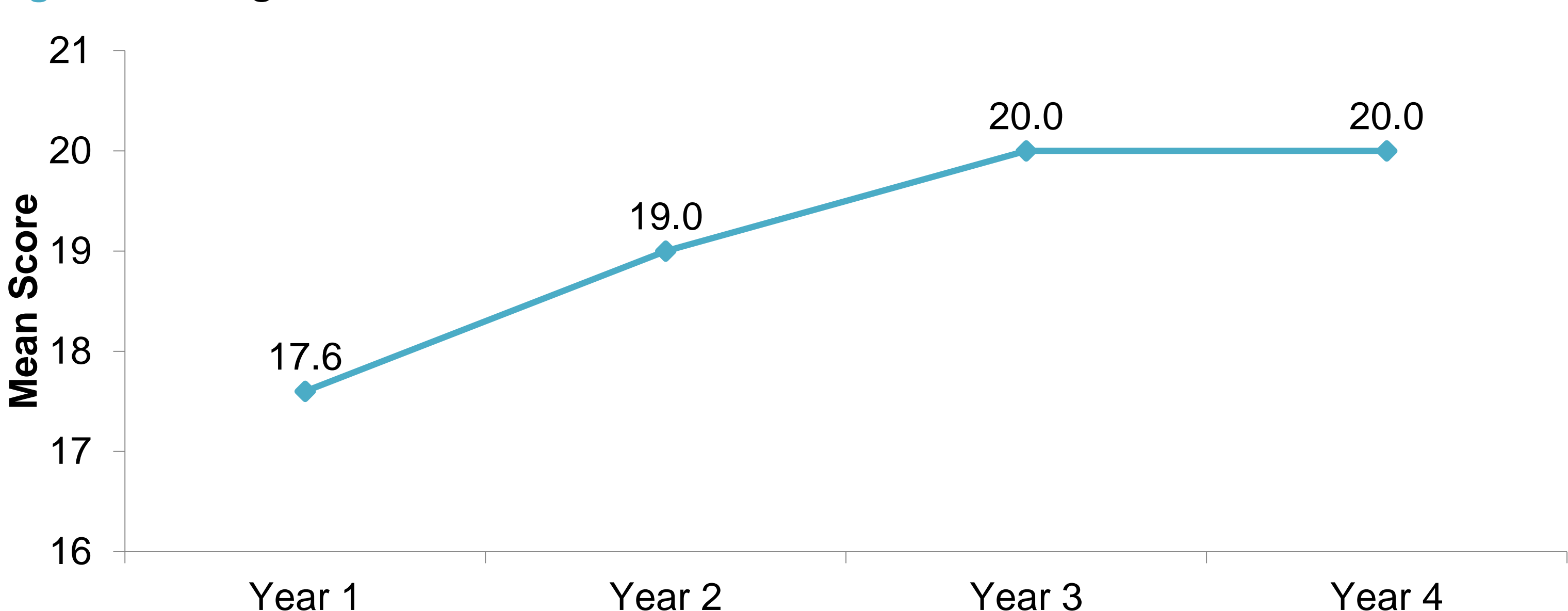


Figure 3. Patient's EQ-5D Scores



- Caregivers' burden increased over time as shown by ZCBI scale which varied from 17.6±12.6 to 20.0±14.8 (Figure 4).

Figure 4. Caregivers' ZCBI Scores



- Caregivers' HRQoL remained unchanged, being EQ-5D index 0.8±0.2, while VAS varied from 73.7±18.6 to 75.0±16.2 (Figure 5 and Figure 6).

Figure 5. Caregivers' EQ-5D Index

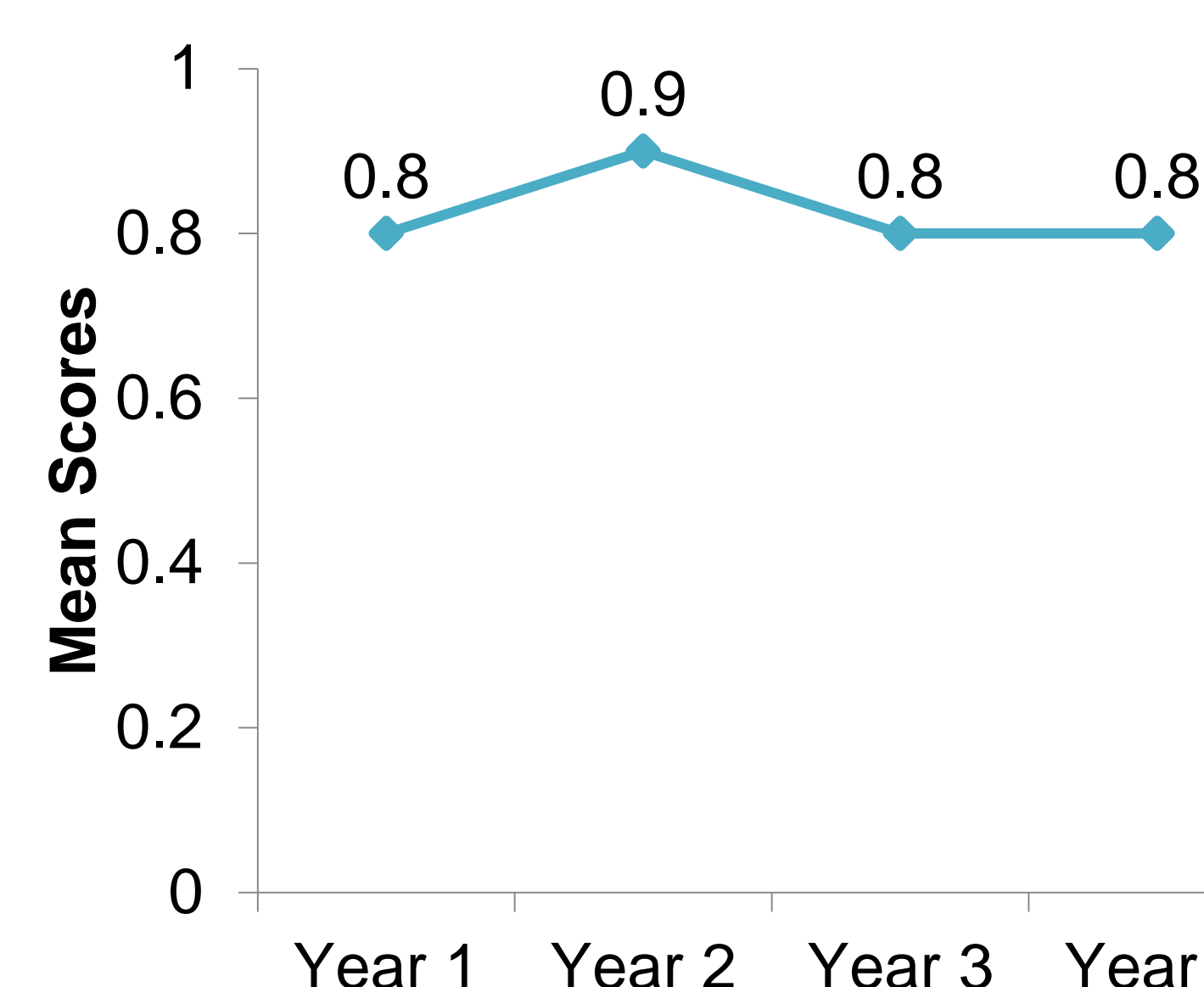
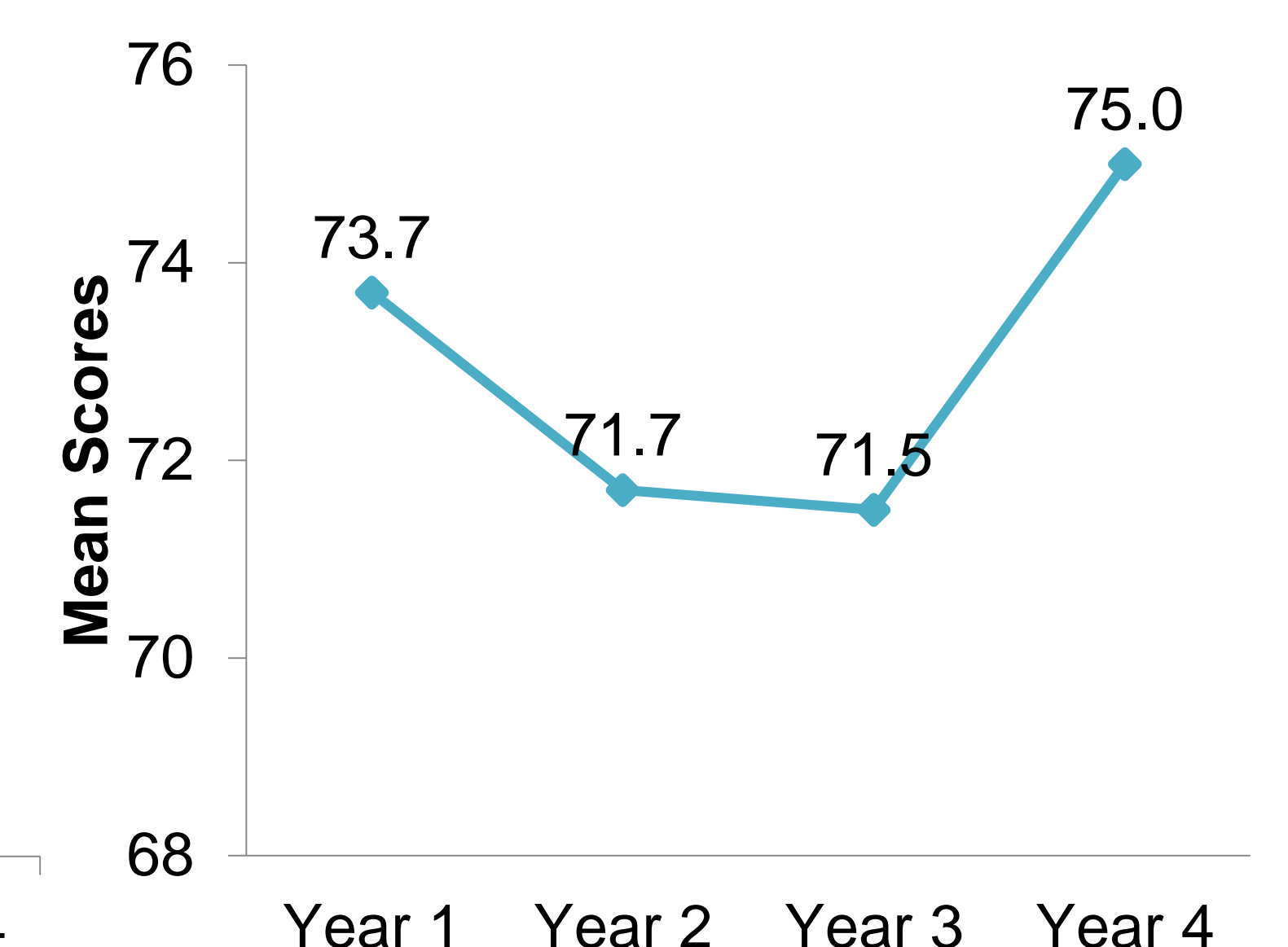
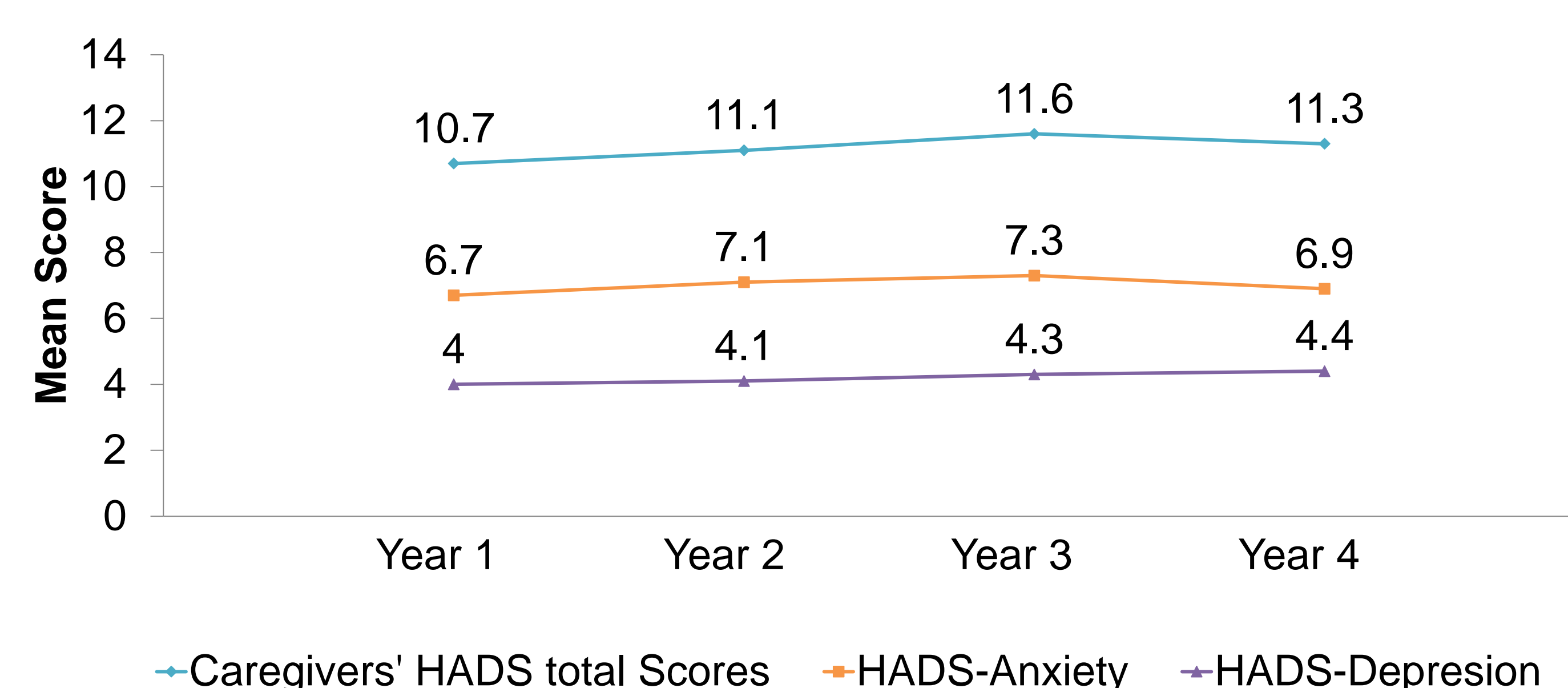


Figure 6. Caregivers' VAS EQ-5D Scores



- Caregivers' depression and anxiety marginally increased over time. HADS-D scores changed between 4.0±3.7 and 4.4±4.3, and HADS-A from 6.7±3.8 to 6.9±4.3 (Figure 7).

Figure 7. Caregivers' HADS Scores



- Linear mixed models revealed that caregivers' anxiety and depression negatively influenced their own perception of disease burden [HADS-A, Estimated coefficient (EC): 1.02 (SE: 0.15), p<0.000; HADS-D, EC: 1.19 (SE: 0.17), p<0.000] (Table 1).

Table 1. Linear mixed model of caregivers' disease burden as a function of their anxiety and depression

| ZCBI | Estimated Coefficient | Standard error | p-value |
|--------------------|-----------------------|----------------|---------|
| Constant | 9.84 | 2.50 | 0.000 |
| HADS A (caregiver) | 1.02 | 0.15 | 0.000 |
| HADS D (caregiver) | 1.19 | 0.17 | 0.000 |

- Patients' motor symptoms predicted worse caregiver burden [SCOPA-Motor EC: 0.22 (SE: 0.09), p=0.014] (Table 2).

Table 2. Linear mixed model of caregivers' burden as a function of patients' motor symptoms

| ZCBI | Estimated Coefficient | Standard error | p-value |
|-------------|-----------------------|----------------|---------|
| Constant | 14.92 | 1.65 | 0.000 |
| SCOPA-Motor | 0.22 | 0.09 | 0.014 |

- Decline in patients HRQoL implied a higher caregiver burden [EQ-5D index EC: -5.56 (SE: 2.70), p<0.041] (Table 3).

Table 3. Linear mixed model of caregivers' burden as a function of patient's HRQoL

| ZCBI | Estimated Coefficient | Standard error | p-value |
|-------------|-----------------------|----------------|---------|
| Constant | 22.75 | 2.06 | 0.000 |
| EQ-5D index | -5.56 | 2.70 | 0.041 |

Conclusions

PD patients' moderate motor symptoms and fair HRQoL worsened over time, as did caregivers' anxiety and disease burden. Improving the control of PD motor symptoms on patients may contribute to prevent anxiety and HRQoL deterioration in caregivers.

References

- Chen JJ. Parkinson's disease: health related quality of life, economic cost, and implications of early treatment. *Am J Manag Care* 2010;16:S87-S93.
- European Parkinson's disease association. Parkinson's disease consensus statement. 2011. Available at: <http://www.epda.eu.com/en/resources/Parkinson-s-consensus-statement/>.
- Abasolo Osinaga A. Prevalencia y coste farmacológico de la enfermedad de Parkinson en España. *Rev neurol*. 2006;43(11):641-645.
- Martinez Martin P. Burden, Perceived Health status, and mood among caregivers of Parkinson's Disease Patients. *Movement Disorders*. 2008;23(12):1673-1680.