

Carers of People living with Parkinson, the 2019 European realities

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Parkinson Disease as a chronic disease interferes with the life of non professional relatives caring for the patient (carers).



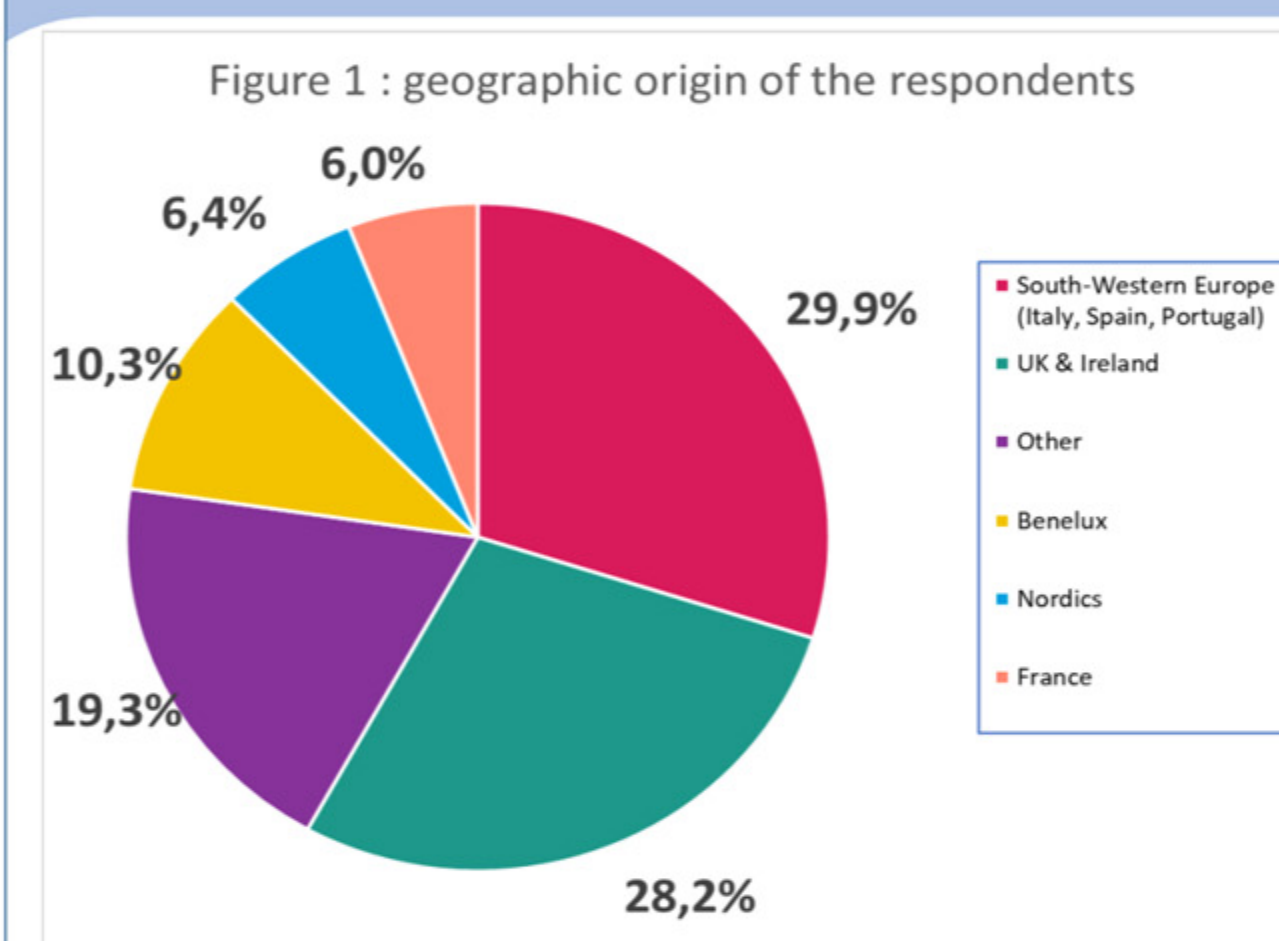
Aim of this survey:
to highlight the **physical, financial and emotional challenges** facing **carers** of people living with Parkinson's (PwPD) across Europe.



By identifying the **individual and societal cost consequences** that caring has on individuals, the **survey results support the European Parkinson's Disease Association (EPDA) to campaign for better and more timely support services aimed at carers of PwPD.**

Results:

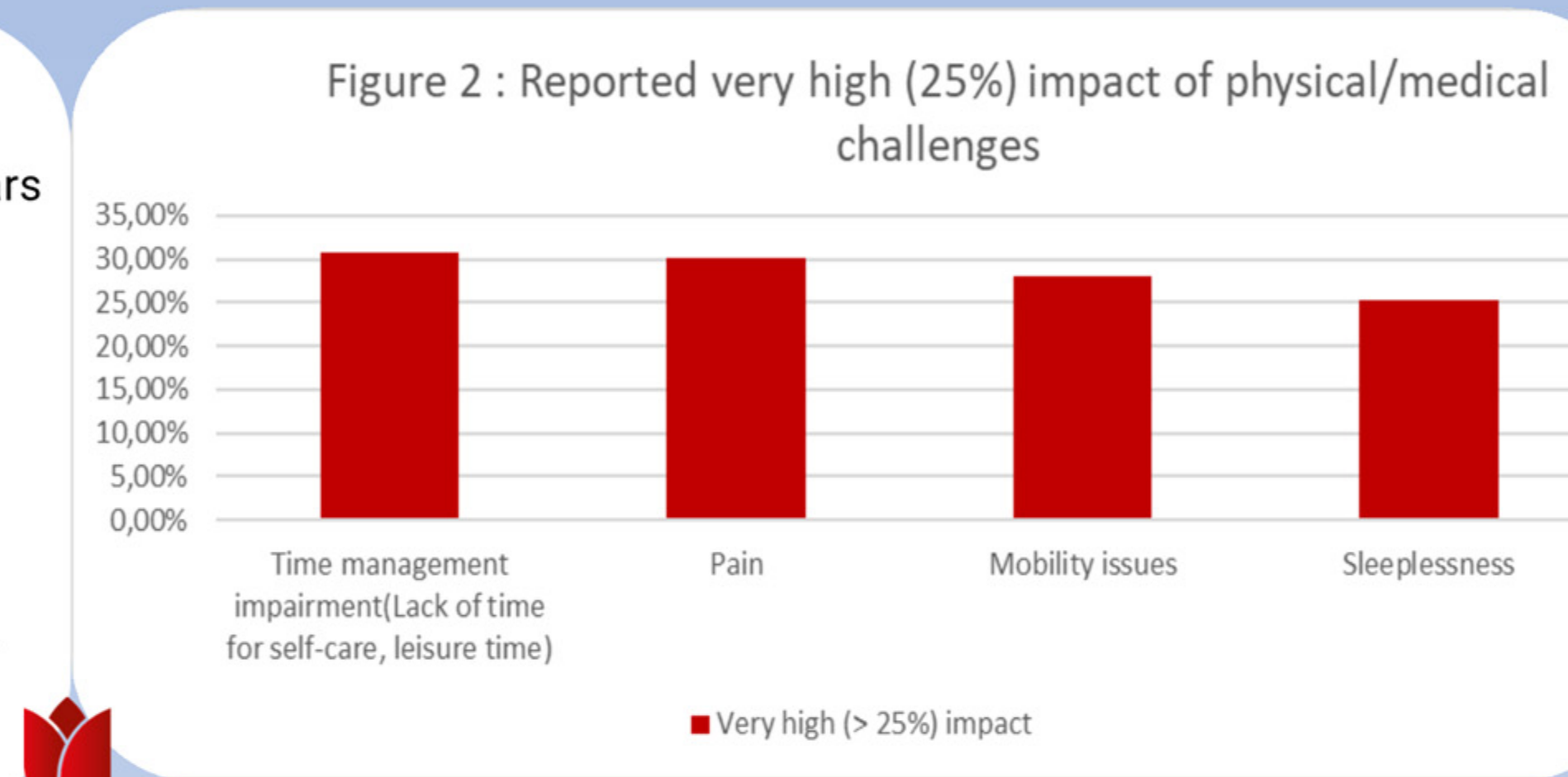
1790 completed questionnaires, from 30 EU countries (**figure1**)



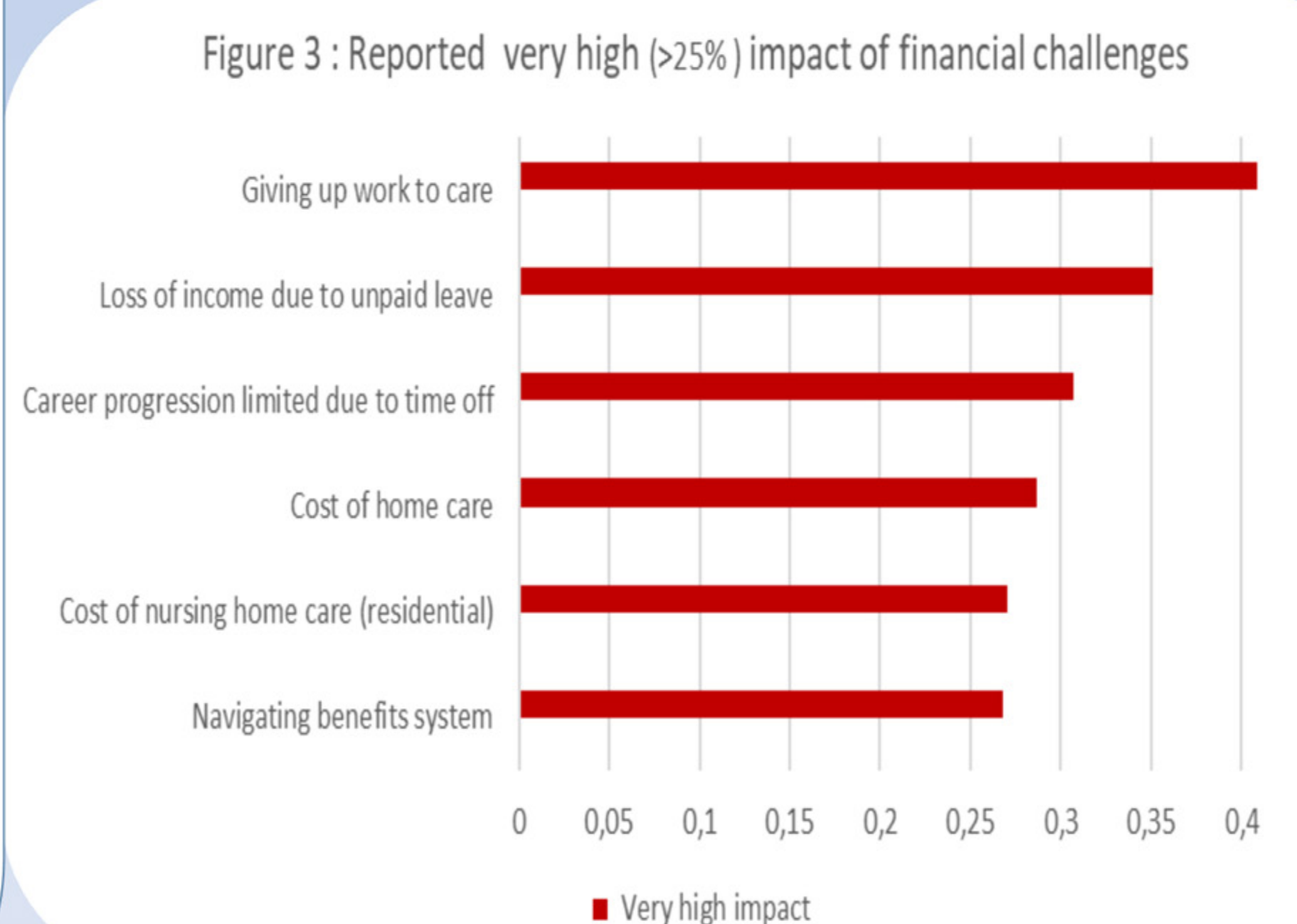
Carers are
- In average 10 years younger than PwPs,
- Mostly women (80,5%), not only spouses but also children

PwPD and carers usually live together

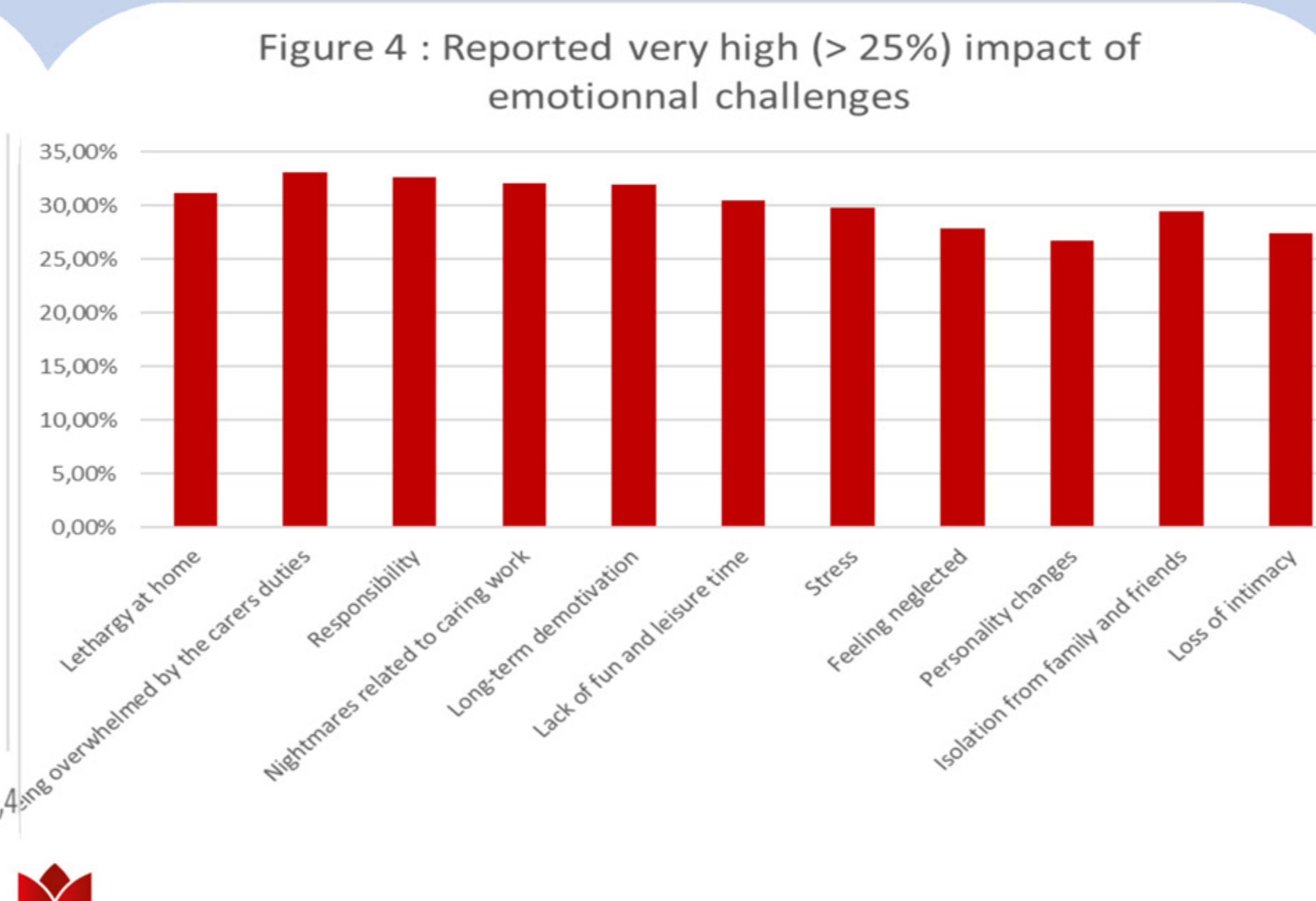
85.9% suffer from a physical strain such as pain (one of the highest impact on carers' quality of life) or fatigue (brought up by 53,8% of them) strongly impacting their life and health (**figure2**)



68.5% face financial issues due to their responsibilities as a carer. (**figure3**).



95.9% of carers are impacted by **emotional** challenges -with stress mentioned by over 50% of them (**figure 4**)



Conclusions

Caring for a PwPD in the EU can lead to **social and financial precariousness** as well as a **decline in health** which is **adding cost** to the healthcare systems.



Tools have to be developed and financed to **counterface** these challenges.



It is a **public health emergency** to develop a **holistic management** of Parkinson Disease

Methods:

Survey questionnaire co-built with representatives of EPDA national member organisations (MO) to address carers' emotional or physical or financials challenges. Launched online (14 languages) on 06/10 closed 09/06 2019 it was promoted by EPDA' MO & physicians. Responses gathered through online questionnaire. Statistical analysis of quantitative data with a confidence interval (margin of error) at 2% and confidence level of 95%. Thematic breakdown of results based on geographic clusters of respondents