

Supplementary Material

Factors Associated with Preferred Place of Care and Death in Patients with Parkinson's Disease: A Cross-Sectional Study

Date of interview:

Questionnaire

Please answer the following questions by putting a cross next to the most appropriate answer.

- 1. Which gender do you feel you belong to?**
 - female
 - male
 - diverse

- 2. How old are you? _____**

- 3. How old were you when you were diagnosed with Parkinson's disease? _____**

- 4. My nationality is**
 - German
 - Other: _____

- 5. What is your marital status?**
 - Single
 - Married
 - Registered civil partnership
 - Widowed
 - Divorced
 - Dissolved civil partnership

- 6. Which of the following religions, beliefs or world views do you profess?**
 - Christianity
 - Protestant
 - Catholic
 - Other community: _____
 - Judaism
 - Islam
 - Buddhism
 - Hinduism
 - Other religion, denomination or world view: _____
 - No religion, denomination or world view

- 7. Where do you live?**
 - In my own household
 - With children or relatives
 - In assisted living
 - In a nursing home/senior residence (continue with 10.)
 - Other: _____

- 8. How many people live permanently in your household, including yourself? _____**

9. Do you receive nursing support?

- No
- Yes, by relatives
- Yes, by a community nursing service
- Yes, by a personal carer
- Yes, by: _____

10. Which residential area applies to you?

- City (100,000 inhabitants or more)
- Middletown (20,000 bis 99,999 inhabitants)
- Small town (5,000 bis 19,999 inhabitants)
- Rural town/rural municipality (less than 5,000 inhabitants)

11. What is your highest level of school education?

- No school leaving certificate
- Hauptschulabschluss (equivalent to 9 years of school education)
- Realschulabschluss (equivalent to 10 years of school education)
- Fachhochschulreife (technical college entrance qualification)
- Abitur/Allgemeine Hochschulreife (university entrance qualification)
- Other qualification: _____

12. What is your highest level of professional education?

- Without professional qualification
- Recognised vocational training (Ausbildung)
- Technical college degree
- University Degree
- Other: _____

13. Have you completed the following documents?

Advance directive

- Yes
- No
- I don't know (anymore)

Lasting power of attorney

- Yes
- No
- I don't know (anymore)

Other document setting out my wishes for end of life care: _____

14. Do you know what palliative care is?

- Yes
- No

15. Do you know what hospice is?

- Yes
- No

In the following, we understand the "last phase of life" as the time preceding death. This is characterised by an increasing occurrence and extent of physical, psychological, existential and social problems, so that the patient, his relatives and his care structures (e.g. nursing service, attending doctors, etc.) may be under strain.

Have you already thought about your wishes for the last phase of life?

- Frequently
- Now and then
- Rarely
- Never

16. Have you already talked to someone about your wishes for the last phase of life?

- Frequently
- Now and then
- Rarely
- Never
- I do not know anymore

If yes, with whom have you discussed your wishes for the last phase of your life (more than one answer is possible)?

- Partner
- Child(ren)
- Family doctor
- Neurologist
- Other: _____

17. Have you ever been asked about your wishes for the end of your life?

- Frequently
- Now and then
- Rarely
- Never
- I do not know anymore

If yes, by whom were you asked about your wishes for the last phase of life (more than one answer is possible)?

- Partner
- Child(ren)
- Family doctor
- Neurologist
- Other: _____

18. In which place would you prefer to spend your last phase of life?

- Own household
- Assisted living
- Nursing home/senior residence
- Palliative care ward in hospital
- Other hospital ward
- Hospice
- In the household of relatives
- Other place: _____
- Not important to me

19. In which place would you prefer to die?

- Own household
- Assisted living
- Nursing home/senior residence
- Palliative care ward in hospital
- Other hospital ward
- Hospice
- In the household of relatives
- Other place: _____
- Not important to me

20. Have you informed at least one relative (e.g. partner, child/ren, siblings) or friend of your preferred place of death?

- Yes
- No
- I don't know (anymore)

21. Have you informed your family doctor of your preferred place of death?

- Yes
- No
- I don't know (anymore)

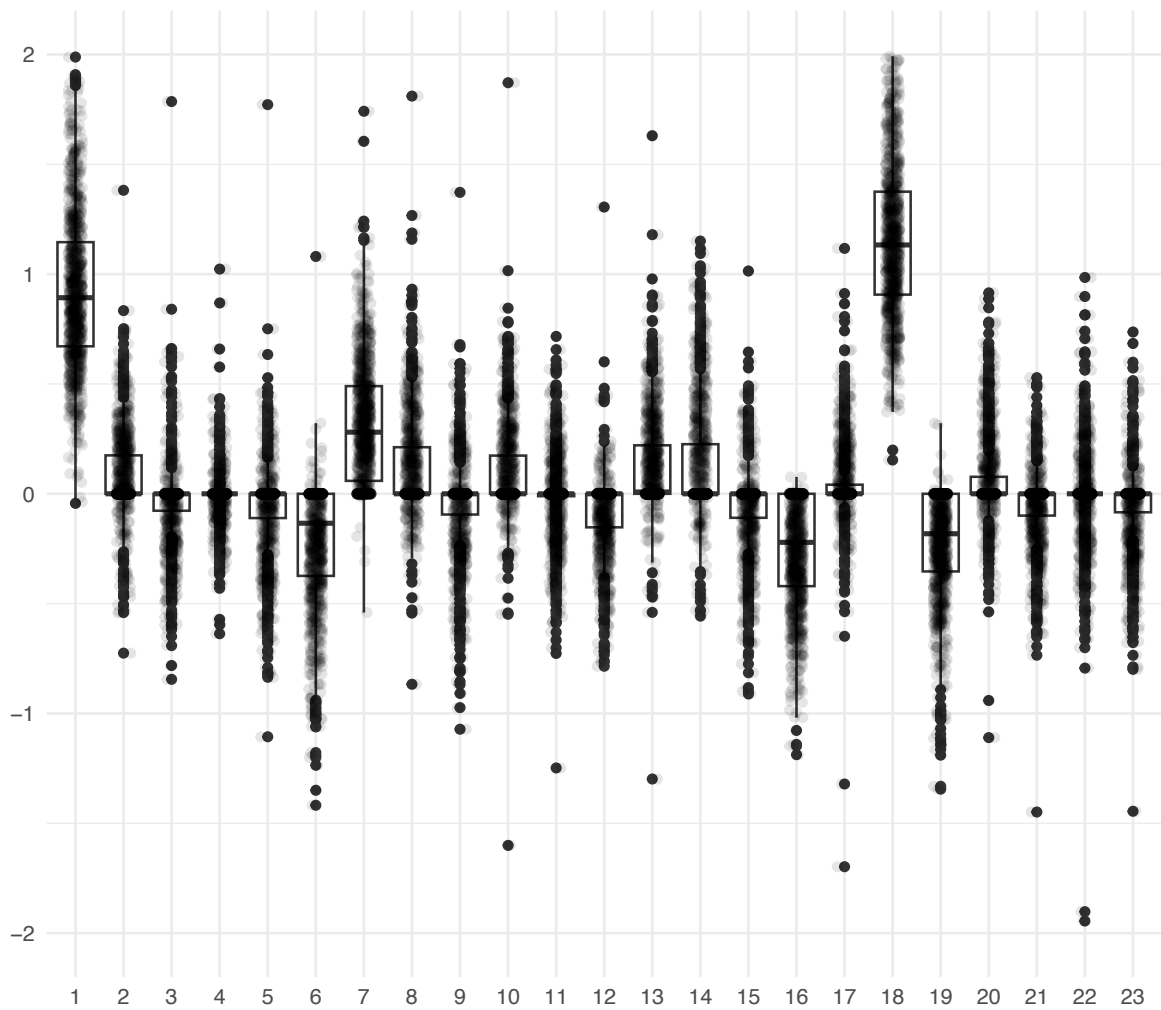
22. Have you informed your neurologist of your preferred place of death?

- Yes
- No
- I don't know (anymore)

23. If you have an advance directive, have you documented your preferred place of death in your advance directive?

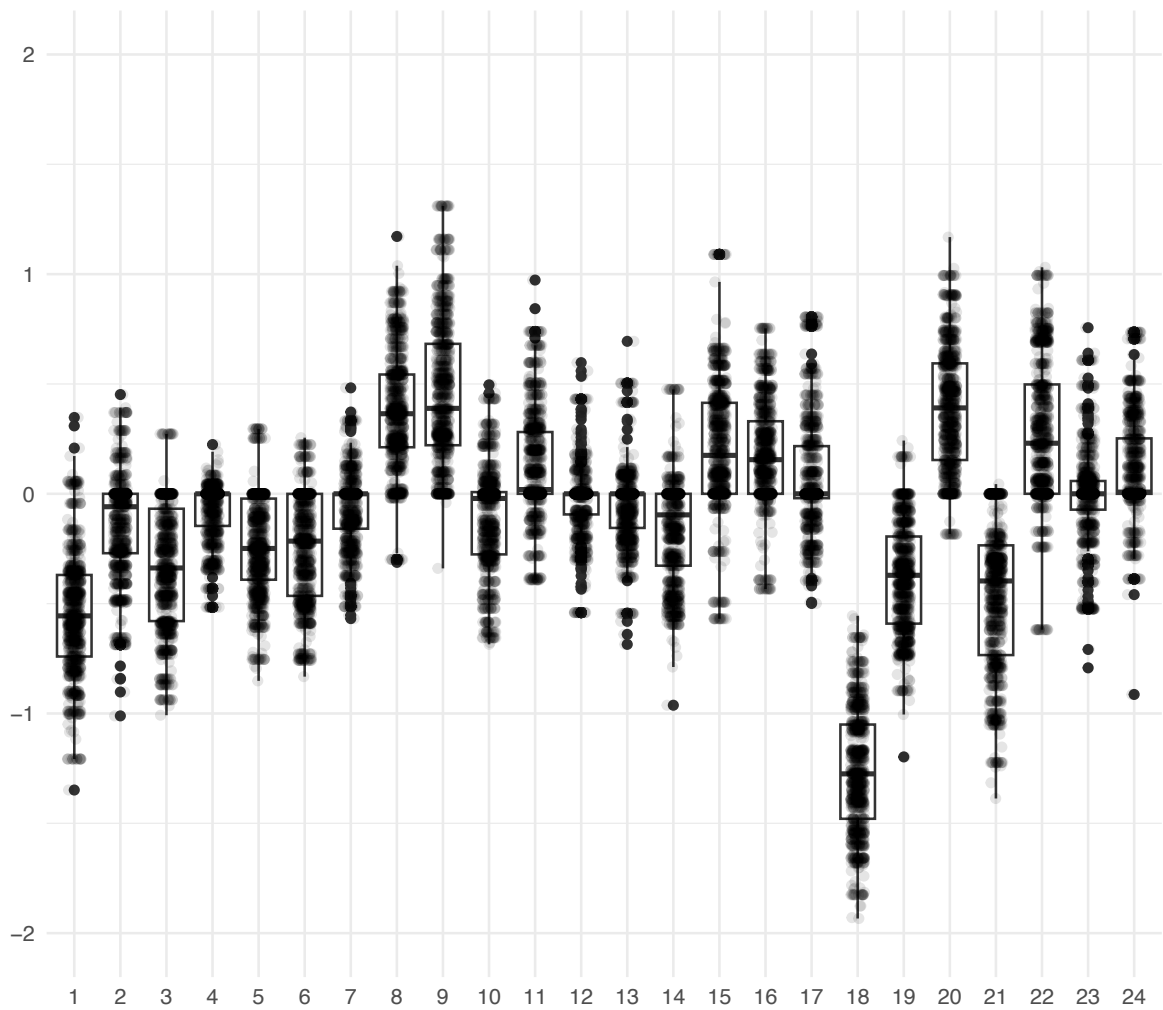
- Yes
- No
- I don't know (anymore)

Bootstrapped coefficients for the penalised regression model (ElasticNet) – HOME CARE



Supplementary Figure 1

Bootstrapped coefficients for the penalised regression model (ElasticNet) – HOME DEATH



Supplementary Figure 2