

Huntington's disease and I, Who am I? [Studyprotocol]

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Background

Huntington's disease (HD) fundamentally impacts lives:

- Decline in bodily, social and psychological functioning
- On average a young age
- Genetic factor
- Affects self-perception of independence and social relations
- Perceived loss of sense of self

Nursing home residents:

- Struggle to preserve identity

Knowledge gap:

- Not clear what is understood by identity
- Identity increasingly subject of research in dementia
- New knowledge not directly transferable to HD

Aims

- To gain insight into how people with HD who reside in nursing homes experience and express their identity in their daily lives.
- To understand whether people with HD perceive the symptoms as an integral part of their identity, and how they incorporate or separate these symptoms from their identity.

Project

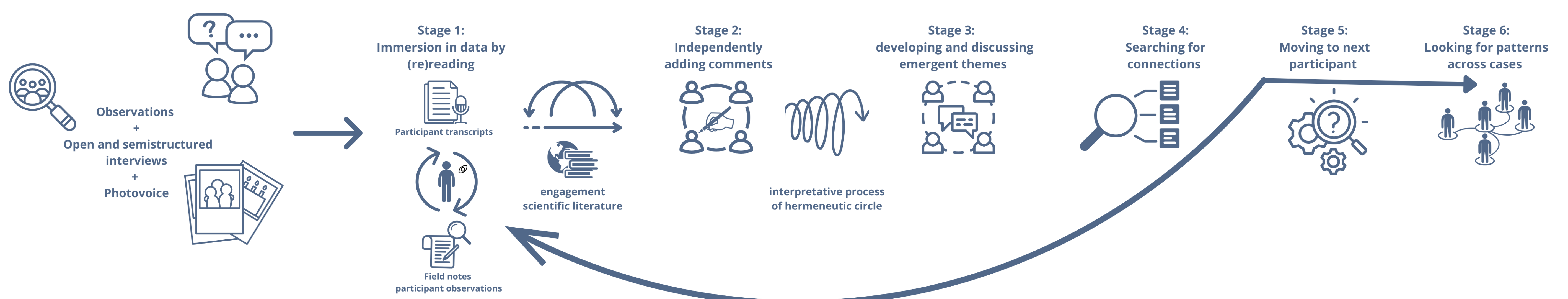
Part of the doctoral research project:

Identity in people with advanced Huntington's Disease in long term care: stable and changing? Implications for care practice.

Funding

Huntington Stimulation Grant 2023.

Methods



Data collection

- 6-10 patients living in Dutch centers of expertise
- Open and semi-structured interviews
- Non-linguistic methods (participant observations + photovoice)

Data analysis

- Interpretive phenomenological analysis (IPA)