Project Overview

**Duration:** 2015 - 2018
**Funding:** DZNE Witten
**Project Management and Coordination:** JProf. Dr. Margareta Hale
**Project Staff:** Claudia Dinand, Dr. Martin Berwig

**Background**
The behavioral variant frontotemporal dementia (bvFTD) is a young onset disorder associated with strong changes in judgment, behavior, personality, and emotions. These changes vary individually and have an impact on the daily lives of those affected and their families. Psychosocial interventions are important and indispensable components in the care of people with FTD and are most effective if they match the specific needs and requirements of the persons concerned. At present, the evidence of these interventions could not be demonstrated. Thus, it is essential to generate further knowledge and insights into frontotemporal dementia as a lived experience.

**Project Aims**
The aim of this study is identifying, collecting, and consolidating practical knowledge and clinical expertise from multiprofessional perspectives to constitute the basis for further development and evaluation of psychosocial interventions for the care of people with bvFTD.

**Methods**
An explorative and reconstructive design is chosen and includes three steps:

1. Development of a literature-based guideline for conducting interviews
2. Consultation of elected informal and formal experts/stakeholders with multiprofessional backgrounds to explore hidden practical knowledge and clinical expertise
3. Further analysis and interpretation of the collected data to generate insights into frontotemporal dementia as a lived experience
following data collection methods (Figure 1)

- Focus groups with relatives / nurses or other therapists, possibly interdisciplinarity
- Guided individual interviews (selected persons, inter- and cross disciplinary)
- Analysis of self-presentations of people with bvFTD in blog entries

3. Data analysis and synthesis includes the identification, arrangement, and interpretation of the data. The findings will be compared to each other and synthesized by conceptual and theoretical frameworks.

Expected Results
Through this project, previously inaccessible sources of knowledge and recommended for further evaluation. This fills a gap within the health care research. The results are prepared for publication. If necessary, an action guide will be developed.

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