

# **IRFD Project Description**

## **On becoming a person: Challenging dehumanization of people living with advanced dementia**

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### **Introduction:**

This PhD aims to improve dementia care by developing a theoretical understanding of personhood<sup>1</sup> in people living with late stages of dementia. Internationally, a growing number of people live with dementia; in Denmark, approximately 90,000 people do so, including 42% of nursing home residents (2-3). According to The Danish National Dementia Strategy 2025, care for people with dementia must be based on dignity, humanity, and respect for the person behind the disease, with limited use of antipsychotics (3). However, people with advanced dementia are at risk of being dehumanized by caregivers (4-7). Their depiction as zombies (8), dementors (9), or empty vessels (10) exemplify dehumanization processes (11) through which these vulnerable elders are not granted the status of being persons and their personhood becomes neglected (4-7). This profound misunderstanding detrimentally affects dementia care practices in nursing homes (12), characterized by social exclusion (13), containment (14), and wide use of antipsychotics that increase mortality for residents with dementia (15-16).

As reflected in recent research and to support priorities in the Danish national dementia strategy, a need exists to better understand why and how people in the late stages of dementia are at great risk of being dehumanized and how care for those with advanced dementia can be supporting their personhood. These are the main aims of the PhD study.

### **Background: State of the art**

Due to declining cognitive skills in dementia, leading to impaired memory, language, and orientation (17), a serious risk in dementia care for people living in the later stages of the disease is being dehumanized (5,7,18); a moral and ethical issue, and also critical due to its well-documented harmful effects (11,19). It has been suggested in literature concerning dementia that caregivers often overemphasize memory loss, language impairment, and orientation issues among people with dementia and misinterpret their actions as meaningless and unrelated to their personhood (7,18). Other reasons linked with dehumanization are negative stereotypes and atypical behaviour in

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<sup>1</sup> A “standing or status” that define you as a human being (1).

dementia (4,14,20-21). However, systematic investigations of reasons for caregivers' dehumanization in the context of advanced dementia are scarce.

To date, the most well-known effort to address dehumanization of people with dementia is Kitwood's (1) seminal work on person-centered care, which is accepted nationally (22) and internationally (23) as essential to high-quality dementia care. Person-centered care requires caregivers to understand the concept of personhood and is acknowledged as an attempt to support personhood for people with dementia (24). However, person-centered care in the late stages of dementia has been criticized (5,7,25) for neglect of caregivers' responsibility to engage with people with advanced dementia in ways that preserve their personhood (5,26) and failure to view people with advanced dementia as active agents capable of supporting their own personhood through their subjective experiences (7,27). In short, person-centered care undervalues essential elements of personhood. Despite the fact that person-centered care has become the primary focus of dementia care practices in western settings (23-24), many nursing home residents with dementia still receives too many antipsychotics (28) and experience poor care (29-30). Thus, a great need exists to understand how the personhood of people with advanced dementia can be acknowledged and used as a foundation for genuinely person-centered care.

Innovative studies shed light on ways to understand seemingly incomprehensible actions, irregular behavior, and unclear communication as part of the personhood of people with advanced dementia (4,27,31-33). These studies are based on theories of embodiment and inter-embodiment with an expanded view of those with advanced dementia: their personhood comprises the ways they continue to be active in their relationships with the world and others (34-35). According to Kontos, people with dementia should be understood through their bodily embedding in the world, i.e., bodily habits, gestures, and actions are meaningful manifestations of embodied personhood (34). Zieler emphasises that human beings stimulate one another's personhood through inter-embodied relationships and that true mutuality and recognition of bodily expressions are essential to keep people with dementia connected to their personhood (35). Although existing reports addressing dementia and embodiment or inter-embodiment mention personhood, the relationship between personhood and the concept of dehumanization is not discussed.

This study addresses this research lacuna by focusing on the importance of a deeper understanding of dehumanization processes and personhood of people with advanced dementia to improve the quality of care. As such, the project aims to contribute to a novel area of dementia research by better understanding the nature of dehumanization of people with advanced dementia and adding nuances

to supporting their personhood. This knowledge has the potential to improve care and reduce use of antipsychotics in dementia care in Danish nursing homes, contributing to achieving the national goals for quality dementia care (3).

### **Overall aim**

The aim of the PhD project is to create new knowledge that can improve person-centered care for people living with advanced dementia by challenging dehumanization and supporting their personhood. To achieve this aim, three sub-studies will:

i) identify reasons for dehumanization in dementia care and ways to counteract it by ii) describe how people with advanced dementia can be understood as people with personhood and meaningful active agents in their own lives, and iii) describe how caregivers experience their relationships with people with advanced dementia as contributing to maintaining their personhood.

### **Methodology, sub-studies, and ethics (Figure 1)**

#### **Study 1: Integrative review of the literature**

**Aim:** To identify reasons for caregivers' dehumanization of people with advanced dementia.

**Method:** Existing knowledge, including qualitative and quantitative studies and grey literature, will be synthesized using updated methodology by Whitemore and Knafl (36) for integrative literature reviews. Based on the findings, new scientific evidence pertaining to reasons for caregivers' dehumanization of people with advanced dementia will be developed. To ensure diversity and quality of selected literature and maintain rigorous and systematic search and data collection processes, academic librarians, scientific databases and verified checklists for scoring qualitative and quantitative research will be used (36).

**Data analysis:** In a four-stage process, data from included sources will be extracted, categorized, conceptualized, and verified (36).

#### **Study 2: Participant observations of nursing home residents**

**Aim:** To explore how people with advanced dementia in nursing homes express their personhood in embodied and inter-embodied ways through interactions with the world and caregivers.

**Method:** Based on Spradley's (37) classical method combined with Ellingson's (38) innovative description of embodied ethnography participant observations will be conducted at Pilehuset and Aalholmhemmet, specialized nursing homes for people with advanced dementia. Understanding the lived experiences of people with limited or no verbal language and memory can be achieved by participate in their daily lives (37), while approaching the observations as bodily and sensory

communicative processes (38). As such, general observations of residents' daily lives will be conducted, including informal conversations and interactions (37). At start findings from Study 1 will guide the focus of 'grand tour observations' through which the most general features of residents lived experience will be captured and described. Gradually, observations will be focused on certain elements of their lived experience, changing them to 'mini tour observations' (37). During a two-month period, observations will be made at both nursing homes, consisting of daily four- to six-hour visits across different shifts and days of the week. To capture observations accurately, descriptive, and reflective field notes will be recorded throughout observations and transcribed daily (39).

**Data analysis:** Transcript data will be analyzed in three steps consisting of holistic, selective, and detailed reviews (40). The material will first be read as a whole, and concise statements capturing the central meaning of the lived experience will be formulated. Second, statements and phrases essential to expressing the lived experience will be selected from the text. Finally, each line of text will be reviewed in detail to identify what single sentences or sentence clusters reveal about the lived experience. The analysis will yield general themes of the lived experiential description (40).

### **Study 3: Semi-structured interviews with nursing home caregivers**

**Aim:** To explore how caregivers experience creating joint interactions with residents with advanced dementia that support their personhood.

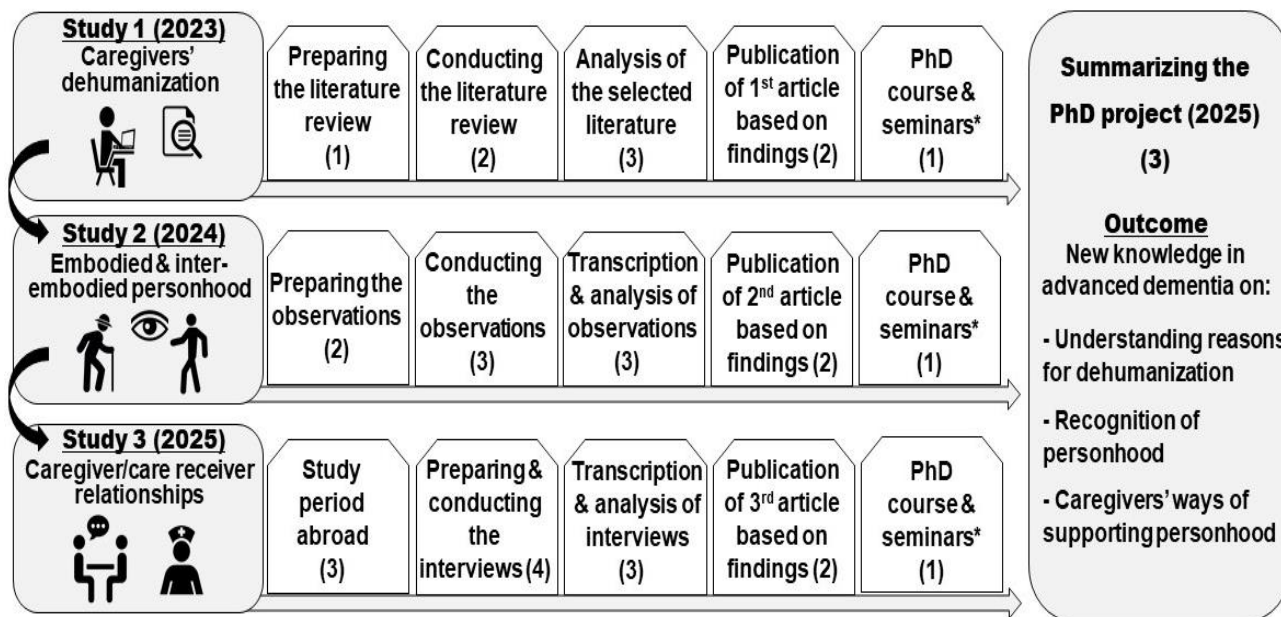
**Method:** Semi-structured interviews will be conducted with 10 care staff at each nursing home. The primary focus of interviews will be elaborating on selected observations from Study 2. To include diverse lived experiences, purposeful sampling (39) will ensure varying participating caregiver characteristics such as educational background, work experience, gender, and age. Interviews will consist of open-ended questions enabling participants to freely provide detailed descriptions of their experiences. Informants will choose interview locations (41). All interviews will be audio recorded, anonymized, and transcribed verbatim (41).

**Data analysis:** As described above for Study 2.

### **Ethics**

Informed voluntary consent will be obtained from all participants (proxies/close relatives if participants are unable to give written or oral consent; see ethical issues explained elsewhere in the application). In accordance with legal and ethical principles, all participants will receive written information about the study purpose and be informed that they can withdraw consent and participation at any time without consequence (42). Throughout the project, the Helsinki Declaration and the guidelines for nursing research in the Nordic countries will be respected (43). Due to the nature of the project, formal ethical approval is not required under Danish law (42).

Figure 1: Sub-study connection, research plan, and timeline (year and number of months in parenthesis)



\*Participation in the Journal Club 'Nursing and health' (<https://phd.health.au.dk/doingaphd/journalclubs>)

### **Project anchoring and roles**

The research project will have excellent synergies internationally and nationally at the Aarhus University, the University College Copenhagen, and the University of Nottingham. All data collection, analysis, publication of research articles, and drafting of thesis will be conducted by the PhD student and will be discussed and reflected upon during monthly meetings with the supervisor group. As the main supervisor with extensive experience doing phenomenological nursing research on people's lived experiences, Associate professor Bente Martinsen will contribute to all project phases. Co-supervisor Senior associate professor Benjamin Bøgeskov will primarily contribute to data analysis, where his academic background as a philosopher can support the project's conceptual roots of dehumanization and embodied and inter-embodied personhood. Co-supervisor Professor in dementia research Tom Dening will take part primarily in planning and conducting the studies and will host the study abroad at the interdisciplinary Centre of Dementia Research group at the University of Nottingham. To further strengthen the project's international perspective and relevance, an advisory board comprising researchers with expertise in personhood in advanced dementia from Scandinavia and the United Kingdom will be involved in annual discussions on each of the project's research studies. The University College Copenhagen will administer the foundation grant in collaboration with Aarhus University, the project's academic host. Research results from all phases will be published in international peer-reviewed journals with open access and be communicated to researchers in elder care fields through a collaborative seminar series held by the involved universities and at international conferences.