Participatory Design with People with Dementia as an Instance of Bridging Design and Ethnographies

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ABSTRACT

This paper discusses how ethnographic methods and design anthropology have been applied in Participatory Design with people living with dementia. Drawing from the literature in Human-Computer Interaction, the importance of empathy, relationality and reflexivity in designing with people with dementia are emphasized. Both the sub-community conducting Participatory Design with people living with dementia in Human-Robot Interaction, and the broader community working with ethnographic approaches may profit from these principles and approaches in bridging ethnographies and design.

CCS CONCEPTS

• **Human-centered computing** → **Ethnographic studies**; *Empirical studies in HCI*.

KEYWORDS

Care Robots, People with Dementia, Participatory Design, Ethnographic Studies, Design Anthropology

1 INTRODUCTION

The International Classification of Diseases (ICD) defines dementia as an umbrella term of various progressive and irreversible neurodegenerative disorders. These disorders are characterized by cognitive impairments, including memory loss, speech and motor difficulties, and altered reasoning, perception, and orientation. Such changes often result in behavioral and psychological challenges for both the individual with dementia and their care network [19]. Age is a key predictor for developing a form of dementia, and in the absence of effective prevention and treatment, the aging global population suggests a surge of worldwide dementia cases from 55 million to 139 million people living with dementia (PwD) by 2050 [16, 20]. In response to associated challenges in providing adequate dementia

care, there is an increasing interest in technological solutions. The World Health Organization for example highlights a demand for innovations along and across all dementia care pathways including solutions such as artificial intelligence and robotics [20].

Research within Human-Robot Interaction (HRI) and social robotics has aimed to develop solutions aiding PwD and their carepartners [for an overview 2]. Yet, dementia is often considered from a pathological, biomedical model, focusing on mitigating dementia-related challenges such as memory loss or speech finding problems through technology [10]. Such an approach is not only inconsiderate of the lived experiences of people with dementia and their carepartners, but may ultimately cause a gap between technological advancements and their adoption or acceptance in dementia care [12, 15]. Therefore, from outside [21] and within academia [9], calls for more inclusive, engaging, and empowering design processes, striving for more meaningful outcomes have emerged. Participatory Design (PD) is one design approach focused on notions of stakeholder inclusion and empowerment and has a long history in the field of Human-Computer Interaction (HCI) [1] and has been successfully adopted to design with PwD [14, 15, 17].

In writing this manuscript, I embody one voice of the transdisciplinary research project Caring Robots // Robotic Care. The project has set out to engage in participatory design processes of robotic care technologies for older adult care in order to develop novel, meaningful solutions. One primary focus within the project involves designing for and with people with dementia. This focus has compelled me to examine existing PD approaches with PwD. In the following section, I illustrate selected methodological approaches and commitments within PD with PwD and hope to illustrate and spark discussion on successfully bridging ethnographic and design research.

2 PARTICIPATORY DESIGN WITH PEOPLE WITH DEMENTIA

Ethnographic methods such as (participant) observations, interviews or video studies have been integrated into the early stages of participatory design processes with the principle goal to understand the practices and context of design from the perspectives of participants, fostering relationships and mutual learning as foundations to initiate following design activities [1]. Applications of ethnographic methods within PD has sparked discussions concerning their nature and purpose in PD, building a bridge to practices of the domain of design anthropology [13]. Design anthropology integrates elements from both ethnographic and design methodologies, combining the descriptive accounts of contexts, relationships and practices, alongside theoretical frameworks derived from ethnographies with the generative processes of creation, innovation and solution inherent

to design. The integration of both aims to develop interventions transforming the present grounded in contextual understandings and theoretical sensitivities [3, 13].

In the participatory design with people with dementia, Hendriks et al. explicitly refer to their approach as one instance of design anthropology, illustrating specific methods and commitments for bridging ethnographic and design research [4].

In their research encompassing multiple workshops, field studies and university courses, the authors delineate a set of qualities and processes for advancing in a design anthropology approach. Central to all activities stand commitments to empathy [18] and to relationality between designers and participants [6], highlighting the importance of meaningful connections. In their perspective designing becomes a collaborative activity between an individual designer and an individual participant. The approach prioritizes the nuanced understanding a designer gains from the engagement with participants' lived experiences, over designing for the collective needs of groups of people [18]. Developing such an understanding requires prolonged interactions without pre-defined design objectives [4] and a grasp of participants' past experiences, their present ways of interpretation and communication, and potential future aspirations [18].

In building empathetic relationships, the authors propose four guiding principles, which are particularly pertinent for designing with PwD in advanced stages of dementia, where participation becomes predominantly implicit [4]. These principles are:

(1) Reflective actions urge designers to consider the nuances in establishing relationships with PwD and potentially other stakeholders. It is essential to identify and navigate decisions in the relationship. In practice, this could be accomplished by keeping extensive field notes or collaborative reflections with fellow designers, aimed at identifying subtle details from the relations, such as specific preferences of the PwD.
(2) Constructing a narrative of the PwD can aid designers in making informed choices, drawing on the portrait of the PwD. At this point, the incorporation of other stakeholders can enrich the narrative, offering a deeper understanding of the PwD and informing possible design choices.
(3) Using role-playing activities to examine the role of design outcomes in everyday scenarios. Such activities can involve secondary stakeholders or be performed with PwD directly.
(4) The last principle entails how materializing empathetic relationships into tangible design narratives and outcomes allows for a holistic evaluation, ensuring rigor and transparency requirements are met.

While not explicitly referencing design anthropology, various researchers have incorporated ethnographic methods into design processes with PwD, and have followed similar pathways as depicted by Hendriks et al. For instance, Morrisey et al. conducted an Experience-Centered Design approach [11] over three years in older adult care homes. Their methodology consisted of extensive fieldwork and participant observations, with one of the authors conducting prolonged visits to the care home. The author documented their subjective experiences and observations throughout the fieldwork, paying particular attention to the nuances of interactions with participating PwD and how their relation formed

and evolved over time. Building on their fieldnotes, the authors report developing a sensitivity for the lived experiences of participants, comprehending PwD's expressions and interactions as input for design processes. This sensitivity was additionally instructive to conducting a collaborative design process, aiding the selection of creative activities that participants would enjoy, and exploring prototypes in manners appropriate to the abilities of participants.

The authors equally articulate several principles conductive to perform their ethnographically inspired design research with PwD [11]:

(1) Embracing openness and flexibility to explore and adjust to participants' experiences, facilitating identifying meaningful design directions and activities.
(2) Entering the often altered realities of PwD in an empathetic manner, promoting collaboration and avoiding to elicit negative emotions by correcting them.
(3) Seeing the design process as a collaborative negotiation of potential futures

Both groups of authors have identified challenges inherent in their design approaches. Morrisey et al. [11] report on increased sensitivity in navigating the relationship with and realities of participants. Designers are called upon to flexibly assume diverse and multiple roles to participants - such as being a family member or care worker of the PwD. Conversely, Hendriks et al. [4] reflect on the complexities of ending engagements with PwD. Building and sustaining empathetic relations with participants involves significant emotional and temporal investments from both partners. As such relationships evolve beyond pragmatic connections between researcher and informant, ending these and withdrawing from the context poses an ethical challenge to researchers.

In scoping the literature within HRI, it becomes evident that participatory design studies with PwD often adopt approaches resembling more traditional PD methods such as workshops, interviews or collaborative prototyping including explicit decision-making phases [8, 9]. Such methods however, might not represent the most effective approaches conduct PD with PwD due to individual progression and expression of their dementia, and aforementioned limited cognitive capabilities [5–7]. Consequently, I hope this position paper offers two impulses to the HRI community: 1) Encouraging exploration of PD of robotic technologies with PwD that incorporate the empathetic, relational and reflexive approaches outlined above; and 2) Urging the broader HRI community, particularly those following ethnographic research methods, to consider principles of design anthropology and applied instances such as designing with PwD as guidance how ethnography and design can be bridged.

Considering the premature state of the approaches, I propose to explore and discuss the following questions with workshop participants:

- What essential qualities can ethnographic research contribute to the design process, and how can ethnographies be conducted to facilitate bridging it with design activities from a perspective of design anthropology?
- How can ethnographic research and design activities be facilitated across teams of researchers, designers, and developers?

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