Looking at the Personhood of Non-Verbal Persons with Dementia Through the Eyes of Their Carers: A Cultural Probe Study

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ABSTRACT

The study presented in this paper is part of the interdisciplinary research project, Blink. which aims to improve the person-centered care (PCC) offered to non-verbal persons permanently residing in care facilities by researching ways to define, access, and integrate their personhood into their daily care. This paper discusses a cultural probe study aimed at accessing the personhood of persons with late-stage dementia through the eyes of their carers. The results from this study will aid the development of a tool(kit) that supports carers and care facilities in developing and implementing their PCC practices. Drawing inspiration from Kitwood's concept of personhood, this study seeks to explore carer's viewpoints, attitudes, and beliefs concerning their own personhood, roles, and profession, as well as their interactions with routines, spaces, objects, and other persons—all in relation to their caregiving responsibilities and the persons with late-stage dementia under their care. Additionally, the research aims to shed light on their perceived reality, barriers, and aspirations related to the discussed care context. By collecting this information, the study aims to uncover important insights into how persons with late-stage dementia are perceived and valued by those around them, and if or how these results are reflected within a care context. Lastly, the results from this study will also aid in the development of the final tool(kit) by providing valuable insight into carers as future users. This study included six direct carers working with persons with late-stage dementia in three different care facilities in Flanders, Belgium. The analysis of the results revealed themes and challenges faced by these carers, as well as insight into how their perceived roles influence their caregiving practices. Additionally, the study provides essential design directions for the final tool(kit)'s development.

Keywords: cultural probe, person-centered care, personhood

1 Introduction

In light of the constantly evolving healthcare landscape and the rising importance of care-centered design, there has been an increased focus on person-centered care (PCC) [1]-[2]. PCC is an approach that focuses on the person and their unique needs, preferences, and values, and ensures that these values are at the forefront of all care-related decision-making. The focus lies on the 'person' receiving care, not the 'patient' [3]. It emphasizes the idea that it is essential to recognize that the person being cared for continues to be a person in possession of their personhood [4]. While PCC has often been praised in dementia care settings [1]-[2], as discussed by Marulappa et al., a scoping review revealed a significant gap in understanding how to effectively implement PCC into practice [5]. Furthermore, the review pointed out that there wasn't enough identification of obstacles and strategies to overcome them [6].

Dementia encompasses varying levels of cognitive decline, including mild, moderate, or severe impairments that impact memory, cognitive abilities, behavior, and the capacity to carry out everyday tasks [7]. Within this study, we work with persons with late-stage dementia meaning that they have severe impairment and are non-verbal. Overall, language abilities deteriorate over time, resulting in various challenges related to

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speech, language usage, and comprehension [8]-[9]. All these factors contribute to creating dynamic and challenging implementation environments.

This rising interest in PCC within dementia care has often been attributed to Kitwood and their ground-breaking research on the concept of personhood within dementia care, challenging pre-existing approaches that were often perceived as disempowering and dehumanizing [10]-[11]. Examples of this can be seen in previous debates on the (loss of) self and ideas of "unbecoming" in the face of the disease [12]. Swinton later discusses similar beliefs that due to dementia "the person has gone" as a commonplace assumption showing an implicit norm within Western culture that memory and productivity are the most important aspects of human beings [13]. Chapman et al. emphasize that Kitwood, several decades earlier, already recognized a similar trend in which the concept of personhood became closely associated with autonomy and rationality [10]-[11]. According to Kitwood, this trend not only influenced the perception of persons with dementia but also directly impacted the care they received [10]-[11]. Suggesting that in order to improve dementia care, one must first improve the cultural and social standing they receive. To combat this perception Kitwood came forward with their definition of personhood as; "*a "status" "bestowed upon one human being, by others, in the context of relationship and social being" and implying mutual respect and trust*" [11]. Essential to this concept is the moral concern for *others* which Dewing describes as the most vital part of Kitwood's definition, which is often being misunderstood or misinterpreted to exclude certain persons such as carers and family members [14]. Nevertheless, Dewing believes that Kitwood's ultimate purpose is a moral concern to *all others* not only *others* with dementia [14]. One such criticism is that this concept of personhood does not fully capture the interdependencies and reciprocity that exist within a caring relationship due to a perceived lack of acknowledgment of *others* [15]. A concern that could be addressed by examining the work of Wallace et al. on how *others* exist and function within personhood. They state, "*...in dementia, the immediate social circle of the person with dementia become guardians and potentially active participants in the maintenance of their sense of self. Of course, the guardian's sense of self is also transformed in their relationship with the person with dementia – it is not a one-way process*" [16]. Tieu et al. on the other hand claim that the use of PCC today no longer aligns with Kitwood's ideas, "*but has become synonymous with an individualistic and consumerist notion of care, in which care recipients are primarily viewed as individual consumers of care"* [17]. This critique again seems to address the dangers of losing relation to *others* within personhood and dissecting the concept from their symbiotic context and as a result, reducing them to passive recipients of care instead of active participants.

In light of this ongoing journey towards not losing the value and impact of *others* in personhood and finding ways to support the implementation of personhood in PCC -and PCC into daily care practices- this paper looks at cultural probes as a design research tool aimed at carers as *others* to aid within this process of access and implementation. The study discussed within this paper is part of the *Blink.* project, an interdisciplinary design-research project between Inter-Actions, Parenting and Special Education, and LUCAS, Center for Healthcare Research and Consultancy, at KU Leuven. The project aims to improve the person-centered care (PCC) offered to non-verbal persons who cannot verbally express their personhood. Within this project, these non-verbal persons are defined as persons with dementia (PwD) and persons with profound intellectual and multiple disabilities (PwPIMD). These two target groups were selected based on the expertise of the researchers involved, and similarities observed within the literature. The final phase of this project is the creation of a tool(kit) that will support carers and care facilities in developing and implementing their PCC practices.

Within this project, three main phases have been identified; define-, collect-, and integrate personhood. During the first phase, the project defined what the personhood of non-verbal persons can be by using a literature review and focus groups with different participants related to these non-verbal persons. Given the interdisciplinary nature of this project, in its second phase, a combination of diverse research methods was employed. Specifically, two qualitative research approaches, frequently applied in the realm of Social Science, were coupled with two participatory research methods commonly utilized in the field of Design Research. These four methods were used to gather insight into the personhood of these non-verbal persons. Two of these methods focused on the non-verbal person themselves, while the other two engaged with *the others*; in this case family members, and carers. One of these methods, engaging with the carers, is the focus of this paper. In the following sections, this paper will present the design, application, and results of a cultural probe study researching the personhood of PwD, through the eyes of their direct carers. For the rest of this paper, the PwD discussed is late stage, so they are also non-verbal. Based on the previously stated challenges, and future application of results, the design of the cultural probe was created with three goals in mind: (1) Explore the carer's viewpoints, attitudes, and beliefs concerning their own personhood, roles, and profession, as well as their interactions with routines, spaces, objects, and other persons—all in relation to the context of their caregiving responsibilities towards both them and the PwD under their care. (2) Examine the perceived reality, barriers, and aspirations of the carers related to their care context. (3) Assess carers as future users of a design tool(kit).

2 Cultural, Technological, Design … Probes?

Cultural Probes is a research method first introduced and discussed in a publication authored by a group of designers led by Bill Gaver et al. [18]. In their work, they described cultural probes as a design-oriented method for gaining insights into users, with a particular emphasis on fostering empathy and engagement. Today cultural probes are seen as a design-oriented method that leverages ambiguity to foster a complex process of shared reflection and sense-making among the participants [19]. Due to their widespread acceptance within the field of design research, they can take many forms and can be applied to a variety of contexts [19]-[20]-[21]-[22]. Even branching off into new research methods, such as technological probes where simple but complete designs are often unmanned and placed within a context, with the intention of inspiring users to reflect on their every day activities differently and send this data back to the designers and researchers [23]. However, in essence, all classical cultural probes are the same and consist of artifacts that enable participants to record their answers in the form of inspirational data concerning a specific topic within a given time frame, without the researcher being present [18]-[22].

Within the scope of design research, the concept of design probes and cultural probes seem to be used almost interchangeably, with Boehner et al. referring to a series of research approaches under the umbrella term of probes that they trace back to Gaver et al.'s introduction to cultural probes [24]-[18], as does Wallace et al. when discussing the creation of design probes in their research [18]-[16]. Nevertheless, the different use of terminology seems to suggest an underlying connection to the original cultural probe design. When discussing design probes, the focus shifts toward the creation of specific artifacts that can almost stand alone, offering greater flexibility for open-mindedness, interpretation, and storytelling. In contrast, the use of the term cultural probes tends to align with the earlier cultural probe designs, where the artifacts are bundled packages consisting of more conventional items such as booklets, maps, and cameras, among others. Given this context and considering the 'conservative' design choices relative to other probe designs, this study opts to use the terminology of cultural probes. Referring to Kitwood's original definition of personhood, carers can be seen as integral to the personhood of PwD as the others. In the context of care, Person-Centered Care (PCC) becomes the intricate interplay between caregivers, PwD, as well as the surrounding spaces, routines, objects, and other individuals. Considering the noted challenges in implementing PCC [6], turning our attention to carers as potential catalysts and keepers of personhood allows us to explore their perceived barriers, opportunities, and aspirations. These insights are essential when striving for future implementation. However, delving into these objectives may potentially place carers in a vulnerable position of introspection. Considering the already existing barriers often present between researchers and participants [25], the unmanned materiality of the cultural probe will not only give the carer room and time for reflection, it aims to offer the participants the opportunity to open up on their terms, within their own time without the constraints of direct research methods. As a small side note, it's important to note that this study is just one of four lenses through which we aim to access personhood. While carers will ultimately be users of the final toolkit due to their physical presence during PCC, the goal is for the spaces, routines, objects, and other individuals involved to facilitate the interplay of PCC between caregiver and PwD without adding undue responsibility or emotional burden onto the caregiver.

3 Application and Design of the Cultural Probe

In the context of the project, this cultural probe was administered to a total of twelve carers. To maintain a consistent research focus, this paper exclusively examines the results obtained from six of these caregivers, all of whom care for PwD. The remaining six caregivers are responsible for PwPIMD; their results will be addressed and compared in future writings. Each of the three care facilities participating in the study selected one PwD and two carers to participate. It's worth noting that all participants, both carers and PwD, identified as female.

3.1 Participation Process

Care facilities were initially contacted through a mailing list compiled based on the networks of the advisory board members of the project and invited to attend an online seminar introducing the research project and its four methods. After the seminar, facilities were asked to contact us via email, the first three facilities in Flanders providing permanent residential care for PwD were selected to participate. Researchers visited these facilities to explain the participation process and plan the research methods. During these visits, participants received information documents and informed consent forms. After confirmation that they would like to participate, the cultural probe packages were explained in person during half-hour visits, and participants had one week to complete the cultural probes before they were collected. These visits were conducted by the first author of this paper. Before introducing the final cultural probe design, we conducted four pilot studies with two carers for PwD and two for PwPIMD, resulting in two adjustment phases of the cultural probe design.

3.2 Cultural Probe Design and Content

Figure 1: *Partial cultural probe content*

The cultural probe, as displayed partially in Figure 1, consists of a black wooden box with a bullseye on the bottom and a fictional floorplan on the lid. Inside, there's a welcome and introduction note, and an activity booklet. To complete the tasks written in this booklet, there are four bags containing various-sized and colored pawns (red, yellow, white, blue), 4 identically shaped white wooden houses, as well as a bag with 6 white and 6 red flags. There is also a small suitcase with 5 empty notes. Lastly, there's a bag with small empty labels and a pen and marker to complete the probe. The activity booklet contains five main questions, numbered on the white pages as 'Q.1,' 'Q.2,' etc., followed by sequential yellow pages labeled as 'Q1.1,' 'Q 1.2,'. These yellow pages are aimed at encouraging further reflection on the respective white page questions.

4 Cultural Probe Results

All results of the probes were photographed and organized according to their question results and overall case results. To reduce waste, after each use, all the paper material was switched out and the other materials were reused, this method ensured that only two complete probe packages needed to be created. Considering the analysis of the results, we align with Gaver et al. their reflection on the danger of summarizing and blunting data, since this holds the danger of reducing exceptional results to average, where the power of cultural probes lies in their exceptionality [26]. However, in order to later compare these results to the other three research methods, some generalizations have been made. The aim was to tailor the analysis method to the received data, some questions look at overarching themes while others highlight possible motives and stories. However, within every cultural probe result the main intention is still to look towards insight into the main three research objectives mentioned previously.

Q.1: The carers were confronted with a fictional situation where the PwD would urgently have to move to another care facility, and they were allowed to write five small notes for the next carer to discover in the PwD's suitcase, that would ensure that they are well taken care of. The responses were categorized and are presented in Table 1. Preferences emerged as the most frequently shared information, including resident's sensory and grooming preferences, as well as food choices.

Table 1: *Q.1 Results and frequency*

Preferences	11
Care techniques	8
Communication	4
Life story	3
Care history	2
Role of family	2

In contrast, aspects such as the resident's life story, care history, and family role were shared less frequently, despite their prominence in current PCC tools in care settings. The disparity of these last three results may be attributed to their perceived commonality, making them potentially self-evident to share. However, it is also important to note that the frequency of information sharing does not necessarily align with their importance. Carers may have favored discussing preferences and care techniques over delving into personal histories or family roles due to privacy considerations.

Q.1.1: Carers were asked to reflect in writing on their ideal situation if a similar scenario were to occur in real life. Here it was interesting to discover how almost all carers addressed that they would prefer to show how to take of the person and show how they would approach them, which is an experience that can be difficult to share when written down. Commonly used words in written Dutch could be translated to; “to demonstrate, to prove, to explain, to show, to walk along.” These verbs can almost all be seen as visual ways to communicate a message which begs the question if there might be a benefit in showing non-verbal care besides writing and speaking about care acts.

Q.2: Participants were asked to identify and label the roles they assign to themselves and to the PwD they care for by writing labels and placing them either on four different-sized pawns for themselves or for the PwD.

Here it was insightful to learn the different approaches to completing the task, where some carers would place one role on one pawn, and others covered the entire pawn in roles suggesting their different perceptions of themselves. Furthermore, it was surprising to learn how frequently their family role was placed on the biggest pawn suggesting the highest importance. 4 out of 6 carers defined themselves primarily as "carers" and secondary as "daughters" and/or "mothers." 5 out of 6 caregivers defined the individuals they cared for as "mothers" first and "resident care receivers" second.

Q.2.1: Carers are invited to reflect on the relevance of these roles within their work in writing. Nearly all carers delved deeply into their familial roles as mothers, daughters, or granddaughters, with three out of six caregivers indicating directly that their roles as "daughters" and/or "mothers" significantly influenced their practice of PCC, enhancing their empathy. This data is not surprising considering that two-thirds of persons with dementia are women, and most carers are also wives and mothers [5], however, it does beg the question if we would see similar results working with male participants. These results also give insight into the perceived relationships between the carer and PwD.

Q.3: The carers are asked to identify four spaces within the facility and place them on a floorplan. Per space, they are tasked to write what happens here, and how a visit with their PwD compares to visits with other residents. They also have the option to share any additional actions that they perform during these visits to support the personhood of the PwD. The living room and personal room were the most frequently identified spaces, this could be attributed to the consistent presence of these spaces in all care facilities. Where the answers to the first two questions gave insight into the overall workings of the facility, the last question gave the most insight into their personal approach. Some carers discussed how the person seems to prefer to be approached, through soft communication on eye level or singing, another carer discussed how they must be wary of the person seeing themselves in the mirror seeing as this could cause discomfort.

Q.3.1: Carers are invited to reflect on their ideal spatial environment, without any restrictions. Many carers recommended a separation of the kitchen from the living room. This suggestion aimed to reduce extra sensory input when residents are relaxing in the living room, promoting a more peaceful and comfortable environment. They also suggested several enhancements for personal rooms, including the incorporation of snoezel elements to provide more sensory experiences and opportunities for individual activities. Some carers proposed integrating neighborhood activities into the care facility, such as setting up an ice shop or a petting zoo. This suggestion aimed to bring the neighborhood community closer to the residents, fostering a sense of belonging and community involvement. These results were exciting to read, as they showed a glimpse into the kind of work environment the carers believe to be beneficial.

Q.4: Carers are tasked with identifying four persons, and three additional objects, and placing these, along with pawns representing themselves and the PwD, onto a bullseye to map their care network. Carers consistently identified other care staff (e.g., carers, doctors, physiotherapists, occupational therapists) and family members (e.g., children, grandchildren, partners) in their care network. Considering important objects, the most identified objects were television, bed, wheelchair, table, garden, and bike. These are almost all generalized care tools, and they may lack a personalized or distinctive quality. Many of these objects serve essential functions but may not offer much room for recreational activities or other forms of engagement beyond their primary functionality.

Q.5: Carers were instructed to identify three disadvantages and three advantages that influence the caring relationship between themselves and the PwD, both for themselves and for the PwD and write them on the accommodating flags. Carers highlighted factors that positively impact their care approach, including having sufficient time, additional staff, lower work pressure, and broader education. Conversely, they identified negative influences such as rushing, poor collaboration with colleagues, personal problems, and stress. Regarding the PwD, positive aspects that enhance care include the presence of family, ensuring a good night's rest, and engaging in singing. Conversely, challenges affecting care included communication difficulties, resident fatigue, and illness. These results are in line with previous studies [6].

Q.5.1: carers were offered the opportunity to reflect on the care mapping and planning they had undertaken throughout the booklet. They were given the option to describe two "bombs" to symbolize events that can negatively impact the process of offering and practicing PCC. This question was explicitly written as optional; four out of six participants answered the question. All four respondents conveyed a similar core message, highlighting the challenges they face when caring for PwD. These key challenges include frequent miscommunications and the difficulty of interpreting the needs of the persons they care for. High work pressure and time constraints were again mentioned as additional barriers. Two carers distinctly shared that due to these challenges, they are not able to offer the care that they would want to offer.

4.1 Overall Reflections on the Probe Design

The design choices made in this study significantly influenced the participants' responses, all probes were completed according to the preferences of the participants, with some participants visibly seeming to spend more time on the completion of the probes by providing longer answers, including additional notes within the booklet to ensure their data was interpreted and contextualized accordingly. In Q.1.1, 2.1, and 3.1, the use of written reflection intentionally aimed to guide the carers' responses toward topics of reflection by framing their thoughts through specific language and available space. They also functioned well as follow-up questions and helped contextualize some of the answers shared previously. Q.2 and Q.4 utilized visual elements like the bullseye and colored pawns to add an aspect of gamification to the cultural probe to make the experience more enjoyable and visual, resulting in diverse interpretations of how these artifacts should, or could be used. While some participants assigned single roles to pawns, others attributed multiple roles, reflecting the varied perspectives on their carer roles. Q.3, which involved wooden houses representing spaces, occasionally led to confusion, as participants sometimes perceived them as separate buildings rather than distinct spaces even though this meaning was shared within the question. Placing the houses on the floor plan didn't consistently yield valuable data. Q.5 employed flags with limited writing space, to encourage the carers to concise their answers and only write the essence of their answer. In retrospect, this caused the data to be easy to compare but also made it generic and it almost lost the point of being a cultural probe due to its closed directness. In Q.4, the use of randomly shaped pawns to identify objects led to diverse approaches and interpretations of what an object could be within this context, however, the overall choice of objects was rather disappointing due to the kind of objects that were chosen, and how limiting their functionality seems to be from a designer-researcher's perspective. Q.5.1 provided participants with a dedicated space to openly discuss challenges they face, or fear to face within their care practice. Here, the metaphorical use of "bombs" allowed carers to symbolically express obstacles, visually disrupting the established relationships and planning previously created during the bullseye mapping. Compared to Q.5, they are both aimed at the same subject, but by making Q.5.1 almost a sort of a wildcard the answers were more varied and richer.

5 Conclusion

This study was designed to answer three main objectives: (1) to understand the context of the carers in all aspects, (2) to explore their perceived reality, barriers, and aspirations, (3) and to assess their abilities as future users of a design tool(kit). Key findings from this study highlight the significance of acknowledging the social context of carers through their family roles, specifically the role of mothers or daughters in the carer's care practice, and their relevance when performing care. Throughout the responses to the probe, there also is a consistent narrative of carers having intentional ideas for enhancing care through architectural or procedural changes. They also integrate personal approaches to PCC when feasible, while expressing high workload and little time as significant barriers that can obstruct these intentions. Lastly, the study provided insight into the carers' way of communicating care through written, performative, and visual language of knowledge transfer. Furthermore, our reflection on the cultural probe design provided insights into how specific prompts, use of space, and artifacts were received by carers, offering valuable insights for the development of a future tool(kit).

6 Declarations

6.1 Acknowledgements

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6.2 Study Limitations

This study has several limitations to consider. Firstly, the sample size was limited to six carers, chosen by the care facilities, which may affect the study's generalizability. Additionally, participants completed the cultural probes during their regular work schedule, the researchers urged the facilities to take this additional workload into account by reducing their regular workload during this week, however, workload consistency cannot be confirmed. This variation in available time might impact data quality and comparability. Lastly, researchers' perspectives and intentions in designing the cultural probe study may introduce bias, despite efforts to mitigate it through reflexivity within the writing of this study. The design of the probe also caused some data to be lacking certain context, potential opportunity for future studies could be to have a follow-up interview with the participants to ensure correct interpretation and contextualization of the research data.

6.3 Funding source

This study is part of an interdisciplinary project funded by KU Leuven IDN funding.

6.4 Ethical Approval

Ethical approval has been granted for this study by EC KU Leuven reference number S66592.

6.5 Informed Consent

Informed consent has been collected from all participants according to EC KU Leuven guidelines.

6.6 Publisher's Note

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