Dualities of co-design in the context of dementia: can handover approaches provide an answer?

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Is co-design together with people with dementia always feasible? Designing for people with dementia is challenging, and co-design has been widely recognised as an effective approach to design products conform to participants’ needs. The inclusion of people with dementia provides designers with an authentic representation of dementia, regardless of stereotypes and assumptions. However, it is not always easy to implement co-design with people with dementia in practice. This paper examines the feasibility of co-design with people with dementia through reflective practice, semi-structured interviews with designers, and a rapid literature review. The study identifies three dualities of co-design, addressing three benefits and three barriers when involving people with dementia in the design process. While co-design should always be prioritised, there is a need to explore alternative approaches to increase the accessibility of designing for people with dementia in design practice. This paper proposes handover approaches as an alternative to address some of the barriers associated with co-design. Handover approaches offer opportunities to include the voice of people with dementia in the design process and their development could contribute to the accessibility of designing for people with dementia in general. However, the paper concludes that the development of handover approaches also poses concerns that require further research in order to identify and develop effective handover approaches.

Keywords: co-design; handover approach; dementia; design research

1 Introduction

The World Health Organisation states that more than 55 million people are living with dementia worldwide (WHO, 2023). With a greying population and no cure in sight, this number is expected to rise. As the cognitive and psychiatric abilities of people with dementia (PwD) deteriorate, additional physical problems occur alongside, affecting each person differently (Cerejeira et al. 2012). Due to the progression of the disease, PwD rely more and more on the support of others. Therefore, dementia affects not only the persons themselves, but also the social network around the person.
Products can increase the quality of life of PwD, provided they are well-designed and conform to the individual’s needs (Smeenk, 2019). The last couple of decades witnessed a shift toward the inclusion of PwD in the design process (Wilkinson, 2002; Suijkerbuijk et al., 2022). Co-design is widely advised as a means for designers to have direct contact with PwD, establish a designer-participant relationship, and design products that meet PwD needs (Kouprie & Sleeswijk Visser, 2009; Lindsay et al., 2012; Houston et al., 2020). Direct contact is seen as “a prime and irreplaceable source for obtaining empathy with users” (Van Rijn et al., 2011, p. 65), resulting in more successful products. This collaborative practice is fully in line with the ideological foundation of co-design to give a voice to the people who interact with the products being designed (Mattelmäki & Battarbee, 2002; Houston et al., 2020).

However, is co-design always feasible in design practice? The involvement of PwD in the design process poses risks due to the nature of dementia (Hellström et al., 2007). In addition, Hendriks (2019) states that to build an empathetic understanding for PwD, one needs to fully immerse oneself in the life of PwD and build a designer-participant connection. This connection takes time and demands effort from the designer, yet investments in time and resources are often limited in design projects (Smeenk, 2019). Ultimately, this paper identifies three dualities of co-design with PwD, addressing benefits and barriers. Although co-design with PwD should always be prioritised, it can be challenging to implement in design practice. In cases when the barriers of co-design are too difficult to overcome, handover approaches (HOAs) could provide an alternative. HOAs transfer information to designers to build an empathic understanding for PwD, without having direct contact with PwD (Smeenk, 2019). This paper demonstrates the ways in which HOAs respond to the dualities of co-design, while also acknowledging that HOAs come with concerns of their own.

2 Methods

2.1 Identifying benefits and barriers

During two years of research, three methods were combined to identify benefits and barriers of co-design with PwD; (1) reflective practice, (2) semi-structured interview sessions with 12 designers, and (3) a rapid literature review.

2.1.1 Reflective practice

Reflective practice (Schön, 1983) was conducted during regular ethnographic participation with PwD (i.e. volunteering once a week in a daycare centre) and practising co-design with PwD in two different project contexts (i.e. the Interreg Certification-D project to evaluate and certify products, and the LUCA Impulse project to integrate co-design methods in design education). Outcomes from the two projects include observations, field notes, sketches, audio and video recordings, informal conversations, and semi-structured interviews, as well as materials, prototypes, and products made by PwD and designers. Knowledge was generated during practice and through reflection on practice, making the analysis process reflective in nature. Benefits and barriers of co-design were identified and clustered through thematic analysis to identify shared learnings and to guide our interpretations of the research.
2.1.2  Semi-structured interviews

In total, twelve one-on-one, in-depth interviews were held, in which designers focussed on their experiences of employing co-design methods and reflected on the benefits and barriers of including PwD in design practice. Designers (i.e. professional and educational context) were recruited using direct communication and chain referral sampling. Each session started with a three-minute introduction video and lasted approximately three hours to ask for immediate clarification or further explanation and to optimise the recall from the designer’s perspective. The interviews were guided by three main questions and subquestions for designers to reflect on their practice, their opinion on the involvement of participants in the design process, and their perspective on the strengths and weaknesses of co-design. Each session was carried out in person and a physical tool was created for the sessions to capture the designer’s output and visually guide the conversation. All twelve interviews were video and audio-recorded with permission and transcribed in full.
2.1.3 Rapid literature review
A literature search was undertaken to identify relevant learnings of co-design in design practice. Google Scholar was used to look for articles with a focus on the inclusion of PwD in co-design. The pragmatic choice for a rapid review was made, given multiple existing reviews address the challenges of co-design. Six eligible papers were identified as holding positive and negative statements on implementing co-design methods with PwD. These statements were clustered, resulting in a list of factors that hinder and support the inclusion of PwD in the design process.

2.2 Clustering benefits and barriers, to define three dualities
The study revealed that, for each benefit identified, a corresponding barrier from the perspective of the designer occurred. To gain a deeper understanding of this phenomenon, a three-step clustering methodology was utilised. Firstly, the primary author used a Miro board to cluster all the identified benefits and barriers, resulting in seven clusters. Secondly, this Miro board was converted into a text format and analysed by the two co-authors of this paper, who have over 20 years of combined experience in co-design involving PwD. Two similar clusters were merged and one was removed due to a lack of supportive data, resulting in four clusters. Thirdly, a focus group consisting of four PhD candidates, whose doctoral research focuses on integrating co-design methods with vulnerable populations, was convened. This group eliminated one cluster that was deemed difficult to establish in the context of dementia, resulting in a total of three dualities of co-design with PwD: (1) emotional connection and emotional burden, (2) ideological positioning and practical restrictions, and (3) mutual gain and individual gain.

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Figure 4. Overview of benefits and barriers in co-design. Source: Lieke Lenaerts.
3 Three dualities of co-design with people with dementia

Co-design is grounded in the idea that people desire to have agency in various aspects of their lives. In the context of design, this translates to involving participants in the design process (Simonsen & Robertson, 2013). As participants, PwD are recognized as individuals with unique wishes and needs (Kitwood, 1996). By being actively involved in the process, they can have a say in the final product outcomes that will impact their lives, and designers can develop an understanding of the experience of living with dementia (Wilkinson, 2002). However, involving PwD in co-design processes can be challenging, due to the nature of dementia. In light of this challenge, three dualities that arise in co-design with PwD were identified: (1) emotional connection and emotional burden, (2) ideological positioning and practical restrictions, and (3) mutual gain and individual gain. In the following description of these dualities, the primary focus lies on the perspective of the designer, while also incorporating viewpoints of PwD.

3.1 Emotional connection and emotional burden

The first duality of co-design with PwD addresses the benefits of an emotional connection, however, in practice the involvement of PwD can emotionally burden all parties involved and thus hinder the design process.

Co-design acknowledges the participant, not merely as an informant, but as a contributor to the design process (Simonsen & Robertson, 2013). To create the required conditions for PwD to participate in the design process (i.e. inviting participants to open up about their life experiences, reflect on their needs and wishes, discuss the future use of products) designers have to invest in designer-participant relationships (Liddle et al., 2022). To emotionally connect with participants, designers need to devote time for in-person contact to establish feelings of trust and empathy (Raman & French, 2022). A longer duration of contact results in a closer relationship to attune participation and ensure richer insights, and is particularly important when a long-term engagement of PwD in the design project is desired (Liddle et al. 2022). In addition, this connection motivates designers (Wilkinson, 2020), as mentioned by a designer during the research: “...what really motivated me was the fact that I had contact with the people, otherwise, I would have never worked on the weekends... in that regard, the connection provided a huge stimulation to walk the extra mile.”

Designers need appropriate skills to connect and participate with PwD, however a lack of skills can turn the co-design process into an emotional burden for both PwD and designers. The involvement can confront PwD with the label of dementia (e.g. recruitment material, during interviews). In cases where a person does not identify as having dementia, this may cause considerable distress (Bartlett & Martin, 2002; Pesonen et al., 2011). Along with this, co-design can confront PwD with the progressiveness of dementia when the project becomes too hard to participate in (Hellstrom et al., 2007; Pesonen et al., 2011). Confusion, behavioural changes and communication difficulties can occur more frequently, so a dynamic capacity is required from designers. Literature refers to this capacity as ‘relational expertise’ (Edwards, 2011) or ‘situational sensitivity’ (Heggestad et al., 2013) and states that it falls within the core expertise of a designer (Dindler & Iversen, 2014). However, designers can lack this capacity (Lindsay et al., 2012). Hubbard et al. (2003) report on situations in which PwD felt distressed during conversations with designers lacking the capacity to communicate about sensitive topics. In the research carried out, the significant differences between PwD and designers often caused communication difficulties. One designer with a different cultural background
and religion as the participants, was “worried about the conversation with them, how that would work out and how [she] could keep the conversation going. It was hard to keep the conversation going.” Additionally, a designers’ stigmatisation of dementia can result in unequal relationships with PwD, and symptoms of dementia like frustration, agitation or aggression can frighten designers to interact with PwD (Wilkinson, 2002; Smeenk, 2019; Liddle et al., 2022). In the research, designers were noticed to be nervous, embarrassed or even scared to interact with PwD.

Moreover, when designers can form an emotional connection, it can have consequences for their well-being. Suijkerbuijk et al. (2022) describe interactions with PwD in deep distress having an emotional impact on the designer, who was unprepared for these circumstances. In the research carried out, it was often emotionally challenging for designers to witness the cognitive and physical decline of participants over the duration of the project. One designer had to process the sudden death of a participant with young-onset dementia, leaving the designer with grief and an unwillingness to build new connections with other participants. Other designers were confronted with care contexts ill-treating PwD (e.g. ignoring patients, using stigmatising language, fixating PwD), emotionally overwhelming one designer for whom “it was hard and [she] had to recover from [her] visits when [she] came home because there were some things in the care home which really shocked [her].” Furthermore, the involvement of PwD may overwhelm designers’ moral obligation, as they feel responsible for PwD. Navigating participants’ questions about their condition, treatment options and available services can be emotionally burdening, especially when the PwD needs support (Pratt, 2002; Pesonen et al., 2011). Kowe et al. (2022) report on situations where designers take on tasks that fall outside of the design project. Balancing a professional and personal relationship in co-design is often challenging, and can negatively impact the design process (Kowe et al., 2022). During the research, one designer “sometimes had the feeling that [she] was so heavily involved that [she] could put less energy in the design.”

On the other hand, designer-participant relationships can enhance social desirability, for example, PwD keeping up appearances instead of honestly sharing their struggles, not daring to be explicit in comments or criticism, or joining co-design sessions as a favour to others, while they prefer not to participate in the project (Hendriks, 2019; Suijkerbuijk et al., 2022). Additionally, the designer-participant relationship can become important within the social network of PwD. Regular visits from designers can bring about a strong personal connection (Liddle et al., 2022). After a co-design project, a designer described that “[the PwD] was really happy with the extra attention, the extra visits, and it became more of a friendship.” At the end of the co-design process, it remains cognitively challenging for PwD to comprehend that the project is finished and that the designers are no longer visiting regularly (Lindsay et al., 2012). Exit strategies are recommended by literature (Hendriks, 2019), however, some participants still experience a loss when the designer-participant relationship ends.

3.2 Ideological positioning and practical restrictions
The second duality of co-design deals with the ideological positioning to shift the power inequalities, even when participants are vulnerable, as is the case for PwD (Wilkinson, 2002; Lindsay et al., 2012). PwD have historically been excluded from direct involvement in the design process, however, the last decades show an increase in the involvement of PwD in the design process and a rise in the requests by clients and funding bodies to include participants in projects (Wilkinson, 2002; Liddle et al., 2022). Co-design is an inclusive approach and provides designers with suitable methods and tools to enable
participation (Wang et al., 2019). Literature refers to co-design as a political and ethical commitment to ensure that the voices of the people with lived experiences are heard (Simonsen & Robertson, 2013; Houston et al., 2020). With their involvement, PwD can be seen by designers as people with valid experiences and whose behaviours are driven by meaning, reducing the stigma on dementia (Wilkinson, 2002). Co-design enables designers to develop a better understanding of what it means to be a PwD and induce real change in the development of products (Wilkinson, 2002; Houston et al., 2020). Co-design taps into a designer’s responsibility (Kowe et al., 2022) and designers often view participation with PwD as “the most important strength” of their design process and reputation (designer with advanced experience with co-design with PwD).

Despite the ideological positioning and cultural emphasis on the value of partnering with PwD, the duality lies in the many organisational factors of design practice that do not support co-design. In the research carried out, several practical hindrances were encountered, making it challenging to involve PwD in design projects.

The design process requires among other things, abstract thinking, imagining future product use, and articulation of opinions and thoughts. Yet, dementia affects a person’s communicative, cognitive and behavioural abilities, making it hard for PwD to perform these tasks (Hendriks et al. 2014; Wang et al., 2019). Since most co-design methods are designed for cognitively and physically healthy participants, designers have to search for dementia-specific methods or tailor existing methods to PwD’s needs (Hendriks, 2019; Liddle et al., 2022). Adjusting methods to the participant’s abilities is a design process in itself especially when designers lack prior experience with PwD, risking delays or a lack of effective contribution from PwD. In some projects (e.g. costly highly defined technical products) adapting the process to include PwD is an unrealistic expectation (Liddle et al., 2022). Furthermore, the individual and unpredictable nature of dementia requires additional effort to recruit participants and makes it hard for PwD to engage for an entire project duration. Drop-outs have to be taken into account, especially in long-term projects (Hendriks, 2019; Liddle et al., 2022). Also, when participants show signs of fatigue, distress or lack of attention, designers should consider pausing or ending the participation, which can cause tension with the time-bound nature of most design projects (Raman & French, 2022). Co-design projects often take more time than anticipated and “today as a designer, your biggest enemy is time” (senior designer during the interview).

Additionally, the inclusion of PwD often requires organisational changes. During the research, it was often difficult for PwD to come to the workplace during working hours (e.g. other care- and work responsibilities, mobility impairments, distress, limited resources) and the use of online meeting tools proved challenging for PwD due to technical deficiency or confusion caused by ‘talking to a stranger on a screen’ (Zallio et al., 2022). Therefore, designers have to make the effort to visit the homes, daycare centres or care homes of PwD in a suitable time frame for the participants (Hubbard et al., 2003; Novek & Wilkinson, 2019). Risk measures and legal obligations are required for designers to gain access (Gerritsen et al., 2018). On the one hand, the question remains if PwD fully understand what it entails to give consent due to their lack of psychological or physical capacities (Tutenel & Heylighen, 2021; Hendriks et al. 2018). On the other hand, these, in most cases lengthy and complex processes of ethical approvals and informed consent-giving add to the workload and project duration, and can make it infeasible to involve PwD in practice. A design educator with advanced experience in co-design
with PwD mentioned that “the time that the students can make a project is too short to have an ethical approval for working with people with dementia.”

Resources (i.e. time, budget, people and expertise) prove crucial to participating with PwD in a meaningful way, however, design projects often lack the necessary adaptations. Therefore, designers may simply not have the means to conduct co-design.

### 3.3 Mutual gains and individual gains

The third duality addresses the mutual gains for both designers and participants, since a genuine co-design process is one of mutual learning, equal roles and mutual benefits (Simonsen & Robertson, 2013; Wang et al., 2019). Co-design teaches designers to be responsive to new changes and perspectives and to adapt methods, tools and the pace of the design process to PwD (Zallio et al., 2022). In the research, designers often automatically adapted to the participant’s abilities, as addressed by a junior designer who “figured out [her] own feedback” since the person with dementia “never said this and this has to be different, it was more how she interacted with products, for example, where [she] got [her] feedback.” Suijkerbuijk et al. (2022) defined this as ‘designer’s adaptivity’. Through experience, designers develop their adaptivity and an understanding of what works and what does not work when involving PwD in co-design sessions (Liddle et al., 2022). Interaction with PwD provides designers with additional competencies and skills (e.g. the ability to communicate with a lay audience, active listening skills, sensitivity) (Wilkinson, 2002; Kowe et al., 2022). These competencies are defined as ‘soft skills’ as they are not directly related to the design discipline (Wilkinson, 2020). There is a lack of research into the long-term impact of soft skills on designers, however, cases in the educational context show a positive impact on young designers, for example, an improved ability to adapt to and empathise with different participants (Wilkinson, 2020).

Co-design aims to give participants and designers equal roles, contrary to design processes in which designers are the ‘experts’ and the participants are merely the objects of investigation. PwD need to gain insight into the design process and product options in order to take on equal roles in the design process. Designers are the source of this knowledge and have to support PwD with design-related information and practical advice (e.g. training for participants) (Wang et al., 2019). However, a designer’s familiarity with the design process will always be advantageous in comparison to the gained design-related knowledge of PwD. Nevertheless, PwD’s contribution and, along with that, shared ownership of the design process and outcomes can evoke positive feelings and build confidence (Suijkerbuijk et al., 2019). In literature, these positive feelings are described as ‘in-the-moment pleasure’ (Kenning, 2017) and in the research carried out, designers often reported a rise in positive feelings from the PwD during co-design sessions. A young designer mentioned the PwD grabbing her and saying “I’m really happy that you come and make time for me.” Furthermore, co-design can give PwD a feeling of empowerment by taking on the role of experts by experience in the design process (Liddle et al., 2022). Unsurprisingly, receiving the diagnosis of dementia often causes distress due to the future progressive loss of abilities. Feeling heard and valued by designers can give PwD a sense of purpose and belonging (Kitwood, 1996). In the research, participants often opened up and expressed personal feelings, opinions, interests and needs (Suijkerbuijk et al., 2022).

Mutual gains (i.e. equal roles, mutual learning and benefits) are a central concept of co-design, however, cannot always be guaranteed in co-design with PwD. Expecting PwD to take on an equal role in the design process is perceived as unrealistic. Hendriks et al. (2014) report PwD lacking initiative,
having problems making choices and understanding tasks given by the designer. In the research carried out, PwD needed continuous help and strict guidance from the designers. Developing trusting relationships can reduce the power inequalities between participants and designers (Hellstrom et al., 2007). However, blurring the roles of designer and participant means conducting design-related tasks together (e.g. formulating project goals, identifying design-related issues, planning the design process, analysing the data collected), with the risk of placing too high demands on PwD regarding the workload and tasks in the design process (Hendriks et al. 2014; Kowe et al., 2022). So, often a hierarchy remains between the designer and PwD. This hierarchy is evident for some designers as expressed during an interview with a junior designer, who believes that “a designer should have a bit of a detached relationship anyway because you are in a power relationship.” However, this hierarchy can cause feelings of tension (Hendriks et al. 2014) and role ambiguity, since the loss of cognitive abilities may cause PwD to forget the role of the designer or the purpose of the project (Pesonen et al., 2011; Pratt, 2002).

Additionally, the cognitive decline experienced by PwD makes it difficult to assess if PwD learned or gained something from their involvement in the design process (Hendriks et al. 2018). In the research, PwD often struggled to recall previous co-design sessions or the abilities they learned during those sessions. For instance, in one project PwD were encouraged to interact with a tablet designed for seniors. While some participants had high hopes of learning how to use this new technology, they experienced disappointment when they were unable to remember how to use the tablet. Consequently, encouraging participants to learn new skills in co-design projects, may result in false hope. Furthermore, given the progressiveness of dementia, often only PwD in the early and middle stages of dementia are involved in the design process. Those in the more advanced stages of dementia are often excluded or only involved in the end stages, where only small changes can be made (i.e. standardisation and tailoring possibilities) or just as a mere audience in the design process (Suijkerbuijk et al., 2019, Liddle et al., 2022). In these cases, the term ‘co-design’ is used as a token for apparent participation, often only serving mandatory demands from clients or funders, or the building of a reputation as an inclusive designer or agency, rather than fostering genuine collaboration with PwD (Vandenberghhe & Slegers, 2016).

Lastly, aspects of the design process make it hard to guarantee equal benefits for PwD. Limited budgets, fixed appointments, tight deadlines and design jargon impose practical restrictions and can cause feelings of exploitation instead of empowerment (Kowe et al., 2022; Liddle et al., 2022). In the research carried out, designers were noticed pressuring participants to meet deadlines, leaving PwD feeling distressed instead of experiencing in-the-moment pleasure. Furthermore, literature states that participants should be paid equally for their valuable contribution, however, limited budgets often prevent this, causing feelings of exploitation for PwD as they participate in the design process, but not as employees (Postma et al., 2012).

4 Handover approaches as an alternative?

At the beginning of a design project the question should be raised whether genuine co-design with PwD is feasible. The benefits of co-design are rich (i.e. the emotional connection, ideological grounds, and mutual gain) so co-design should always be prioritised. However, its potential benefits must be balanced against potential risks to the welfare of both participants and designers and the practical
feasibility of their inclusion in the project. The barriers to the inclusion of PwD (i.e. the emotional burden, practical restrictions, and individual gain) are unfortunately still quite common in design practice and demonstrate the need for designers to explore alternative processes (Van Rijn et al., 2011; Smeenk, 2019). Specifically, this research investigates the use of handover approaches (HOAs) as an alternative process. An HOA is defined as a coherent set of organising principles, methods and tools to carry out the process of transferring information about PwD to designers who are unable to meet PwD in person. This definition distinguishes HOAs from other tools that generalise, objectify or quantify participant insights (e.g. persona, marketing data). HOAs focus on the transfer of an empathic understanding for PwD as unique individuals, through anecdotal and relational insights based on emotional connections with PwD. This definition is based on our research and the studies of Smeenk, who developed the Empathic Handover approach (Smeenk, 2019). In the Empathic Handover approach, first a consistent point of contact establishes a connection with PwD to collect first-person experiences. These experiences and insights are then transferred to designers who did not meet the PwD in person, following two sequential activities; (1) the use of empathic questions to elicit empathy for PwD through autobiographical memory, and (2) the use of roleplay to enact and imagine daily life situations of PwD (Smeenk, 2019). The Empathic Handover approach can be regarded as an example to further examine how the use of HOAs could tackle some of the identified barriers of co-design.

4.1 Handover approaches tackle the barriers of co-design

The first identified barrier of co-design with PwD is the emotional burden co-design can cause for both participants and designers. McKeown et al. (2010) state that the ethical complexity and sensitivity of dementia demand particular knowledge and skills, which not all designers possess. “Designers can be great and very systematic, but they can lack being empathetic” (senior designer during the interview). In the research carried out, designers were observed to be unable to connect or empathise with PwD. An HOA eliminates direct contact, and with this, the risk for designers to emotionally overwhelm or burden participants. Additionally, designers can be hesitant or unwilling to work with PwD, as confirmed by a designer with advanced experience in co-design projects: “If it’s not for you, it’s not for you. At our studio, at the start of the dementia project, there were people who clearly said ‘I don’t feel like doing that’.” In these cases, an HOA can engage designers in another way, avoiding direct contact with PwD.

Secondly, practical restrictions hinder the involvement of PwD in design practice. The involvement of PwD implies the recruitment of participants, addressed by a senior designer as “a real problem” and “an investment you want to avoid”. Furthermore, organisational tasks such as risk measures, ethical approvals, and preparation of dementia-specific methods, are necessary for the participation of PwD. These tasks often take more time than anticipated resulting in higher budget needs. By using HOAs, organisational tasks for the recruitment and inclusion of PwD can be eliminated.

The third barrier identified the risk of individual gain for designers instead of mutual gain for designers and participants. In design practice, the focus often purely lies on the designed outcomes, with the risk of pressuring participants to reach target goals (Postma et al., 2012). A time-bound product-centric design process can be at odds with the fundamental concepts of co-design (e.g. mutual learning, equal roles, mutual benefits) as mentioned by a senior designer who “has to take shortcuts, because sometimes [he] only has 80 hours and at the end, there has to be a design.” In these circumstances, HOAs offer a shortcut.
4.2 Handover approaches come with concerns of their own

In design processes where barriers (i.e. the emotional burden, practical restrictions, individual gain) make it challenging to involve PwD, using HOAs can be a viable alternative. However, while HOAs present opportunities, transferring participant insights is challenging and there are concerns to be addressed (Smeenk, 2019). By comparing research on HOAs to the three dualities of co-design with PwD, three major concerns emerged: (1) a potential lack of emotional connection between designers and participants, (2) ethical restrictions that may arise, and (3) HOAs transferring an individualistic view.

4.2.1 Lack of emotional connection

There is widespread agreement that the level of empathic understanding designers have for participants significantly influences both the design process and its outcomes (Kouprie & Sleeswijk Visser, 2009, Van Rijn et al., 2011). In-person contact with PwD is widely recommended to attain an empathic understanding. It gives designers insight into the actual experience of living with dementia (Houston et al., 2020). After a co-design project with PwD, a designer mentioned that “by really entering their world and sitting there every week and seeing, experiencing how things happen there and how people with dementia experience it... you learn so much more”. Simonsen & Robertson (2013) use the term ‘practice’ to recognise the value of everyday practical action of participants. However, the lack of understanding of the practices of PwD may lead to single-mindedness and reinforcing stereotypes, a major concern of HOAs. Furthermore, ‘being there’ is an important addition since much of the knowledge gained during in-person contact tends to be tacit (Spinuzzi, 2005). In-person-contact allows designers to observe a PwD’s body language, tone of voice, and other mannerisms. Visits to the homes or care context of PwD offer designers an understanding of the environment in which the outcomes of the design process will be used (Simonsen & Robertson, 2013; Liddle et al., 2022). This contextual knowledge can provide designers with stimulus and inspiration, beneficial for the course of the project (Wilkinson, 2020). However, with the use of HOAs, designers risk losing tacit and contextual knowledge about PwD, making it harder for designers to reach a certain level of motivation and empathic understanding.
4.2.2 Ethical restrictions

Designers’ ethical commitment to include the voice of those who will use the outcomes is at odds with the use of HOAs (Simonsen & Robertson, 2013). ‘Ideological positioning’ was identified as a benefit of co-design, to shift the power inequalities inherent to the design process (Wilkinson, 2002). PwD should participate in the design of products that will affect their daily life, however, by offering alternative design methods like HOAs, there is a risk of designers assuming that it is too challenging to involve PwD in the design process. In the past, barriers have been used to justify the exclusion of PwD from the design process (Hellstrom et al., 2007). This research does not want to contribute to the justification of the exclusion of PwD from the design process. Contrary, this research wants to provide designers with alternative processes to incorporate the voice of PwD in the design process, in cases where co-design is not feasible. However, advocating HOAs to the design community could lead to the reinforcement of negative stereotypes of incapacity, reduced participation or exclusion of PwD in design processes, a step backwards for the empowerment of PwD.

4.2.3 The individual view

Designers who are unable to meet PwD have to gain a considerable amount of knowledge to be able to design for PwD. In this regard, HOAs should transfer enough valuable, inspirational and informative insights from PwD. A challenging task for the maker and facilitator of the HOA. In the Empathic Handover approach of Smeenk (2019) a consistent point of contact between PwD and the designers has to transfer their experiences, represent participants realistically, and engage and align designers to design successful outcomes. However, transferred knowledge risks being biased by representing the individual view of the maker or facilitator of the HOA. Who PwD really are, is often very different from the way they are described or depicted by others (Van Gorp & Vercruysse, 2011). Representations of PwD risk the portrayal of general recommendations (i.e. what PwD should do or might ideally do ‘in theory’) and broad existing assumptions about dementia (Van Gorp & Vercruysse, 2011; Liddle et al., 2022). Moreover, designers run the risk of projecting their individual assumptions and emotions about PwD. During the research, a senior designer mentioned that “because of [his] parents [diagnosed with dementia], he had his own image of what dementia is and how to deal with it.” The use of HOAs may lead to the transfer of insufficient knowledge, single-mindedness and reinforcement of the stigma of dementia. Dealing with this individual view on dementia is the third major concern of HOAs.

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<td>PRODUCT-CENTRIC GAIN &gt; THE INDIVIDUAL VIEW</td>
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Figure 6. Comparison between the two methods. Source: Lieke Lenaerts.
5 Conclusion

Designers have to foster an empathic understanding for PwD to design products that meet participants’ needs. Co-design is widely recommended for achieving an empathic understanding, however, implementing co-design in practice is not always feasible. This paper describes the benefits and barriers encountered during two years of research, defining three dualities of co-design in practice; (1) the emotional connection and the emotional burden, (2) ideological positioning and practical restrictions, and (3) mutual gain and individual gain. When starting a design project in the context of dementia, designers have to consider the dualities of co-design, weighing the benefits of participation against the barriers, to determine a suitable trajectory for all parties involved.

Although co-design should always be prioritised, this paper examines HOAs as a promising alternative to represent the voice of PwD in a design process and transfer an empathic understanding for PwD, without direct contact between designers and participants. However, limited research is available on the use of HOAs in design for dementia, and the use of HOAs raises considerable concerns pending the exclusion of participants. This paper identifies three major concerns related to the use of HOAs: (1) lack of emotional connection, (2) ethical restrictions, and (3) the individual view. To address these concerns, the next step is to review existing HOAs in different contexts and investigate their potential to represent participants with dementia, and to test their use in design practice. Since both methods hold considerable value, in addition to a comparison between HOAs and co-design, the research aims to look at HOAs as a contribution to co-design, making the design process for PwD more accessible.

References


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**About the Authors:**

**Lieke Lenaerts:** PhD-candidate looking into the accessibility of designing for people with dementia. Designer-researcher focusing on design and dementia projects. Previous related experiences include design and research projects with a focus on the communicative aspects of design.

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