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# Co-designing with people with dementia: A scoping review of involving people with dementia in design research

Gubing Wang<sup>a,\*</sup>, Chiara Marradi<sup>a</sup>, Armagan Albayrak<sup>a</sup>, Tischa J.M. van der Cammen<sup>a,b</sup>

<sup>a</sup> Faculty of Industrial Design Engineering, Delft University of Technology, Delft, The Netherlands

<sup>b</sup> Section of Geriatric Medicine, Department of Internal Medicine, Erasmus University Medical Center, Rotterdam, The Netherlands

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## ABSTRACT

Co-designing with people with dementia (PwD) can uncover their needs and preferences, which have been often overlooked. It is difficult for PwD to understand designers and express themselves in a conventional co-design session. This study aims to evaluate the effects of involving PwD in design research on both PwD and the design process; to identify the trends of involving PwD in design research; to extract tools, recommendations, and limitations of involving PwD from reviewed studies to update the recommendations on how to co-design with PwD. A scoping review was carried out within the electronic databases PubMed and Scopus, and eight research questions were proposed, in order to gain specific knowledge on the involvement of PwD in design research. Twenty-six studies met the inclusion criteria, and 32 sessions were evaluated. Beneficial effects on both PwD and the design process were reported. The number of studies involving PwD in the moderate and severe stages of dementia has increased. Based on the review, an update of the existing tools and recommendations for co-designing with PwD is provided and a list of limitations of involving PwD is presented. The review shows that involving PwD in design research is beneficial for both the PwD and the design process, and there is a shift towards involving people who are in the moderate and severe stages of dementia. The authors propose that multidisciplinary meetings and case studies should be carried out to evaluate and refine the list of tools and recommendations as well as the list of limitations generated in this review.

## 1. Introduction

Fifty million people worldwide were living with dementia in 2018 and the numbers are expected to triple to 152 million by 2050 [1]. Dementia is the loss of cognitive functioning in a way that, most of the time, compromises the person's daily-life activities and social interactions [2]. Some of the main functions affected in people with dementia (PwD) are memory, verbal skills, visual perception, and attention span [3]. These cognitive impairments hinder PwD from expressing what they want and how they feel, which makes caring for PwD different from caring for older adults who can communicate their needs and preferences. Therefore, PwD should be approached differently, and we believe a co-design approach with PwD could uncover their needs and preferences. Co-designing with PwD can offer novel ways of complementing existing approaches to care to improve their quality of life [4].

Co-design is a well-established approach in design practice [5]. Including users and other stakeholders in the design process can lead to designs that meet their needs and preferences [6]. Co-design refers to

“the creativity of designers and people not trained in design working together in the design development process”. Most people are creative and can contribute to design if provided with appropriate settings and tools [5]. The benefits of co-design have led to its application in designing for people with cognitive impairments, such as people with acquired brain injury (ABI) [7], and people living with dementia [4]. For ABI, co-design has been applied to generate an ecosystem of supports with the latest technology for people with ABI and their families [7]. For PwD, co-designing aids to create a common knowledge base among designers, users and other stakeholders about what living with dementia means, and helps to gain insight into what the remaining capabilities of PwD are; in fact, though, so far, most of the non-pharmacological interventions developed for PwD have failed to consider the remaining capabilities of PwD [8]. The process of co-design could also have a positive impact on the subjective well-being of PwD because it fosters social interaction and enhances empathic connections between participants [6]. As Kitwood states, “a person with dementia must be recognized as a person with thoughts, emotions, and wishes”; thus PwD should be included in the design process [9].

\* Corresponding author.

E-mail address: [g.wang-2@tudelft.nl](mailto:g.wang-2@tudelft.nl) (G. Wang).

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Despite the above benefits, there are challenges when co-designing with PwD [10]. Due to their cognitive impairments, PwD cannot always verbally communicate their needs and preferences in a conventional co-design session [11]. Co-design activities often ask participants to describe previous situations or imagine future scenarios, and many PwD find these activities difficult [12]. The designers become the researchers as they start to modify a conventional co-design session to make it more suitable for PwD. Where applicable, we have elucidated this aspect in this review. In 2013, Span et al. reviewed studies which specifically involved PwD in the design of supportive information technology (IT) applications [13]. In the same year, Hendriks et al. abstracted a list of guidelines for co-designing with PwD from previous studies on designing together with PwD, people with amnesia or aphasia, and older adults [11]. Though a starting point, that list of guidelines has not been updated since.

We propose that a wider perspective, that is, reviewing studies not only in the field of co-design with PwD, but also studies which involved PwD in design research, could inform researchers how to conduct more effective co-design sessions with PwD. By “involving PwD” we mean PwD communicated their needs and preferences in the study rather than acting solely as test subjects, as in a clinical trial. Therefore, we reviewed the literature (a) to evaluate the effects of involving PwD in design research on PwD and on the design process; (b) to identify the trends over time of involving PwD in design research; and (c) to extract tools, recommendations and the limitations of involving PwD from the reviewed studies to update the recommendations for how to co-design with PwD.

## 2. Methods

We conducted this study as a scoping literature review based on guidelines by Arksey and O'Malley [14]. Scoping reviews are defined as a process of mapping the existing literature or evidence base to identify trends and summarize research findings [15]. Compared with a systematic review, a scoping review answers broader research questions; does not regard study quality as the initial priority; and synthesizes findings more qualitatively than quantitatively [16]. We decided on a scoping review rather than a systematic review because our research questions are exploratory, and our goal is to map the current literature from a broad perspective.

### 2.1. Search terms

The search terms related to co-design were developed based on the current landscape of human-centered design research visualized by Sanders and Stappers [5]. The inter-relationships between the set of search terms is illustrated in Fig. 1. Co-design is the collective creativity of designers and people not trained in design as it is applied across the whole span of a design process [5]. In contrast, co-creation, defined as any act of collective creativity, is a broader term with applications “ranging from the physical to the metaphysical and from the material to the spiritual” [5]. The notions of co-creation and co-design originate from participatory design, which is an approach to participatory research [17]. In participatory research, the researchers work in partnership with participants throughout all stages of the research process to gather deeper insights into the world of the participants [18]. Participatory research has its roots in social science, and it supports socially marginalized people to investigate and analyze their reality so as to take collective actions to change their current situation [17]. In Scandinavia, participatory design dates back to the 1970s and is more research-oriented [19]. Recently, the notion of generative design research, which is more design-oriented, is proposed as an approach to bring stakeholders directly into the design process through design in order to ensure their needs and wishes can be met [20]. In generative design research, designers create tools for non-designers to let them look into possible futures and express themselves creatively.

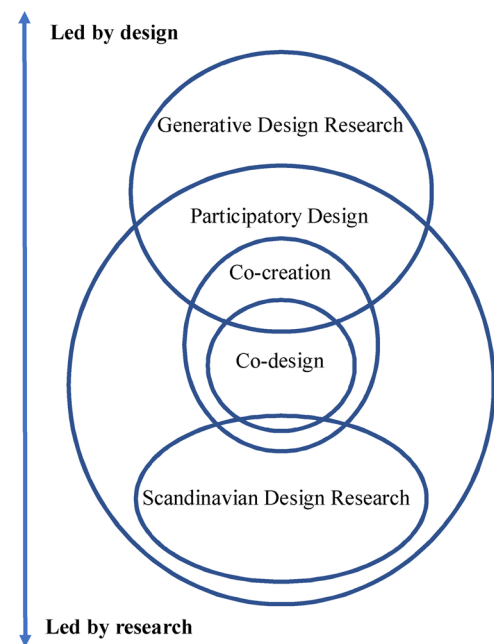


Fig. 1. Inter-relationship between search-terms related to co-design (not in scale).

Therefore, the terms, co-design, co-creation, participatory design, generative design research and Scandinavian design research are interconnected. To fully review the relevant literature, we decided to do a thorough search, thus absorbing the learning from a wider area than co-design. Accordingly, the first set of search terms consisted of “co-design”, “co-creation”, “participatory design”, “generative design research” and “Scandinavian design research”. The second set of search terms was related to dementia, and included *dement\**, *Alzheimer\** and all other subtypes of dementia.

### 2.2. Inclusion criteria

The current review was conducted in two electronic databases: Scopus and PubMed. The search covered all studies published up to December 31, 2018. The inclusion criteria were: (1) studies that involved participants with a diagnosis of dementia; (2) studies that explicitly stated PwD were involved in the study process; (3) studies that reported outcomes; (4) studies written in English and published in a peer-reviewed journal.

### 2.3. Research questions

Each selected study was analysed by the following research questions. We define a “session” as a period of time arranged for a particular activity involving PwD. Thus, some studies consist of a few sessions. Each session was analysed individually for research questions 3 to 7.

- 1 What is/are the aim(s) of the study?  
Since the studies included in our review are wider than the scope of design, we first distinguished if a study was a design study, that is, if the aims of the study involved delivering a product or service that could be used by a wider population.
- 2 What is/are the outcome(s) of the study?  
The outcomes of the studies enable us to evaluate if involving PwD in design research has a positive effect on PwD and/or the design process.
- 3 Which dementia stage were PwD participants in for each session?  
As dementia is progressive, the cognitive impairments of PwD will increase over time. The WHO has divided dementia into three stages

according to the symptoms, namely, mild, moderate and severe, and the recommended caring practice for PwD in these three stages is different. Therefore, we recorded the dementia stage of the PwD involved in the studies reviewed and categorised the tools and recommendations based on the dementia stage.

- 4 If the study is a design study, in which stages of the design process and for how many stages were PwD involved for each session?

By answering this question, how PwD contributed to the design process could be identified. The whole design process in general consists of four stages according to Sanders [21], which are:

- 5 Pre-design: understand users' experiences in the context of their lives, determine what is to be designed  
 6 Generative stage: producing ideas, insights and concepts and developing them into designs  
 7 Evaluative stage: assessing the effect or the effectiveness of the designs with users; users then give feedback on the design  
 8 Post-design stage: how the designs are experienced by the users  
 9 Who were the participants in each session?

We could get additional insights into how a session was organized by recording who was involved in the session in addition to the PwD and the researcher.

- 10 What was the setting of each session?

More insights into how a session was organized could be gained by recording where the session took place and whether it was an individual or group session, which in this review are referred to as an environmental setting and an organizational setting respectively. In this review, an individual session is defined as a session involving only one PwD, although that person could be accompanied by informal or professional caregivers; and a group session as a session involving more than one PwD, again who could be accompanied by informal or professional caregivers or other participants.

- 11 How were PwD involved and what were the tools and recommendations for involving PwD for each session?

To answer this question, the relevant information from the reviewed papers was extracted to form a list of tools and recommendations for co-designing with PwD.

- 12 What is/are the limitation(s) of the study?

The limitations mentioned in the studies were extracted and summarized into a list to help future researchers to see the full picture for deciding whether or not to involve PwD in design research. The limitations identified could also be regarded as areas for improvement in future studies.

### 3. Results

The search disclosed 137 records, from which 35 studies were

selected as potentially relevant with regard to the scope of this paper; of these, 26 studies met all the inclusion criteria (see Fig. 2).

All the studies showed qualitatively that involving PwD has either a positive effect on PwD or the design process or both. The benefits for PwD include: the imagination of PwD was positively affected; PwD expressed pride and felt valued; PwD engaged in activities; PwD made more social interactions; PwD felt understood by others. The benefits for the design process include: PwD can give valuable feedback on the design; PwD can help with exploring design opportunities and defining creative solutions; preconceptions of the designers changed based on the insights gathered via designing with PwD; PwD can make useful remarks on the design details. Further information on each study can be found in the supplementary file.

A summary of the included studies per year is shown in Table 1, which shows the trend in designing with PwD over time, with one study carried out in 2007 [22], three studies in 2009 [23–25], one study each in 2010 [26], 2012 [27] and 2013 [28], two studies in 2014 [29,30] and 2015 [19,31], four studies in 2016 [32–35], three studies in 2017 [36–38], and peaking at eight studies in 2018 [6,10,17,39–42]. Since some of the studies consist of more than one session, the total number of reviewed sessions is 32. According to Table 1, for design studies, PwD were mainly involved in the pre-design and evaluative stages of the design process, and most of the sessions involved PwD only in one design stage; however, more recent sessions had begun to involve PwD in more than one design stage and sometimes in all stages of the design process.

The majority of sessions involved PwD in the mild stage of dementia, while more recent sessions had begun to involve PwD in moderate and severe stages. Most of the sessions involved a wide range of stakeholders in addition to PwD; interestingly, more recent sessions included PwD only, and these PwD were usually in the mild stage. There was also an increase over time in the number of sessions involving PwD together with professional caregivers. The majority of sessions were conducted in a group setting, and this remained stable over time. The majority of sessions were conducted in a community environment; however, more recent studies had started to conduct sessions in a nursing home environment.

The list of tools and recommendations is shown in Table 2. The tools and recommendations were categorized into “location”, “researcher”, “recruitment”, “structure”, “involvement methods”, and “specific tools and recommendations according to dementia stage”. In the last category, some tools and recommendations could be applied to all dementia stages, whereas others are more specific to one or two dementia stage(s).

The list of limitations is summarized in Table 3. There are 12 limitations in total from the perspectives of researchers, PwD and

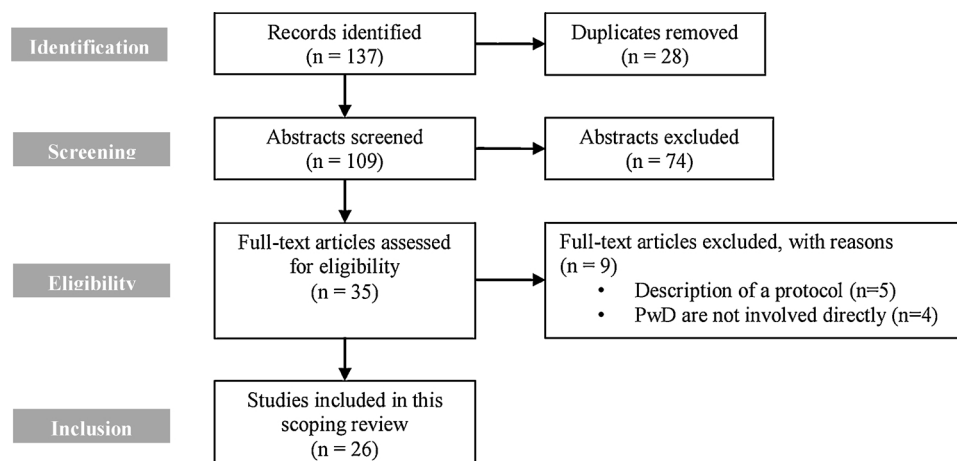


Fig. 2. Flow diagram of the scoping review.

**Table 1**  
 Summary of sessions from reviewed studies by year of publication (for each session, the answer for each research question is indicated by “v”. The research questions are: “number of design stages in which PwD are involved”, “design stage(s) in which PwD are involved”, “dementia stage of the involved PwD”, “participants”, “environment setting” and “organizational setting”, for each answer, the total number of sessions is summed per year).

sessions organized by publication year and first author name	Number of design stages in which PwD are involved										Design stage(s) in which PwD are involved					Dementia stage of the involved PwD				
	one stage	two stages	three stages	four stages	not a design session	pre-design	generative	evaluative	post-design	not a design session	mild	moderate	severe	not mentioned	Dementia stage of the involved PwD					
															mild	moderate	severe	not mentioned		
Hanson Year 2007	0	v 1	0	0	0	v 1	0	v 1	0	0	v 1	0	0	0	0					
Faucounau Nomura Robinson	v v v					v v v		v	v		v v v	v	v	v	0					
Year 2009	5	0	0	0	0	2	0	2	1	0	4	4	0	0	0					
van Rijn Year 2010	0	v 1	0	0	0	v 1	0	v 1	0	0	v 1	v 1	0	0	0					
Meiland Year 2012	v 1	0	0	0	0	0	0	v 1	0	0	v 1	0	0	0	0					
Martin Year 2013	v v 2	0	0	0	0	v 1	0	v 1	0	0	v 2	0	0	0	0					
Meiland Span Year 2014	v v v 4	0	0	0	0	v v v 2	0	v v 2	0	0	v v 4	v v 1	0	0	0					
Branco Tobiasson Year 2015	1 1 2	0	0	0	0	0	0	v v 2	0	0	v 1	v 2	v 2	0	0					
Goeman Lopes Subramaniam Treadaway Year 2016	v v v 0	v v v 1	0	0	2	v v 1	0	v v 1	0	2	v v 2	v v 1	v v 1	0	0					
Branco Renehan Tziraki Year 2017	v v v 4	0	0	0	0	v v 2	0	v v 2	0	0	v 1	v 2	v 2	2	2					
Clarke Hendriks Jamin	v v v		v			v v v	v	v v v	v		v	v	v	v	v					

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**Table 1 (continued)**

sessions organized by publication year and first author name	Number of design stages in which PwD are involved						Design stage(s) in which PwD are involved						Dementia stage of the involved PwD																
	one stage	two stages	three stages	four stages	not a design session	pre-design	generative	evaluative	post-design	not a design session	mild	moderate	severe	not mentioned															
Rodgers				v	v					v																			
Span											v																		
Thoft					v																								
Treadaway																													
Tsekleves																													
Year 2018	4	0	0	0	2	5	3	5	3	2	3	1	3	3															
Organizational setting																													
Environment setting																													
Participants																													
sessions organized by publication year and first author name	PwD only				PwD with informal caregivers only		PwD with informal and professional caregivers		PwD with informal and/or professional caregivers and other stakeholders		community		home		nursing home		combined		not mentioned		individual		group		combined		not mentioned		
Hanson	0	1	0	0	0	0	0	0	0	0	1	1	0	1	0	0	0	1	0	0	0	1	1	1	0	0	0	0	
Faucounau																													
Nomura																													
Robinson																													
Year 2009	0	3	0	0	0	2	4	1	0	0	0	0	0	0	0	0	0	0	0	0	2	4	4	1	0	0	0	0	
van Rijn																													
Year 2010	0	0	0	0	1	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	0	
Meiland																													
Year 2012	0	1	0	0	0	0	0	1	0	0	0	1	0	0	0	0	0	0	0	0	1	0	0	0	0	0	0	0	
Martin																													
Year 2013	0	0	0	0	0	2	0	2	0	0	0	2	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	
Meiland																													
	v																												
	v																												

(continued on next page)

**Table 1 (continued)**

sessions organized by publication year and first author name	Participants					Environment setting					Organizational setting							
	PwD only					PwD with informal caregivers only					PwD with informal and/or professional caregivers and other stakeholders							
	PwD only	PwD with informal caregivers only	PwD with professional caregivers only	PwD with informal and professional caregivers	PwD with informal and/or professional caregivers and other stakeholders	community	home	nursing home	combined	not mentioned	individual	group	combined	not mentioned				
Span Year 2014	2	0	1	0	1	v	4	0	0	0	0	0	0	0	v	4	1	0
Branco			v												v			
Tobiasson Year 2015	0	0	1	0	1	v	0	0	2	0	0	0	0	0	v	2	0	0
Goeman															v			
Lopes								v	v	v	v	v	v	v	v	v	v	v
Subramaniam				v														
Treadaway Year 2016	0	0	0	1	2	v	1	1	3	0	0	0	0	0	v	2	1	0
Branco								v							v			
Renehan	v					v												v
Tziraki	v					v									v			
Year 2017	2	1	0	0	1	v	3	1	0	0	0	0	0	0	v	1	0	1
Clarke	v																	
Hendriks	v								v						v			
Jamin	v							v	v						v			
Rodgers	v																	
Span								v	v						v			v
Thoft	v							v	v	v					v			
Treadaway				v														
Tseklevs								v	v						v			
Year 2018	5	0	0	1	3	v	5	3	2	1	0	0	0	0	v	6	1	0

**Table 2**

Tools and recommendations for co-designing with PwD based on the current review of the literature.

- 
1. Location
    - Offer a quiet environment
    - Offer a familiar environment
    - Offer an environment which suits the social status of PwD
    - Minimize travelling
  2. Researcher
    - Be flexible
    - Be empathetic
    - Be patient
    - Be well-informed about the daily life of PwD
    - Value different forms of participation
    - Present ethical concerns throughout the research
  3. Recruitment
    - Contact with the potential participants directly
    - Keep recruitment open throughout the project
    - Recruit people who have experience with caring for PwD to be present in the session
  4. Structure
    - Organize smaller groups than the usual focus groups for a group session
    - Allow informal breaks in the sessions
  5. Involvement methods
    - Doing daily activities together with PwD
    - Workshops
      - with the purpose of creating
      - with the purpose of giving feedback
      - with the purpose of identifying needs
    - Interviews
      - with the purpose of identifying needs
      - with the purpose of providing feedback
    - Focus groups
      - with the purpose of identifying needs
      - with the purpose of providing feedback
    - Usability testing
      - by observing how PwD interact with the prototype
      - by PwD providing verbal feedback on the prototype
  6. Specific tools and recommendations according to dementia stage
    - Mild
      - Apply Think Aloud methods
      - Create scenarios
      - Make storyboards
      - Apply visual prompts
      - Let PwD build rapport with each other
      - Make vignettes
      - Use self-observation diary
      - Select PwD who know each other for group discussion
      - Separate PwD from their caregivers if PwD can express themselves independently so that PwD can give their opinions freely
      - Provide a few concepts instead of just one
      - Use a topic guide to make session structure clear to PwD
    - Mild and moderate
      - Formulate questions in a way that PwD would not feel that they are being tested
      - Acknowledge the contribution of PwD
      - Use videos
      - Recap the last session before every new session
      - Ensure questions are not confronting
      - Let PwD engage in one activity at a time
      - Use external memory aids
      - Use environmental cues and triggers
      - Use subtle physical prompts
      - Compartmentalize a main task into subtasks
      - Create a routine for a specific task
      - Plan tasks which are suitable for the educational level of PwD
      - Plan tasks to have a purpose
    - Mild, moderate and severe
      - Use tangible materials
      - Use functional prototype
      - Apply Wizard-of-Oz method
      - Consider physical limitations (eyesight, hearing)
      - Let PwD tell their story as they wish to tell it, no matter if it is true or not
      - Use repetitions when necessary
      - Use clear and short sentences
      - Personalize the final design (e.g. with pictures of PwD)
    - Moderate and severe
      - Use auditory stimuli

**Table 2 (continued)**

- 
- Pay attention to facial expressions and body language
  - Encourage caregivers to support PwD
  - Choose activities that PwD are familiar with (e.g. drawing, make collages, reminiscence)
  - At least two persons (including the researcher) should be present in addition to PwD
  - Give physical instructions by touching and supported physical movements
  - Let caregivers act as interpreter of the behaviors of PwD and be aware of the opinions of the caregivers involved
  - Talk along and help PwD like a caregiver would do instead of taking notes
  - Bring probes and observe the reactions of PwD towards these probes
  - Plan activities based on hands-on daily tasks
  - Severe
    - Apply person-centered care principles
- 

**Table 3**

Limitations of involving PwD in design research based on the current review of the literature.

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Limitations of involving PwD in design research

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- Caregiver burden of participation
  - Potential stress in PwD
  - Restricted to PwD who can express themselves verbally
  - Difficult to manage a continuity of information with PwD
  - Time consuming for researcher
  - Expensive to execute
  - Difficult to generalize the findings
  - Small and sometimes biased sample size
  - The duration of sessions is usually short
  - Researchers could influence what PwD say and do
  - Potentially high drop-out rate
  - PwD could be distressed if a prototype does not work
- 

caregivers. These limitations are inter-related; for example, the potential burden to the caregiver of participating in a study can cause caregivers to refuse to participate [41] and thus might lead to a small and sometimes biased sample size in a study.

#### 4. Discussion

The current review demonstrates that involving PwD in design research is beneficial to both PwD and the design process, and is the first review to analyze the trends in the field of involving PwD in this type of research. We identified that there was a shift towards involving PwD in the moderate and severe stages of dementia from 2014. Besides, tools and recommendations have been developed for involving PwD in the moderate and severe stages over the years. Last but not least, researchers have become more open-minded about the modes of PwD participation. Branco et al. explicitly state that it would be beneficial for researchers to be open about how PwD would like to participate, and can do so, including non-verbal participation [36].

Some of the trends identified could be inter-related. Since PwD in the moderate to severe stages tend to reside in nursing homes, more recent studies were carried out in nursing homes. As informal caregivers are not always present in the nursing home environment, professional caregivers become the participants who accompany PwD in the sessions, which could explain the increase in the number of sessions involving PwD together with professional caregivers.

The other trend about involving PwD in the mild stage is organizing sessions with PwD as the sole participant(s), because researchers have noticed that the opinions of PwD could be interfered with by other stakeholders, and PwD in the mild stage can usually express themselves adequately without help from caregivers. One study which organized separate sessions for PwD and their informal caregivers found that the needs of PwD and informal caregivers could be conflicting [27].



On the basis of a comparison with the review by Span et al. [13], there appears to have been an improvement in involving PwD in design research. The current review demonstrates that before 2017, PwD were mainly involved in the pre-design and evaluative stages of the design process, which concurs with the findings by Span et al. [13]. The current review also found that researchers began to involve PwD in all stages of the design process in 2018. Span et al. [13] could find no study focusing exclusively on the involvement of PwD in the severe stages, and the current review adds that the first study of involving PwD in the severe stages was published in 2015.

In general, the tools and recommendations generated by the current review coincide with the earlier guidelines proposed by Hendriks et al. [11]; the current review was able to add more detail to those earlier guidelines [11]. Due to an improvement in the reporting of dementia stage in most of the studies, we were able to categorize recommendations according to the dementia stage of the PwD participants. An overview of the limitations of involving PwD in design research has not been addressed in previous studies, and a list of limitations was created based on the current review.

The current review has two limitations. First, since five reviewed studies did not mention the dementia stage of the PwD involved, the tools and recommendations of these studies were interpreted based on the experience of co-designing with PwD of the authors, to classify them to the most suitable dementia stage(s) they could be applied to. We encourage future studies to mention the dementia stage of PwD. Second, because involving PwD in design research is a recent development, the number of studies included in this scoping review is limited.

## 5. Conclusion

The contribution of the current review is three-fold: 1) we demonstrated involving PwD in design research is beneficial for both PwD and the design process; 2) we found that more recent studies have begun to involve PwD in the moderate and severe dementia stages in design research; 3) we developed a list of tools and recommendations together with a list of limitations for co-design with PwD.

In the near future, the list of tools and recommendations together with the list of limitations should be evaluated and refined in multi-disciplinary meetings; they could then be evaluated by conducting case studies using these lists. The current review could help researchers to conduct more effective co-design sessions, which could better complement existing care approaches in order to improve the quality of life of PwD.

## Contributors

Gubing Wang participated in the literature review, and in the writing and revision of the manuscript.

Chiara Marradi participated in the literature review, and in the writing of the manuscript.

Armagan Albayrak participated in the revision of the manuscript.

Tischa J.M. van der Cammen participated in the literature review, and in the writing and revision of the manuscript.

All authors saw and approved the final version of the review.

## Conflict of interest

The authors declare that they have no conflict of interest.

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## Provenance and peer review

This article has undergone peer review.

## Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.maturitas.2019.06.003>.

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