

# People With Dementia as Active Agents in Nursing Homes: A Scoping Review

SAGE Open  
 April-June 2023: 1–13  
 © The Author(s) 2023  
 DOI: 10.1177/21582440231180585  
[journals.sagepub.com/home/sgo](https://journals.sagepub.com/home/sgo)  


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## Abstract

People with dementia (PWD) are fragile and need aid and care in their daily lives. This scoping review explores the extent to which PWD can be involved in society and their daily lives. Publications were selected according to PRISMA guidelines. We graded the level of participation/involvement in daily life and research using a five-level participation model developed by Shier. A higher grade means a greater ambition to involve PWD in decisions. Of the 11 included studies, three reached level three according to Shier's model. The studies describe ways of and potentials for participation, capabilities of PWD, caregivers' opportunities to foster involvement, and cooperation between PWD caregivers and relatives. Caregivers and managers must have the attitude that PWD can be involved in decisions and caregivers need opportunities to actively promote such involvement. Shier's model can be a tool with which organizations strive to involve PWD.

## Keywords

social work, social sciences, participation, dementia, nursing home, human rights, political sociology, sociology

## Living With Dementia Is a Growing Social Challenge

Fifty million people are living with dementia worldwide (World Health Organization [WHO], 2020), and social workers must be prepared for the increasing number of such people needing everyday support to live their lives as well as possible. According to the International Federation of Social Workers (IFSW, 2020), the profession can promote older adults' dignity and inclusion in decision-making at all levels of society. Social workers focus on the social inclusion of people with dementia (PWD) as a crucial part of their roles (Hokenstad & Roberts, 2011). In some countries, social workers can be care managers, and social workers are responsible for the assessment and placement of people with dementia and follow-up of placements when conditions change. Social workers are sometimes managers of nursing homes. Thus they have an important role even if they are not always involved in the daily care of the PWD (Österholm, 2016; Vård och omsorgsanalys, 2021).

We use the acronym PWD in this study. However, we are aware that people with dementia should not be assumed to lack the capacity to participate in decision-making, even if they no longer live independently, as for example emphasized in the UK Mental Capacity Act (National Health Service, 2005). As dementia is among

the most common reasons for living in a nursing home (NH) (Smith et al., 2000; Toot et al., 2017), caregivers must find ways to involve NH residents despite their cognitive disabilities (Jakobsen & Sörlie, 2010), and caregivers' approaches to the involvement of residents in decisions range from independent decision-making to exclusion from decision-making (Erlandsson et al., 2022). However, the social worker can support caregivers to work toward greater involvement of residents (Hardy et al., 2020).

## Civil Rights/Human Rights

According to the WHO (2020), people's participation is defined in terms of their engagement in particular life situations, and civil rights are as essential for PWD as they are for other citizens. PWD must be seen as active agents in society (IFSW, 2020). Shakespeare et al. (2019) argued that PWD can be considered people with a

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disability, whose daily experience is affected by their environment. Dementia is often considered a disease, but here we define dementia as a disability according to the reasoning of Shakespeare et al. (2019). We will strengthen the rationale of PWD as people with disabilities. We therefore include the group of PWD in The United Nations (UN, 2006) Convention on the Rights of Persons with Disabilities (CRPD), which states that people with disabilities have rights to independent living (article 19), freedom of expression (article 21), and participation in culture, recreation, and leisure (article 30). Cieza and Kostansjek (2021, p. 1), referring to the International Classification of Functioning, Disability and Health (ICF), argued that “the individual, the experience of health and disability depending on the physical, human-built, attitudinal, and socio-political environment all play a role for an inclusive environment.”

Nedlund and Bartlett (2017) emphasized that PWD are active agents who exert power over their own lives as actors in society. Informal/formal caregivers must support PWD so that they can interact with those in their social context. Citizenship concerns autonomous persons and their ability to understand their situation; however, this may sometimes be impossible for PWD due to cognitive impairment. Citizenship must therefore be explored in a different way. The citizenship of PWD has been studied in terms of rights to, belonging to, access to, and participation in the community (Nedlund & Bartlett, 2017). According to Kelly and Innes (2011), PWD may be denied human and civil rights when caregivers prioritize protection from harm instead of considering human rights. Kelly and Innes (2011) suggested a practice based on dignity and respect, and how such a practice works depends both on caregivers’ understanding of human rights and on having the right conditions to promote participation. Caregivers and care managers must develop a culture in which participation in daily life is prioritized (Helgesen et al., 2014). There is a link between empowerment among caregivers and empowerment among care receivers. Laschinger et al. (2010) identified empowerment as a precondition for both care recipients and caregivers if care recipients are to be supported. According to Kontos (2011), PWD can be involved in care decisions even if they cannot communicate their wishes. Haugen et al. (2019) stated that PWD can be involved in care decisions if they are supported by relatives or caregivers.

### *Previous Research About Daily Life in Nursing Homes for PWD*

Symptoms of dementia may worsen if psychosocial needs such as attachment, comfort, identity, inclusion, and love go unmet. Kitwood (1997) advocated person-centered care to meet PWD needs. In person-centered care,

caregivers treat all PWD as unique individuals. Scales et al. (2017) examined the interaction between people and their environment and noted that formal caregivers need empowerment to enhance person-centered care. According to Boumans et al. (2019), formal caregivers should have a flexible attitude toward residents’ needs, behaviors, and wishes, and should welcome informal caregivers and efforts to promote residents’ autonomy. The care environment and technology can improve autonomy for NH residents. In a systematic review, Davies et al. (2019) described how decision aids (i.e., videos, booklets, or web-based tools) can improve caregivers’ abilities to facilitate decisions regarding PWD. Moreover, caregivers need the knowledge to promote autonomy in NH residents. However, balancing PWD’s opportunities for autonomy against protection from harm is a difficult and ongoing effort (Holm, 2001; Sammet, 2007). Taghizadeh Larsson and Österholm (2014) found that most care decisions regarding PWD were made by relatives alone with no PWD involvement. These researchers noted that more research was needed regarding PWD and their right to make decisions about care services. Bolling et al. (2016) recommended further research on how to involve PWD in decision-making in NHs, given that most relevant research emphasizes the caregiver perspective, not that of PWD. This includes both PWD and the caregivers’ efforts to support PWD. A social worker can play an essential role in supporting caregivers in nursing homes, according to Hardy et al. (2020). Examples of what a social worker can contribute within a nursing home are holistic care, supporting the needs of staff, residents, and their relatives, advocacy, and supporting decision-making between PWD and staff.

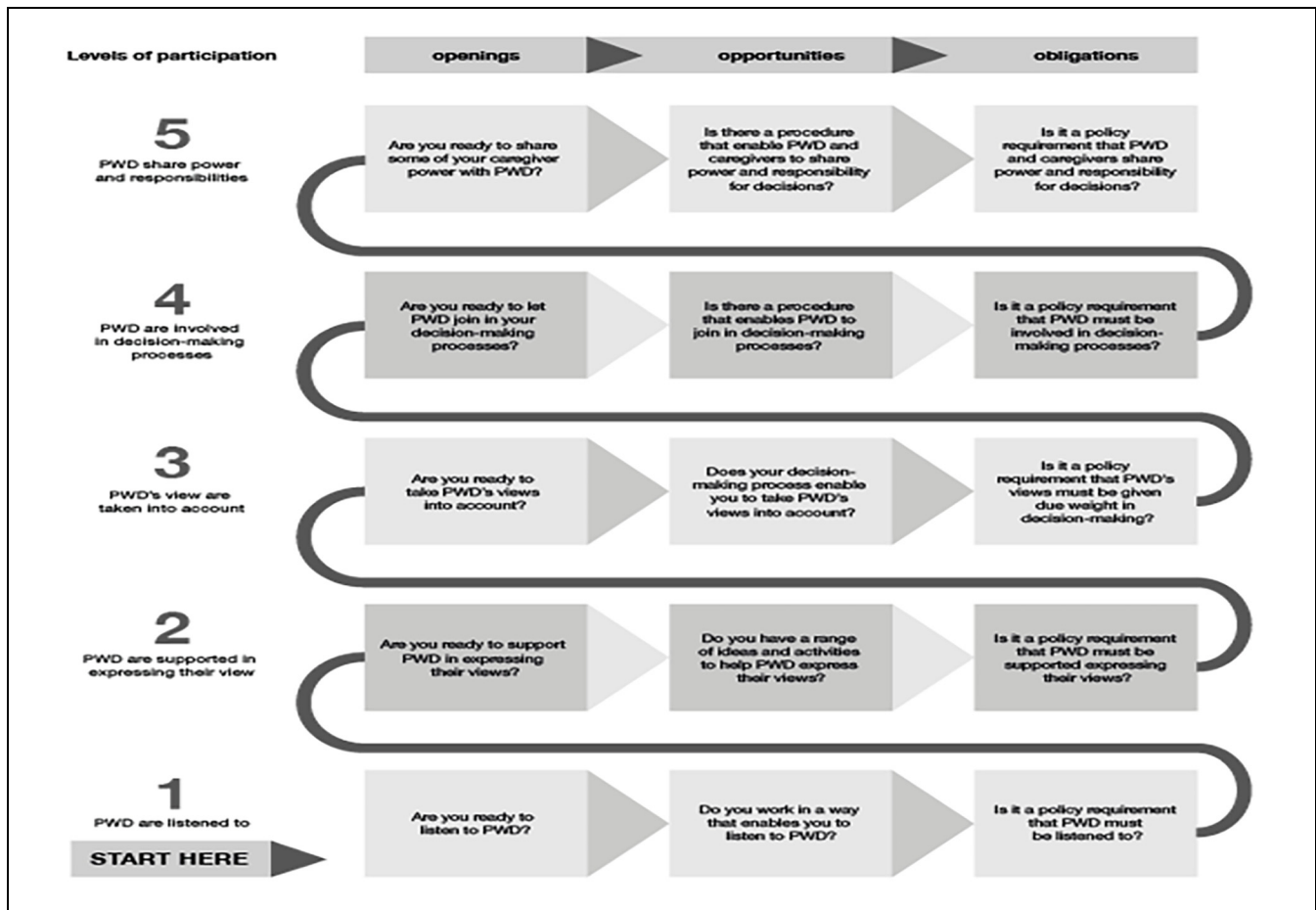
### *Aim of Study*

Since both PWD and how they are supported by staff play a role in the agency of PWD, we included both perspectives in this scoping review. The following research questions were accordingly formulated:

- What is known from the literature about PWD living in NHs and their opportunities to be active agents in their daily lives?
- How do caregivers facilitate participation (methods and level of influence) among PWD living in NHs?

### *Theoretical Framework for Participation*

Shier’s (2001) model can be used as a tool by organizations when planning for and facilitating user participation. The model contains five levels of participation and



**Figure 1.** Levels of participation of people with dementia.  
Source. Adapted from Shier (2001, p. 111) to the PWD target group by the authors.

was originally constructed to describe children's opportunities to participate in decisions. In addition to levels of involvement, the model is also based on three stages of commitment—*openings*, *opportunities*, and *obligations*—in which the organization fosters participation in different ways. There is one question for each level in the model, so organizations can determine at which level they are positioned regarding participation among children (Shier, 2001). Although Shier was mainly describing children's participation, the model is also used among adults with cognitive disabilities (Talman et al., 2019). Furthermore, Talman et al. (2019) noted that people with intellectual disabilities depend, in their daily lives, on others who also control their opportunities to participate. A similar situation faces PWD regarding their opportunities to participate (Figure 1).

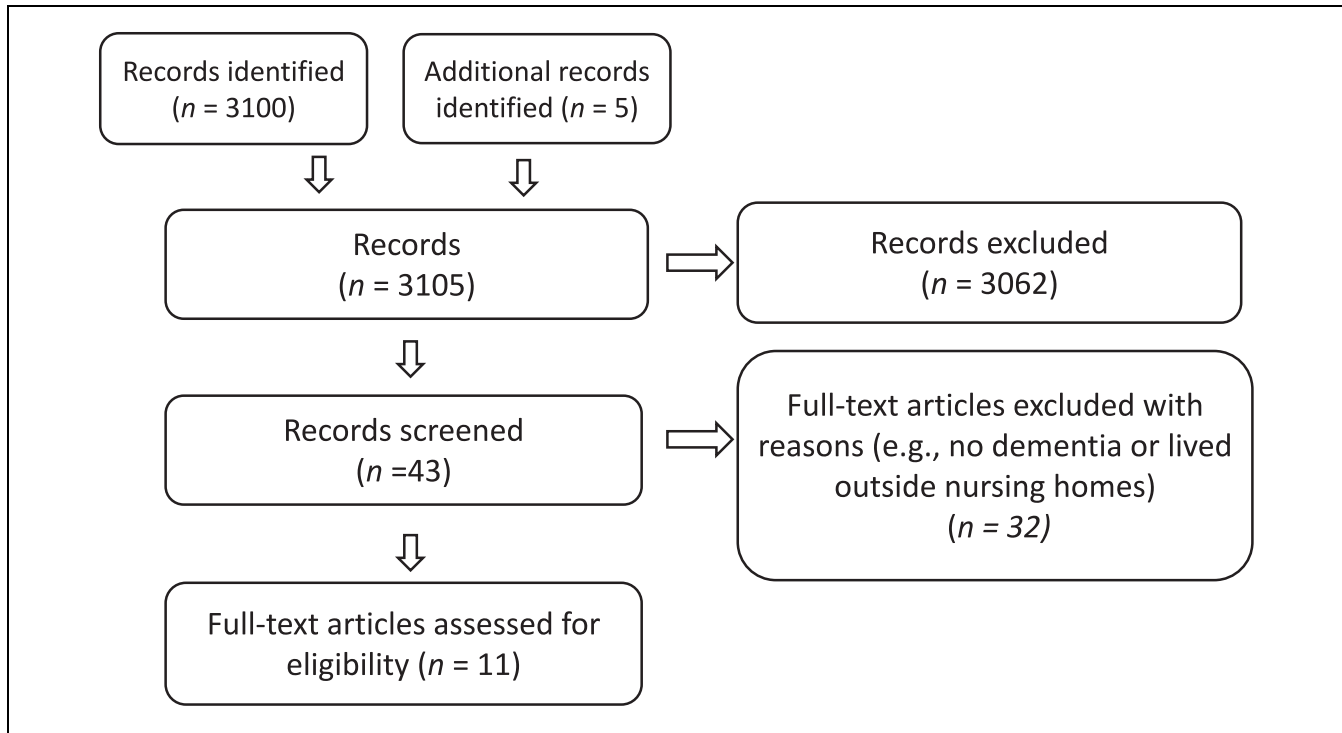
## Method

To answer the research questions, a scoping review was chosen as the appropriate research design (Arksey &

O'Malley, 2003). We used the PRISMA extension for scoping reviews (Tricco, 2018).

## Included Papers

- Original peer-reviewed empirical papers written in English and published between 2010 and 2020.
- The papers had to examine PWD living in NHs and explore how PWD can be active agents in their daily lives.
- PWD's own viewpoints had to be treated in the papers. PWD must have interacted with the researcher(s) in interviews, informal talks, and image support.
- We identified the included papers using Shier's (2001) theoretical framework of participation to capture whether (according to the papers) PWD were involved in their daily lives, how their perspectives were considered, and how caregivers facilitated PWD involvement.



**Figure 2.** Flow chart according to PRISMA.

### Excluded Papers

- Studies about moving into NHs
- Studies of PWD, including those in palliative care, if they did not describe PWD involvement in daily life in NHs
- Studies of PWD living in their own homes, with or without homecare, or visiting daycare
- Observational studies in which PWD were not involved as agents
- Reviews and books

**Information sources.** To identify potentially relevant abstracts, we searched the following bibliographic databases from January 2010 to June 2020: PubMed, Psych Info, SocIndex, Cinahl, WoS, Scopus, Academic Search Elite, Science Direct, Social Services Abstracts, and Sociological Abstracts. The following search terms (and similar terms) were used: TITLE-ABS-KEY: dementia, nursing homes, autonomy.

### Data

We extracted data on how the NHs involved PWD in decisions regarding their daily lives and how the researchers and caregivers interacted with PWD to facilitate such involvement. We synthesized the included papers and

analyzed them regarding the involvement of PWD in decisions and the NH organizations' preparedness to facilitate such involvement.

### Selection of Sources of Evidence

Two of the authors independently screened the sampled titles and abstracts using Rayyan, a web application for screening abstracts (Ouzzani et al., 2016). In total, 3100 abstracts were identified, and a library technician removed duplicates. To promote transparency, we used a PRISMA flow chart (Moher et al., 2009). After reviewing the abstracts, we discussed the 42 remaining full-text publications. A third author was consulted if disagreements occurred regarding abstracts or regarding the evaluation of articles related to Shier's (2001) model. The selection process ended with the identification of ten publications. In addition, we searched the reference lists of the included publications for relevant papers and found five, one of which was included in the review. In total, 11 publications were selected for the scoping review (Figure 2 and Table 1).

### Results

**How we used Shier's model.** We interpreted and rated the papers in accordance with Shier's five-level model. To illustrate this rating approach, we use Serarano

**Table 1.** Included Publications.

No., author, year, title, and journal	Aim	Method	Results	Conclusions
1. Helgesen et al. (2010). "Patient participation" in everyday activities in special care units for persons with dementia in Norwegian nursing homes. <i>International Journal of Older People Nursing</i> .	Explore patient participation in everyday activities among PWD living in special care units in NHs	Grounded theory (GT), interviews, and observations	The study highlighted the great impact of personnel presence in terms of body, mind, and morale on the participation capacity of the residents.	Personnel presence in terms of body, mind, and morale has an impact on the participation capacity of residents. The nurse leaders were under stress, being responsible for organizational issues.
2. Godman et al. (2013). Preferences and priorities for ongoing and end-of-life care: A qualitative study of older people with dementia resident in care homes. <i>International Journal of Nursing Studies</i> .	Explore how PWD discuss their priorities and preferences for end-of-life care	Guided conversations with 18 PWD living in six care homes	Key relationships with family and staff and whether PWD accepted the care home as their home were important. When given the opportunity, PWD can articulate preferences for care and views of living in a care home.	For PWD, the experiences of living and dying in a care home are inextricably linked. Decision-making by healthcare professionals, care home staff, and family could be enriched by exploring and documenting preoccupations, key relationships, and wishes about everyday care of PWD.
3. Heggstad et al. (2013). "Like a prison without bars": Dementia and experiences of dignity. <i>Nursing Ethics</i> .	Investigate how life in Norwegian NHs may affect experienced dignity among PWD	Participant observation in two NH units combined with qualitative interviews with five residents	PWD's freedom is restricted, and they feel homesick and not seen as autonomous persons.	To maintain dignity in PWD, see the persons behind the diagnosis and focus more on their abilities than limitations and on who they were in the past. There will also be conflict between public and private life.
4. Serarano Cardona et al. (2013). Activity Engagement: Perspectives from Nursing Home Residents with Dementia. <i>Early Human Development</i> .	Describe types of current activity involvement and barriers to activities reported by NH residents with dementia	Thirty-one NH residents participated in short, open-ended interviews, and six completed in-depth semi-structured interviews.	PWD previously enjoyed various hobbies and activities before moving into NHs, but their current activities in NH settings were very limited.	Activities should be expanded and tailored to PWD's needs and interests. Keeping residents at the center of activity planning and decision-making will improve their engagement in relevant and meaningful activities.
5. Godwin (2014). Color consultation with dementia home residents and staff. <i>Quality in Ageing and Older Adults</i> .	RQ1: How can people with moderate/advanced dementia be helped to participate in consultation? RQ2: How can communication impairment be circumvented?	Consultation with PWD using novel methods to explore views of an aspect of their environment; every resident was met individually and was helped to express color preferences.	Most residents appeared to express an opinion on the potential decor; others chose a color while not necessarily grasping the context.	Explores ways of communicating that avoid privileging the spoken word, revealing seldom-recognized abilities in people with moderate/advanced dementia. Service providers may widen their expectations of inclusivity in consultation.

(continued)

Table 1. (continued)

No., author, year, title, and journal	Aim	Method	Results	Conclusions
6. Niemeijer et al. (2015). The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care. <i>Nursing Ethics</i> .	Explore how clients in residential care experience surveillance technology to assess how surveillance technology might influence autonomy	Observation combined with informal conversations with clients; formal interviews with family and staff	Coping with new spaces caused clients to wander around, get lost, and resist surveillance technology because they felt stigmatized, missed company, and did not like being "watched."	Technology entails ambivalence, due to the variety of surveillance technology devices used and their presupposition of an ideal user. Technology can bolster the autonomy of clients in long-term care, but only within a truly person-centered approach.
7. Bangerter et al. (2016). "Make me feel at ease and at home": Differential care preferences of nursing home residents. <i>The Gerontologist</i> .	Explore how specific clinical responses to how residents interpret and conceptualize their preferences may be needed to balance health and safety concerns against preferences	Interview responses to a subset of eight open-ended items from the Preferences of Everyday Living Inventory; 337 NH residents with moderate to mild dementia according to the MMSE test	Residents identified preferences for interpersonal interactions (e.g., greetings, staff showing care, and staff showing respect), coping strategies, personal care, and care discussions. Respondents highlighted specific qualities and characteristics about care interactions that are necessary to fully meeting their everyday preferences. PWD expressed, for example, that they were not autonomous and could not eat with friends.	Results contribute to an emergent body of research that utilizes patient preferences to achieve the goals of person-centered care. Care staff could be better qualified to make proxy decisions for residents following cognitive decline. Identifying NH residents' desire to participate in their health discussion network may give NH administrators an opportunity to bring individuals together to make decisions with NH residents.
8. Bolling et al. (2016). Nothing to complain about: Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. <i>Nursing Ethics</i> .	Explore NH residents' and their relatives' perceptions of ethical challenges in Norwegian NHs	Interviews with NH residents and focus-group interviews with relatives; total of 25 residents of nine NHs in Norway and 18 relatives	Ethical challenges in NHs were lack of resources for maintaining a good life, autonomy, and self-determination; the relationship with staff was most important.	Residents and relatives experienced several ethical challenges in Norwegian NHs, mostly connected to "everyday ethical issues."
9. McKeown et al. (2016). "It is like stepping into another world": Exploring the possibilities of using appreciative participatory action research to guide culture change work in community and long-term care. <i>Action Research</i> .	Explore the opportunities for transformation when appreciative participatory action research (PAR) is used by diverse participants interested in working together to change the culture of dementia care in long-term care and community care settings	Culture change coalition (CCC) that included PWD, family partners in care, and staff researchers; the study included interviews, group sessions, and art-based sessions with PWD to capture their experiences.	CCC identified opportunities for transformation associated with culture change: an appreciative approach, valuing different experiences, and engaging new ways of communicating.	Staff recognized the importance of spending more time with residents. Some staff highlighted changes in their leadership style, sharing how the culture change process helped them be more participatory and open to seeking input from others when making decisions.

(continued)

**Table 1. (continued)**

No., author, year, title, and journal	Aim	Method	Results	Conclusions
10. Mondaca et al. (2018). Influencing everyday activities in a nursing home setting: A call for ethical and responsive engagement. <i>Nursing Inquiry</i> .	Explore how influence can be situated contextually, how it can emerge through activities, and how it is negotiated every day by frail older adults living in a NH	Residents, staff members, and significant others from a NH in an urban area of Sweden participated in this study, which used fieldwork, participant observation, and formal and informal conversations.	There is a gap between the client-centered framework and lived experience regarding older adults' influence on everyday activities. Spontaneous activities emerging from the everyday, such as time to rest even if it is outside the routines, could be seen as challenging the translation into practice. Lack of time and short staffing affected spontaneous activities.	Influence on everyday activities, a central aspect of person-centered care, is not necessarily exercised in a direct and explicit manner, as exemplified in the findings; consequently, professionals must actively look for and act upon it.
11. Shura et al. (2011). Culture change in long-term care: Participatory action research and the role of the resident. <i>The Gerontologist</i> .	PAR to promote residents' competence; culture change process with active engagement and leadership	Seven unit-specific PAR groups, each consisting of 4–7 residents, 1–2 family members, and 1–3 staff, met to identify areas in need.	Groups generated novel ideas concerning limited resident access to information and a sense of participation in everyday life that are needed to foster change.	PAR is a viable method to stimulate creative resident-led reform ideas and initiatives in long-term care. Residents' expertise has been overlooked.

Cardona et al. (2013) as an example. In the first column of Table 2, we consider the level of involvement in daily life: in Serarano Cardona et al. (2013), PWD expressed their viewpoints, but could not affect decisions and were not helped to express their views. The caregivers were ready to listen to PWD, achieving level one in Shier's model; for a higher level, they must take responsibility for helping PWD to express their views.

The second column is about *openings*, that is, how to facilitate caregivers and the involvement of PWD. In Serarano Cardona et al. (2013), the caregivers only attained level one, as they did not help PWD overcome barriers to expressing their views (e.g., the PWD had limited *opportunities* to affect the schedule when they chose activities). Column three is about opportunities for PWD to express their views, and whether staff have time to listen to them. The organization studied in Serarano Cardona et al. (2013) lacked a range of methods to facilitate PWD involvement (e.g., if the organization had tools such as visual methods to facilitate PWD opportunities to express views, it would have achieved a higher level according to Shier's model).

Column four is about *obligations*, and in Serarano Cardona et al. (2013), these referred to guidelines the NH should follow regarding participation. The fifth column is about how the authors of the included publications interacted with PWD; according to the inclusion criteria, the researchers had to determine the PWD's viewpoints. In Serarano Cardona et al. (2013), the researcher interviewed PWD and reported their viewpoints in the results, resulting in a higher level (i.e., level three) according to Shier's model. Table 2 presents the publications categorized according to Shier's model: column one, participation in care; column two, the organization's openings for participation; column three, the organization's opportunities for participation; column four, the organization's obligations regarding participation; and column five, the ladder of participation in the research.

*Synthesis of the results.* PWD could be involved in decisions related to their cognitive and physical abilities (Helgesen et al., 2010), express opinions on NH architecture (Godwin, 2014), and express viewpoints on how to live their daily lives (Godman et al., 2013). The NH organizations could set rules that PWD had to follow; for example, PWD could not enter all the rooms in the NHs (Heggstad et al., 2013). According to Serarano Cardona et al. (2013), care workers tried to determine what PWD were interested in, but the activities were not adapted to PWD's wishes. The PWD-caregiver relationship was the precondition for participation (Bolling et al., 2016; Helgesen et al., 2010; Mondaca et al., 2018). Studies described by Godwin (2014), McKeown et al. (2016), and Shura et al. (2011) reached the highest level of

**Table 2.** Interpretation of Shier's Key Concepts.

Study no.	Daily life	Openings	Opportunities	Obligations	Research
1.	<p>1–2: Due to the elderly people's abilities, different units of caregivers and PWD differed. The caregivers had to be present in mind and body, and the leadership was also affected.</p> <p>2: The caregivers strove to help PWD express their wishes.</p>	<p>1: Caregivers mostly asked PWD for their views, but they did not always listen to the answers.</p> <p>1: Some PWD mentioned that they could not participate due to their dementia.</p>	<p>1: Caregivers' working conditions and leadership affected PWD participation.</p> <p>1: Caregivers strove to involve PWD in decisions and to help them express their views, but if PWD had limited abilities they could not express their views.</p>	<p>2: Grounded in humanistic values and legal rights, PWD in Norway must have opportunities to express their wishes.</p> <p>There were no obligations.</p>	<p>3: PWD were observed, and were interviewed when possible.</p> <p>3: PWD's viewpoints expressed during interviews as well as observations of PWD both mattered.</p>
3.	<p>1: PWD could express their views but had to follow NH routines; they could not enter the kitchen and sometimes could not lock their own rooms.</p>	<p>1: PWD could not enter important rooms such as the kitchen; caregivers saw PWD as incapable due to dementia.</p>	<p>1: Institutional frames, such as routines and locked doors; caregivers had no methods to help PWD express their views and saw them as incapable of making decisions.</p>	<p>There were no obligations.</p>	<p>3: PWD's viewpoints expressed during interviews as well as observations of PWD both mattered.</p>
4.	<p>1: PWD's interests and previous hobbies were taken into account, but PWD could not influence activities such as bingo and music, they could only choose to not participate.</p>	<p>1: The NH sometimes facilitated activities based on PWD's interests, but PWD could not choose activities like their hobbies.</p>	<p>1: They could express their views but in a limited way.</p>	<p>1: The guidelines required the NH to provide a sufficient and ongoing activity program.</p>	<p>3: The researchers interviewed PWD and respected their viewpoints.</p>
5.	<p>3: PWD had opportunities to express their opinions regardless of their disabilities and PWD's viewpoints were important.</p>	<p>3: The NH listened to PWD and helped them express their views.</p>	<p>3: The NH developed a tool to help PWD express their views, which were taken into account.</p>	<p>1: There were policies like government guidelines.</p>	<p>3: The researchers included all residents' viewpoints and took them into account.</p>
6.	<p>2: PWD could express their views and their autonomy was supported with technology.</p>	<p>2: Due to the technology, PWD could be more autonomous, but some of them did not appreciate that.</p>	<p>3: PWD could do what they wanted in some ways, but some PWD felt lost and stigmatized.</p>	<p>There were no obligations.</p>	<p>1: PWD could express their views, which were taken into account, but PWD expressed their views only in informal discussions and not in interviews.</p> <p>3: PWD had important information for the research.</p>
7.	<p>1: Many PWD from different NHs participated, but one cannot discern the ladder of participation at each NH; mostly, the caregivers just listened but did not actively seek PWD's viewpoints.</p>	<p>1: Caregivers did not help PWD express their views.</p>	<p>1: Caregivers had no tools to help PWD express their viewpoints.</p>	<p>1: The obligations referred to person-centered care.</p>	

*(continued)*

**Table 2. (continued)**

Study no.	Daily life	Openings	Opportunities	Obligations	Research
8.	1-2: Depended on the NHs, caregivers, and PWD's capabilities 3: It was not clear, but in the art sessions and group discussions, PWD expressed their views.	1: Depended on the NHs; most PWD were disappointed with their opportunities to make their own decisions. 3: In art sessions and group discussions, PWD's viewpoints were important.	1: Caregivers listened to PWD but did not facilitate opportunities for them to express their views. 3: The NH took into account what PWD expressed and used a tool to help them express their views.	There were no obligations. 1: Person-centered care	3: PWD were interviewed and their opinions were taken into account. 4: PWD participated in the group, working with the process; the researchers also tried to include PWD during art sessions. 3: Researchers interacted and conversed with PWD during their daily lives as well as observing life in the NH.
10.	1: PWD could not choose activities and if they proposed something the answer was "no." If PWD called for help, caregivers sometimes did not respond because they had too much to do. 1-3: PWD participated in the group sessions when the NH changed its policy due to PWD's wishes.	1: PWD were listened to but were not supported to express their views. 3: The NH was sometimes ready to listen to PWD.	1: The NH offered limited activities and the caregivers had too much administrative work and could not be with the PWD. 2: The NH strove to help PWD express their views.	1: There were policy documents. There were no obligations.	3: PWD's viewpoints mattered.

participation in all dimensions of Shier's model. The caregivers created groups working with managers, PWD, and relatives in the studies by McKeown et al. (2016) and Shura et al. (2011). When ideas were raised in these working groups, they were tried out in a practical context. Moreover, these two studies involved PWD participation in decisions regarding the NH organization, whereas PWD participation in the other studies was mostly relevant to individual decisions. Godwin (2014) used tools to facilitate participation so that even persons with severe disabilities could be involved in decisions. In the studies by Godwin (2014), McKeown et al. (2016), and Shura et al. (2011), the organization tried to help PWD express their viewpoints, resulting in a higher Shier's model score regarding openings and opportunities.

In the study by Niemeijer et al. (2015), technology helped PWD to be more autonomous, but not all of them appreciated the technology: some felt stigmatized, and that the technology did not help them express their viewpoints and wishes. Heggstad et al. (2013) found that caregivers asked PWD for input but did not listen to the responses, so caregivers did not help PWD express their views. Feeling at home was complicated, because PWD did not recognize the other residents in NHs (Heggstad et al., 2013). Most PWD were dependent on caregivers to involve them in decisions regarding their daily lives (Bangertter et al., 2016; Bolling et al., 2016; Godman et al., 2013; Heggstad et al., 2013; Helgesen et al., 2010). Moreover, PWD described a lack of autonomy (Bangertter et al., 2016; Bolling et al., 2016; Heggstad et al., 2013), and PWD could make decisions regarding their lives if given the opportunity (Godman et al., 2013). Lack of caregiver time and short staffing reduced interactions with PWD and their opportunities to be involved (Mondaca et al., 2018).

Involvement in research generated a higher level of PWD participation, according to our interpretation of Shier's model, due to our inclusion criterion that PWD should be involved. Most publications reported factors affecting PWD's opportunities to be involved in decisions, for example: caregiver attitudes, caregiver working conditions, architecture, relatives, PWD capabilities, technology, leadership, and cooperation between PWD's caregivers and relatives.

Regarding obligations for PWD to be involved in decisions affecting their daily lives, we found five studies that did not refer to policy documents (Bolling et al., 2016; Godman et al., 2013; Heggstad et al., 2013; Niemeijer et al., 2015; Shura et al., 2011). Two studies referred to person-centered care (Bangertter et al., 2016; McKeown et al., 2016), and four referred to documents concerning civil rights or local policies (Godwin, 2014; Helgesen et al., 2010; Mondaca et al., 2018; Serarano Cardona et al., 2013).

## Discussion

The included publications were about *how* PWD could be involved in decisions regarding their daily lives as well as any required interactions with researchers. The first question was: *What is known from the literature about PWD living in NHs and their opportunities to be active agents in their daily lives?*

PWD could be involved in decisions regarding their daily lives and the NH organization, but most reviewed publications described such participation as at a low level in terms of Shier's model and the individual level (Table 2, column one). Some of the included studies referred to policy documents concerning civil rights and person-centered care that addressed PWD involvement in decisions. Moreover, this review shows that there are civil rights demands related to PWD involvement in NHs, and that NHs can themselves strive to foster PWD involvement. Furthermore, person-centered care and a holistic approach to PWD are essential.

The second question was: *How do caregivers facilitate participation?* Each interaction between PWD and their caregivers is unique, depending on various factors such as PWD capability, caregiver experience and attitudes, the working environment, resources, support, and leadership that facilitates the caregiver role. Using the categorization of Shier's ladder of participation, we found that *nursing homes should be prepared to value and facilitate participation*. If the caregivers obtained support from their organizations and managers, they had better preconditions for addressing PWD participation.

According to Haugen et al. (2019), caregivers or relatives must help PWD take part in decision-making. If caregivers are to help empower PWD to become involved in decisions regarding their daily lives, they must first experience their own empowerment. If caregivers are to empower PWD, they need access to information, support, resources, opportunities to learn/grow, and formal/informal power, all of which affect their behavior and work attitude in the workplace (Laschinger et al., 2010). According to Mondaca et al. (2018), caregivers need time and sufficient staffing to support PWD participation. PWD participation was not prioritized in hectic daily life in NHs, and unskilled caregivers could not strive to involve PWD. Caregivers were more interested in satisfying colleagues' expectations than in involving PWD in decisions. The results of this scoping review confirm that some PWD need support from caregivers, and that, if they get this support, they can participate in decisions regarding both the organization level and their own lives, according to the CRPD (UN, 2006).

According to Kitwood (1997), person-centered care means that caregivers should involve PWD in decisions. However, Kitwood also noted that all PWD differ, and that caregivers should consider PWD's lived experiences.

Our results highlight the complex interactions between PWD and caregivers, who all are unique. Using Shier's model, we identified the enablers of and barriers to achieving participation, including dimensions affecting participation: capabilities, caregivers' conditions for addressing participation, and cooperation between PWD, caregivers, and relatives.

The studies reporting the highest level of involvement according to Shier's model (i.e., Godwin, 2014; McKeown et al., 2016; Shura et al., 2011) used some form of aid (ballot card) or model (PAR) to facilitate PWD involvement. Decision aids could facilitate the involvement of PWD in decisions (Davies et al., 2019). Most publications reviewed here found that NHs lacked such aids. Attitudes toward involving PWD and seeing them as autonomous affected how the studied NHs managed such involvement (Bangerter et al., 2016; Bolling et al., 2016; Heggstad et al., 2013).

Shier's model has been criticized, mainly because its different steps or levels could be interpreted as a hierarchy of participation illustrating how adults in organizations could help children express their views (Cahill & Dadvan, 2018). Our review found that PWD could not reach the highest level of participation due to their cognitive capabilities and reliance on decision aids in their daily lives (Haugen et al., 2019). However, Shier's (2001) model could be a first step toward developing an action plan addressing PWD participation, and the model could help NH staff identify where they are on the ladder regarding work on participation.

### The Role of Social Workers

The reviewed articles did not specifically discuss social workers' role in NHs and how they could help promote PWD participation. Perhaps both social workers and NHs have some work to do regarding this, particularly to improve the preconditions for participation. Social work is sometimes viewed as a human rights profession (Mapp et al., 2019; Reynaert et al., 2022); and, according to the IFSW (2020), social workers must promote civil rights for PWD. However, Erlandsson et al. (2022) argues that caregivers in NHs need policy documents that clarify involvement for PWD and organizational support to implement that. Furthermore, some caregivers in NHs exclude PWD from decisions and act based on their observations without asking for the PWD's opinion. This scoping review confirmed that nursing homes could improve the work with participation from PWDs' point of view. Social workers can support caregivers' readiness to involve PWD in decisions (Hardy et al. 2020).

Moreover, if we define *dementia* as a disability in line with Shakespeare et al. (2019), then social workers have grounds to strengthen the work in NHs according to the

civil rights of PWD and support formal caregivers to work in line with CRPD (UN, 2006). Furthermore, social workers in some countries work as care managers and are responsible for assessing needs and the placing of PWD in nursing homes (Österholm, 2016). As care managers, social workers can promote Shier's model as a tool in the effort to increase participation. Hardy et al. (2020) argued that social workers can use an interdisciplinary approach to finding ways to help stakeholders improve PWDs' psychosocial life, dignity, well-being, worth, and quality of life. Examples of roles for social workers in NHs are supporting PWD's and formal/informal caregivers' needs, facilitating PWD decision-making, and striving for a holistic approach to care in NHs. Bangerter et al. (2016) illustrated the importance of interpersonal interactions that promote person-centered care. Heggestad et al. (2013) emphasized the importance of caregivers seeing the whole person and their abilities. Moreover, social workers could have a crucial role in person-centered care in NHs and in supporting decision-making by PWD, who are unheard due to their disabilities (Hardy et al., 2020).

### Limitations

We only included studies that reached at least participation level one according to Shier's model, due to our inclusion criterion requiring the active involvement of PWD in decisions about daily life, as shown in the reviewed research. Many studies only observed PWD but did not actively interact with them in the research process, and those studies were excluded. The reviewed articles came from different countries, and we have no information about who the studied caregivers and managers were, what kind of education they had, or whether the NHs were for-profit or nonprofit institutions.

### Conclusion

Despite the complexity of PWD participation, we propose that PWD can be involved in decisions at different levels in NH organizations, but that they need support in this.

- The Shier (2001) model can help organizations identify how to manage PWD involvement in decisions.
- Managers should strive to involve PWD in decisions and give caregivers time and tools to work with PWD, mainly because of demands for civil rights for PWD.
- More professionals applying a holistic/person-centered approach would help promote PWD participation in NHs.



### Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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