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Factors affecting user participation for nursing home residents with dementia: a critical interpretive synthesis

Faktorer som påvirker brukermedvirkning for beboere med demens i sykehjem: en kritisk fortolkende analyse

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ABSTRACT
User participation has been one of the central guiding principles in health and social services for decades, but there are many obstacles in practice, especially when service users' have difficulties in exercising their autonomy. Many residents with dementia in nursing homes belong to this group. This article is based on a critical interpretive review of the factors affecting user participation for residents with dementia living in nursing homes. The search yielded 1555 articles; in total 82 full-text articles were retrieved, of which 38 met the inclusion criteria. Six broad analytical themes were identified; characteristics of the residents, staff, co-residents, relatives, tools for promoting participation and socio-material context, which indicates that user participation for this group and this context is multifactorial. Another interesting finding is that very few of the included articles question to whether the residents have real power in influencing the provision of individual services; moreover user participation on collective level with the overall aim of influencing service delivery in nursing homes was non-existent. An open question is whether residents with dementia in nursing homes are primarily considered patients more than fellow citizens.

KEYWORDS
User participation; dementia; nursing home; citizenship

NØKKELORD
Brukermedvirkning; demens; sykehjem; medborgerskap

SAMMENDRAG
Brukermedvirkning har vært et av de sentrale ledende prinsippene i helse- og sosialtjenester i flere tiår, men det er mange hindringer i praksis, spesielt når tjenestebrukere har vanskeligheter med å utøve sin autonomi. Mange beboere med demens på sykehjem tilhører denne gruppen. Denne artikkelen er basert på en kritisk fortolkende litteraturstudie av faktorer som påvirker brukermedvirkning for beboere med demens som bor på sykehjem. Søket ga 1555 artikler; totalt ble 82 fulltekstartikler hentet ut, hvorav 38 oppfylte inklusjonskriteriene. Seks brede analytiske temaer ble identifisert; egenskaper hos beboerne, ansatte, medboere, pårørende, verktøy for å fremme deltakelse og sosiomateriell kontekst, noe som indikerer at brukermedvirkning for denne gruppen og denne konteksten er multifaktoriell. Et annet interessant funn er at svært få av de inkluderte artiklene stiller spørsmål ved om beboerne har reell makt til å påvirke tilbudet av individuelle tjenester; dessuten var brukermedvirkning på kollektivt nivå med det

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overordnede målet å påvirke tjenesteytelsene på sykehjem, et ikke eksisterende tema. Et åpent spørsmål er om beboere med demens på sykehjem først og fremst betraktes som pasienter mer enn medborgere.

Introduction

The aim of this literature review is to identify factors that enable or hinder user participation among nursing home residents with dementia. Our working definition of 'user participation' is that it generally takes place on both an individual and collective level. Moreover, it includes both autonomous and relational aspects, and it is linked to nursing home residents' legal rights as citizens. User participation in dementia care is also described as a triadic collaboration between residents, relatives, and professional caregivers and tied with the activities of everyday life (Sørly, 2017; Helgesen et al., 2013). By exploring important factors of user participation among residents with dementia in nursing homes, our intention is to promote professional practice that includes both care for people in vulnerable situations and justice with regard to societal participation.

For 20 years, models of ensuring personhood have provided a lens for conceptualising dementia practice and research (Cahill, 2018). Personhood and person-centred care models have laid the groundwork for improving care and raising professional consciousness regarding the status of people with dementia (Brooker & Latham, 2015). Twenty-four years ago, Kitwood (1997) identified psychological needs experienced by persons living with dementia: comfort, attachment, inclusion, occupation, and identity. However, focus on personhood has been criticised for individualising personal needs, and, consequently, the political dimension is absent (Bartlett & O'Connor, 2007, 2010). To promote autonomy and improve quality of life, political and legislative changes are also needed. Bartlett and O'Connor (2007) introduced citizenship as a possible lens through which to further promote the status of persons with dementia. Cahill (2018) argues that we should understand dementia as a disability, and thus understand that the individual is entitled to the rights set by the United Nation's Convention on the Rights of Persons with Disabilities in 2006. A human rights approach implies the recognition of the civil, political, social, economic, and cultural rights of persons with dementia as well as their right to quality of life. This means that persons with dementia should be able to engage in decision-making regarding matters that are important to them, exercise autonomy, and, whenever necessary, receive support to do so while being valued and treated with dignity and respect (Cahill, 2018, p. 9). These rights include the right to protection, freedom from discrimination, free expression, and privacy. Dementia is also a health condition, and persons with dementia have the right to obtain personal fulfilment and assistance. Residents living in long-term nursing homes often exhibit health and functional impairment in more than just the cognitive domain, and they often face social barriers (Wang et al., 2013). Therefore, we believe that it is necessary to perceive residents in nursing homes as citizens, service users, and patients, and it is important to note that they can move in and out of these different roles just like everybody else.

Theoretical and conceptual framework

The theoretical understanding and the practice of participation are contested. 'Citizen participation', 'user involvement', and 'patient participation' are terms often used as synonyms in the literature and represent different political and professional points of view (Arnstein, 1969; Halabi et al., 2020; Tritter, 2009). In dementia care, participation is often related to shared decision-making, especially with regard to defining goals and preferences for future medical treatment and care, among the persons with dementia, their relatives, and health-care providers (Goossens et al., 2020).

The literature describes different levels of participation. Service users can participate on an individual or a collective level. User participation in dementia care is usually limited to individual participation, where the aim is to influence the services each individual receives, while the aim of collective participation is to improve services for everyone in the same situation (Seim & Slettebø, 2011), for example through user boards in nursing homes, user surveys etc. Participation also refers to the power service users have on influencing the shape and delivery of services. This point was clearly expressed in Arnstein's classic article (1969) *A Ladder of Citizen Participation*, where she stated 'The fundamental point is that participation without redistribution of power is an empty and frustrating process for the powerless' (p. 216). However, nursing home residents are often portrayed as vulnerable and powerless.

Participation in residential care is also about residents having an influence on everyday life and what constitutes quality of life and staff involving them in non-medicalised activities, which, in turn, can facilitate a climate of 'at-homeness' and well-being in dementia care (Edvardsson et al., 2012). Along with Sørly (2017), we believe that participation should also be understood as a relational concept – in terms of the relationship between people with dementia, their relatives, and the professional caregivers – as the voices of people living with dementia are most likely to be heard within the context of support and partnership. The quality of these relationships will often regulate how accessible participation is to nursing home residents with dementia.

In an analysis of the literature on user participation among people with dementia *living at home*, Haugen et al. (2019) found that the factors affecting user participation were related to individual, professional, decision-based, relational, and organisational characteristics. In this paper, we explore whether the same factors affect participation among residents with dementia living in nursing home settings are similar to the factors affecting participation among people with dementia living at home. This could give us a broader picture of how participation is understood and practised in the broader area of dementia care.

Our primary research question for this review is:

What factors affect user participation among nursing home residents with dementia?

Materials and methods

This literature review was based on the methodology of Dixon-Woods et al. (2006), which is called critical interpretative synthesis (CIS). A characteristic of this approach is that qualitative and quantitative studies can be included in the same meta-synthesis. Furthermore, it is possible to make a strategic selection of relevant literature and allow for maximum variation in the inclusion criteria. The method also allow for an adjustment of the research question, with the purpose of further developing knowledge and concepts by means of interpretation – instead of just describing existing research – and ask critical questions about assumptions that are taken for granted. The intention behind conducting a critical interpretive approach was to expand the understanding on the make-up of everyday, triadic perspectives on user participation in nursing homes and investigate the possibility of residents' influence and the redistribution of power.

Search strategy, inclusion and exclusion criteria, and quality assessment

The literature search was conducted between April and May 2019. We chose our search terms based on the following categories:

1. Dementia OR Alzheimer OR Alzheimer's Disease
2. Nursing homes OR Nursing Home Patients
3. Autonomy OR user autonomy OR patient autonomy OR client autonomy OR consumer autonomy OR empowerment OR user empowerment OR patient empowerment OR client empowerment OR consumer empowerment OR participation OR user participation OR patient participation OR client participation OR consumer participation OR involvement OR user involvement OR patient involvement OR client involvement OR consumer involvement OR

decision-making OR person-centred OR person-centred OR patient-centred OR patient-centred OR self-determination.

The search was conducted using the following databases with a combination of keywords and MeSH terms – or a database equivalent to MeSH: Academic Search Elite, Amed, Cinahl, Cochrane, Embase, Medline, Ovid Nursing, Psycinfo, Scopus, and SocIndex. The formal search yielded 3,845 hits; after duplicate checking, it yielded 1,555 hits.

Our inclusion criteria were articles published from 2000 to 2019 in peer-reviewed journals and written in English or a Nordic language. After reading, adjusting inclusion from 2005 to 2019, excluding review articles, and assessing relevance to our study, we obtained 38 included articles.

The quality assessment of the sample is consistent with the CIS, with relevance a higher priority than methodological quality. We conducted an MMAT assessment ensuring a good methodological quality (Hong et al., 2018). We obtained all 38 items following the assessment (Figure 1 and Table 1).

Synthesis

The first analytic step of this review process was a detailed inspection of the papers, where we progressively identified recurring themes and developed a critique of some of the established assumptions about participation in dementia care. In a thematic analysis of 38 included scientific articles,

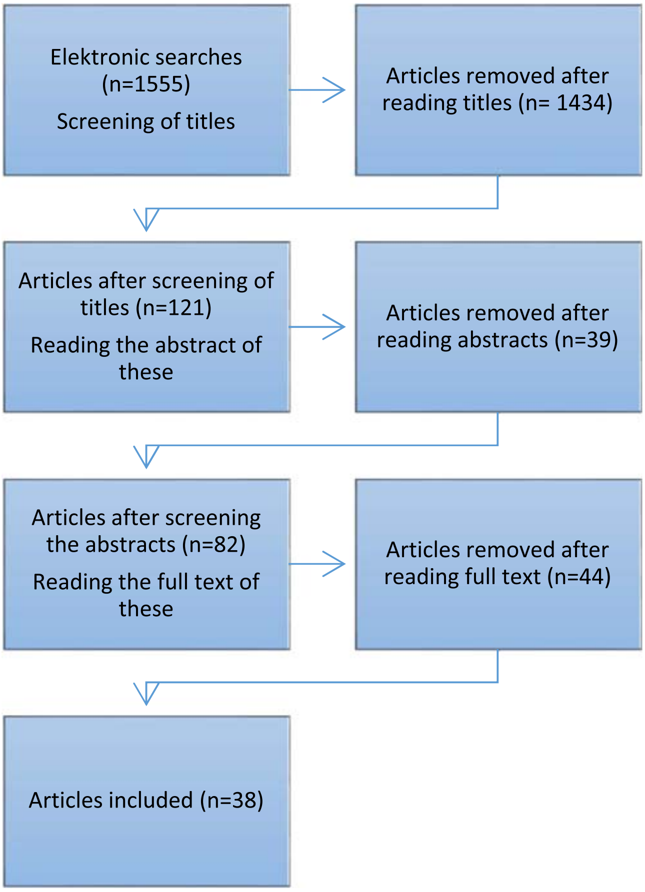

Figure 1. Flowchart of selection process.

Table 1. Summary table of included studies.

Author information, publication year, title, and journal	Country	Design, methods, and sample	Aims	Extract of findings
Aasgaard, H. S., et al. (2017). Healthcare personnel's experiences of enhancing social community for people living in dementia special care units. *Nordic Journal of Nursing Research 37*(4): 186-193.	Norway	A qualitative descriptive design Four focus-group interviews 15 healthcare personnel	To explore healthcare personnel's experiences of enhancing social community in common spaces in dementia special care units.	Experiences of enhancing social community in common spaces were related to three main themes, expressed as dilemmas between knowing versus not knowing each other, safety versus unsafety and presence versus absence.
Argyle, E. (2012). Person centred dementia care: problems and possibilities. *Working with Older People: Community Care Policy & Practice 16*(2): 69-77.	UK	Observational study Five care home residents, female, ages ranged from 77 to 92 The activities observed included physical, intellectual or social components	To use Dementia Care Mapping (DCM) to assess the utilisation and efficacy of a person-centred approach with a group of care home residents.	The care home appeared to provide a stimulating and inclusive range of activities with leisure pursuits (49%) and exercise sessions (24%) being the most commonly occurring activities
Barbosa, A., et al. (2015). Supporting direct care workers in dementia care: effects of a psychoeducational intervention. *American Journal of Alzheimer's Disease and other Dementias 30*(2): 130-138.	Portugal	An experimental study using a pre–post-test control group design Four aged care facilities were randomly assigned to a psychoeducational or an education-only intervention (control). Data were collected from 56 direct care workers through measurements of burnout, job, and stress and focus-group interviews.	To assess the effects of a person-centred care-based psychoeducational intervention on direct care workers' stress, burnout, and job satisfaction.	Results showed significant positive effects in emotional exhaustion and positive but no significant effects in stress and job satisfaction. Psychoeducational interventions may contribute to reduce direct care workers' burnout.
Belzil, G. & Vezina, J. (2015). Impact of caregivers' behaviours on resistiveness to care and collaboration in persons with dementia in the context of hygienic care: An interactional perspective. *International Psychogeriatrics 27*(11): 1861-1873.	Canada	Two hundred and forty hygienic care routines, observed in eight nursing home residents, were analysed with a video-assisted systematic observation methodology and a sequential statistical analysis strategy.	To assess the role played by various physical and verbal behaviours of professional caregivers in the onset of restiveness to care (RTC) and collaborative behaviours of nursing home residents with dementia, in a daily hygienic care routine context.	Caregiver and care recipient behaviours are interdependent in the hygienic care routine context. Physical instrumental behaviour, neutral, negative, and positive statements, positive and negative instructions, and verbal distraction emitted by caregivers are significantly and moderately associated with the onset of RTC in persons with dementia, but the strength of relationships observed depends on the care recipient's behaviour prior to the caregiver's action. Positive instructions are moderately associated with the onset of collaboration in residents with preserved language abilities. However, for residents with severe language impairment, these same instructions were linked to RTC behaviours.

(*Continued*)

Table 1. Continued.

Author information, publication year, title, and journal	Country	Design, methods, and sample	Aims	Extract of findings
Bentwich, M. E., et al. (2018). Human dignity and autonomy in the care for patients with dementia: differences among formal caretakers from various cultural backgrounds. *Ethnicity & Health 23*(2): 121-141.	Israel	A mixed-methods research design: semi-structured interviews and self-reported questionnaires Twenty formal caretakers participated in the qualitative portion, and approximately 200 caretakers were included in the quantitative portion, recruited from three nursing homes and one hospital in the Galilee region (Israel)	To explore whether gaps exist between caretakers from different ethno-cultural groups (Israeli-born Jews [Sabras], Israeli Arabs [Arabs], and migrants from Russia [Russians]) regarding their perceptions of autonomy and human dignity of patients with dementia	A multi-variable regression, focusing on caretakers from nursing homes, showed the most significant influencing variables on the indexes of autonomy and dignity were ethno-culture Arab/Russian and the patient's family. Regarding the autonomy index, being a female caretaker also had a significant influence. In the hospital, no influence emerged for the ethno-culture variables, and neither type of institution showed any influence of religion or religiousness as well as societal or community norms.
Berendonk, C. and Caine, V. (2017). Insights Into Care Providers' Understandings of Life Story Work With Persons With Dementia: Findings From a Qualitative Study. *Research and theory for nursing practice 31*(3): 272-294.	Canada	A qualitative study with GT design. 36 care providers in seven nursing homes participated in semi-structured interviews or group discussions	To gain insights Into Care Providers' Understandings of Life Story Work with Persons with Dementia	A great variation in participants' understandings of life story work. Some participants were unsure if and how life story work influences persons with dementia.
Bollig, G., et al. (2016). Nothing to complain about? Residents' and relatives' views on a "good life" and ethical challenges in nursing homes. *Nursing Ethics 23*(2): 142-153.	Norway	A qualitative design In-depth interviews with 25 nursing home residents, and focus-group interviews with 18 relatives of nursing home residents.	To study what nursing home residents and their relatives perceive as ethical challenges in Norwegian nursing homes.	The main ethical challenges from the residents' and relatives' perspective were: (a) acceptance and adaptation, (b) well-being and a good life, (c) autonomy and self-determination, and (d) lack of resources. The relationship with the staff was of out-most importance and was experienced as both rewarding and problematic.
Bramble, M., et al. (2011). A quasi-experimental design trial exploring the effect of a partnership intervention on family and staff well-being in long-term dementia care. *Aging & Mental Health 15*(8): 995-1007.	Australia	A quasi-experimental design 57 family caregivers and 59 staff from two LTC facilities were recruited. Participants were assessed once pre-intervention and three times post-intervention for knowledge, stress, and satisfaction outcomes. Pre- and post-intervention interviews from a purposive sample of family caregivers were conducted to enhance understanding of FIC benefits.	To explore the effect of the family involvement in care (FIC) intervention on family and staff well-being over a nine-month period in a long-term care (LTC) facility providing dementia care.	Beneficial intervention effects associated with family caregivers' knowledge of dementia were found. Negative intervention effects were also found for family satisfaction outcomes in relation to staff consideration of their relatives and management effectiveness. In addition, staff well-being and job satisfaction were found to be negatively affected by their perceived inappropriate behaviour of residents with dementia.

Carter, G., et al. (2018). The experiences and preparedness of family carers for best interest decision-making of a relative living with advanced dementia: A qualitative study. *Journal of Advanced Nursing 74*(7): 1595-1604.	UK	20 semi-structured interviews were conducted of family carers of nursing home residents living with advanced dementia.	To explore the experience and the preparedness of family carers in their caregiving role as best interest decision-makers of a relative living with advanced dementia.	Three themes were identified: (1) Caring for someone living with dementia. The impact on the carer's holistic well-being and their experience of being a best interest decision-maker; (2) Accessing support. The influential nature of formal and informal networks; (3) Perceived knowledge and understanding of the dementia trajectory of carers and nursing staff.
Clifford, C. & Doody, O. (2018). Exploring nursing staff views of responsive behaviours of people with dementia in long-stay facilities. *Journal of Psychiatric & Mental Health Nursing 25*(1): 26-36.	Ireland	A qualitative descriptive study utilizing in-depth audio-recorded interviews of nine nurses, recruited from private and public care facilities	To explore nurses' views of supporting people with dementia and responsive behaviours in long-stay facilities	Four themes emerged: recognizing and understanding responsive behaviour, resources and interventions to support people with dementia and responsive behaviour, the impact of education on nursing practice, and the care environment.
Cohen-Mansfield, J., et al. (2010). The impact of past and present preferences on stimulus engagement in nursing home residents with dementia. *Aging & Mental Health 14*(1): 67-73.	US	A self-identity questionnaire was used to determine participants' past/present interests (as reported by relatives) in the following areas: art, music, babies, pets, reading, television, and office work.	To examined engagement with stimuli in 193 nursing home residents with dementia.	Analysis revealed that residents with current interests in music, art, and pets were more engaged by stimuli that reflect these interests than residents without these interests.
Cohen-Mansfield, J., et al. (2010). Engaging nursing home residents with dementia in activities: the effects of modeling, presentation order, time of day, and setting characteristics. *Aging & Mental Health 14*(4): 471-480.	US	Engagement was assessed through systematic observations using the Observational Measurement of Engagement (OME), and data pertaining to setting characteristics were recorded via the environmental portion of the Agitation Behaviour Mapping Inventory 193 nursing home residents with dementia recruited from seven nursing homes	To examine the impact of setting characteristics and presentation effects on engagement with stimuli	Study participants were engaged more often with moderate levels of sound and in the presence of a small group of people (from four to nine people). As to the presentation effects, multiple presentations of the same stimulus were found to be appropriate for the severely impaired as well as the moderately cognitively impaired. Moreover, modeling of the appropriate behaviour significantly increased engagement, with the severely cognitively impaired residents receiving the greatest benefit from modeling.

(*Continued*)

Table 1. Continued.

Author information, publication year, title, and journal	Country	Design, methods, and sample	Aims	Extract of findings
Cooney, A., et al. (2014). 'Seeing me through my memories': a grounded theory study on using reminiscence with people with dementia living in long-term care. *Journal of Clinical Nursing 23*(23-24): 3564-3574.	Ireland	A grounded theory study In-depth interviews were conducted with residents with dementia (n = 11), relatives (n = 5), healthcare assistants (n = 10), nurses (n = 9) and nurse managers (n = 3).	To understand people with dementia, staff and relatives' perspectives on reminiscence, its impact on their lives and experience of care and care giving	Reminiscence enabled staff to see and know the person beneath the dementia. It acted as … a key revealing the person to staff, enabling them to engage with the person with dementia in a different way. Knowing the person enabled staff to understand (through the lens of the person's past) and sometimes to accommodate the person's current behaviour.
Dassa, A. (2018). "Opening Our Time Capsule"-Creating an Individualized Music and Other Memory Cues Database to Promote Communication Between Spouses and People with Dementia During Visits to a Nursing Home. *Frontiers in Medicine 5*: 215.	Israel	A qualitative research was used to explore spouses' experience during visits and the process of creating and using the individualized database. Participants included three women who regularly visited their partners The data included interview reports (pre-post intervention), preparation meetings reports, spouses' recorded reactions at the end of each of the four visits, and the music therapist's written log during the program.	To help alleviate caregivers' burden during visiting hours, by promoting communication opportunities. The program included the creation of an individualized database using personal music and photos that present life episodes.	All documented data revealed the difficulties, mostly the communication barrier, encountered by the three women during their visits to the nursing home. All reported that using the individualized database helped them to find ways to communicate with their partners, relive shared past experiences, and alleviate the stress and feelings of disconnection during visits.
Dobbs, D., et al. (2005). Characteristics Associated With Lower Activity Involvement in Long-Term Care Residents With Dementia. *Special Issue: Dementia Care and Quality of Life in Assisted Living and Nursing Homes. 45*(SpecIssue1): 81-86.	US	400 residents and their direct care worker participated in on-site interviews. The facility administrator provided facility-level data, and the family provided information about their level of involvement in care.	To describe the characteristics associated with activity involvement in 400 residents with dementia in 45 assisted living facilities and nursing homes.	Activity involvement was related to family involvement in care and staff encouragement, after adjusting for resident age, gender, race, cognitive and functional status, and comorbidity.
Edvardsson, D., et al. (2014). Everyday activities for people with dementia in residential aged care: Associations with person-	Sweden	A cross-sectional design was used to collect questionnaire data on activity participation, unit person-centredness and quality of life in a	To explore the point-prevalence of participation in everyday activities for residents with dementia within a national	Only 18% of residents participated in everyday activities such as making coffee, setting or clearing the table, cleaning or watering plants, 62% participated in outdoor walks, 27% participated in parlour games, and

centredness and quality of life. *International Journal of Older People Nursing 9*(4): 269-276.		sample of residents in residential aged care (n = 1266)	sample of Swedish residential aged care units and to explore if residents participating in everyday activities lived in more person-centred units and/or had higher quality of life as compared to residents not participating in everyday activities.	14% and 13% participated in excursions and church visits, respectively. Those residents who had participated in everyday activities lived in more person-centred units, had significantly higher quality of life and higher cognitive scores as compared to those residents who had not participated in everyday activities.
Evans, E. A., et al. (2018). Care home manager attitudes to balancing risk and autonomy for residents with dementia. *Aging & Mental Health 22*(2): 261-269.	UK	Semi-structured interviews with 18 managers from care homes offering dementia care.	To determine how care home managers, negotiate the conflict between maintaining a safe environment while enabling the autonomy of residents with dementia.	Three areas were reported balancing safety and risk against the individual needs of residents. Firstly, the physical environment created a tension between safety and accessibility to the outside world, which meant that care homes provided highly structured or limited access to outdoor space. Secondly, care home managers reflected a balancing act between an individual's autonomy and the need to protect their residents' dignity. Finally, care home managers highlighted the ways in which an individual's needs were framed by the needs of other residents to the extent that on some occasions an individual's needs were subjugated to the needs of the general population of a home.
Fain, K. M., et al. (2015). Markers of Impaired Decision Making in Nursing Home Residents: Assessment by Nursing Home Staff in a Population-Based Study. *Journal of the American Medical Directors Association 16* (7): 563-567.	US	Participants were 13,013 residents in the 2004 National Nursing Home Survey. Logistic regression was used to determine the association between resident characteristics and impaired (vs independent) decision-making.	To identify potential markers of impaired decision-making, they investigated the association between a range of nursing home resident characteristics and impaired decision making in a population-based sample.	After controlling for depression and anxiety diagnoses, as well as gender, age, race, and recent hospitalization or pain, characteristics associated with impaired decision making included depressed, sad, or anxious mood; diagnosed dementia or living on a dementia hall; number of ADL requiring assistance; length of nursing home stay; and history of falls or fractures in the last 6 months. Residents reporting pain in the last week were less likely to have impaired decision-making.
Fetherstonhaugh, D., et al. (2016). "The Red Dress or the Blue?". *Journal of Applied Gerontology 35*(2): 209-226.	Australia	A qualitative study conducted with 80 direct care staff members.	Little is known about how staff in Age Care Facilities perceive that they support decision making for people with dementia within	Findings revealed that the participants utilized a number of strategies in their intention to support decision making for people with dementia.

(*Continued*)

Table 1. Continued.

Author information, publication year, title, and journal	Country	Design, methods, and sample	Aims	Extract of findings
			their everyday practice, and this article seeks to address this knowledge gap.	
Forsund, L. H., et al. (2016). Constructing togetherness throughout the phases of dementia: a qualitative study exploring how spouses maintain relationships with partners with dementia who live in institutional care. *Journal of Clinical Nursing 25*(19-20): 3010-3025.	Norway	Qualitative interview conducted with 15 spouses ranging from 64-90 years of dementia afflicted persons living in institutional care	To explore and describe how spouses involve themselves in the relationship with their partners with dementia living in institutional care.	The spouses adopted different visiting routines to provide continuity in their relationship throughout the phases of dementia. Three categories were developed: ‘maintaining involvement and intimacy to preserve continuity in their relationship’, `structuring visits to facilitate interaction and communication‘ and ‘pursuing moments of mutuality to preserve continuity in a deteriorating relationship’
Heggestad, A. K. T., et al. (2015). Dignity and care for people with dementia living in nursing homes. *Dementia: The International Journal of Social Research and Practice 14*(6): 825-841.	Norway	Participant observation in two nursing homes combined with qualitative interviews with five residents living in these units	To investigate how life in Norwegian nursing homes may affect experiences of dignity among persons with dementia	The residents feel that their freedom is restricted, and the describe feelings of homesickness. They experience that they are not being seen and heard, as individual, autonomous persons may be a threat to their personal dignity.
Heggestad, A. K. T., et al. (2013). ’Like a prison without bars’: Dementia and experiences of dignity. *Nursing Ethics 20*(8): 881-892.	Norway	Participant observation in two nursing homes combined with qualitative interviews with seven relatives of patients with dementia	To study how the dignity of patients with dementia is preserved or harmed when they live in a nursing home.	It was important for the relatives that their family member with dementia was confirmed as a relational human being. But the relative’s experiences lack of resources and task-centred care as threats to confirming, relational care and to patients’ dignity.
Helgesen, A. K., et al. (2013). How do relatives of persons with dementia experience their role in the patient participation process in special care units?	Norway	Qualitative interviews with twelve close relatives of persons with dementia in special care units - interviewed twice	To explore the role of relatives in the patient participation process for persons with dementia living in special care units	The relative’s role in the participation process was experiences as transitions between different roles to secure the resident’s well-being, which was understood as the resident’s comfort and dignity. They described their roles in categories like: ‘being a visitor’, ‘being a spokesperson’, ‘being a guardian’ and ‘being

Journal of Clinical Nursing 22 (11-12): 1672-1681.				a link to the outside world'. Different situations and conditions triggered different roles, and the relatives' trust in the personnel was a crucial factor.
Helgesen, A. K., et al. (2014). Patient participation in special care units for persons with dementia: A losing principle? *Nursing Ethics 21*(1): 108-118.	Norway	Eleven nursing personnel in three special care units for persons with dementia in nursing homes were interviewed twice.	To explore the experience of nursing personnel with respect to patient participation, focussing on everyday life	Patient participation is regarded as being grounded in the idea that being master of one's own life is essential to the dignity and self-esteem of app people.
Jacobsen, F. F., et al. (2017). A mixed method study of an education intervention to reduce use of restraint and implement person-centered dementia care in nursing homes. *BMC Nursing 16*: 55.	Norway	Mixed –method design combining quantitative and qualitative methods, assessing the Person centred Care Assessment Toll (P-cat) in 24 nursing homes in Norway	To investigate ~~which~~ factors hindered or facilitated staff awareness related to confidence building initiatives as an alternative to restraint in residents with dementia in nursing homes	Increased staff awareness to using restraint or not in PCC.The role of the nursing home leader combined with staff culture appeared to be a pivotal element promoting or hindering PCC, but leadership –staff relations varied across institutions, as did staff awareness related to restraint and person-centeredness.
Kellett, U., et al. (2010). Life stories and biography: a means of connecting family and staff to people with dementia. *Journal of Clinical Nursing 19*(11-12): 1707-1715.	Australia	A qualitative descriptive approach. Family Biography Workshop involving seven family care givers and seven staff and one researcher during six weekly two hours sessions – design to help them build a biography of the person with dementia	To assesses the Family Biography Workshop (FBW) designed to support family and staff to co-construct the history of the person with dementia in residential care.	For family caregivers, reviving memories of their relatives as 'whole' persons enabled some to 'stand outside' and see beyond the disease-saturated context. For staff, 'opening possibilities' of 'seeing' the resident within the family context empowered them to engage in genuine participatory practices.
Kontos, P. C., et al. (2010). Neglecting the Importance of the Decision Making and Care Regimes of Personal Support Workers: A Critique of Standardization of Care Planning Through the RAI/MDS. *Gerontologist 50*(3): 352-362.	Canada	Qualitative study utilized focus groups and semi-structured interviews with 26 Personal Support Workers (PSW) and 9 supervisors	To examine the decision making and care practices of personal support workers (PSWs) in relation to the RAI/MDS standardized process	The instrument does not capture biographical information and residents' preferences. Restrict the care plan to standardized interventions, overlooking individual preferences, style, and vocational history – vital for an accurate deciphering the meaning of behaviour. Do not promote individual care, customized care.
Lindholm, C. (2016). Boundaries of participation in care home settings: Use of the Swedish token jaså by a person with	Finland	Conversation analytic study of how one elderly person with dementia hand her interlocutors interact in a care home setting	Participation is studied in the form of response action of the person with dementia.	Even though the sequential placement of the response token indicates interactional competence, other factors reveal limited competence and communication impairment. Communications challenges can increase in care home settings when a person with dementia is

(*Continued*)

Table 1. Continued.

Author information, publication year, title, and journal	Country	Design, methods, and sample	Aims	Extract of findings
dementia. *Clinical Linguistics & Phonetics 30*(10): 832-848.				exposed to a setting characterised by background noise and multiple simultaneous stimuli.
Lykkeslet, E., et al. (2014). Sensory stimulation-A way of creating mutual relations in dementia care. *International Journal of Qualitative Studies on Health and Well-being 9*. 23888	Norway	Two-year actions research project. Focus group interviews and participant observation. An intervention program consisting of lectures and practical guiding in sensory stimulation was implemented.	To improve the interaction between care workers and patients with dementia in a nursing home by means of sensory stimulation.	The analysis revealed that the participating care workers experienced a process of change in attitude toward the patients. They increasingly recognised the importance of developing relationships in human interaction. The changes emerged gradually through a combination of supervision in practice, continuous reflection, and acquisition of knowledge: gradually viewing symptoms as meaningful expressions and gradually realizing the importance of human relationships.
Mobley, C., et al. (2017). Examining Relationships between Physical Environments and Behaviors of Residents with Dementia in a Retrofit Special Care Unit. *Journal of Interior Design 42*(2): 49-69.	US	A case study, unit with 9 residents, photo documentation, observations, and survey	To determine the capacity of the physical environment to enhance person-centred care and identify potential design opportunities to help patients adapt and cope with dementia progression to maintain quality of life.	The study shows that quite small retrofit Special Care Unit (SCU) design interventions (colour, hide doors, wayfinding, lighting, visual access to all relevant locations etc,) have the potential to support PCC goals significantly. Staff lack awareness of the capacity for the SCU physical environment to improve the patients' quality of life.
Mondaca, M., et al. (2018). Influencing everyday activities in a nursing home setting: A call for ethical and responsive engagement. *Nursing Inquiry 25*(2): e12217.	Sweden	A case study involving residents, staff members and significant others, data gathered through fieldwork, participant observation and formal and informal conversations.	To focus on influence that older adults living in nursing homes have over everyday activities. Aims to shed light on how influence can be situated contextually.	Focus on how influence is situated contextually, how it emerges through activities and is being negotiated. The importance of the staff identifying the possibilities in everyday life and situations. The staff must have the necessary competence and sufficient time
Norheim, A. & Vinsnes, A. (2008). Patient involvement in dementia care - opportunities and challenges. *Norsk Tidsskrift for Sykepleieforskning 10*(4): 3-15.	Norway	Transcribed documentation from nursing journals on three patients and focus groups interviews with 11 staff members	The aim was to study the possibilities and challenges of participation among residents with dementia in nursing homes	Three main categories were formed: self-determination, participation and limited participation and different opportunities and challenges according to these categories. The staff claims that dignity is independent of patient involvement and includes treating the patient with respect. Clinical judgement and professional reflection are fundamental for giving power to the patients.

Perry, J., et al. (2005). Nurse-patient communication in dementia: improving the odds. *Journal of Gerontological Nursing 31*(4): 43-52.	Canada	Conversational analysis of eight residents participating in nurse lead socialization groups from three units, met weekly for ten weeks, eight women, sessions audiotaped. Family members were invited to observe.	To investigate the use of a range of conversational strategies in nurse led socializations groups	The analyses resulted in two taxonomies: A taxonomy of the nurse conversational strategies (clarifying, exploring, moderating, validating rescuing and general discourse makers, and a taxonomy of patents responses (discourse markers, limited engagement, expanded responses, personalized response, self – initiated participation and disconnected and fragmented participation). The effectiveness of the nurse conversational strategies was reflected in the encouraging level of resident participation rates.
Savundranayagam, M. Y. & Moore-Nielsen, K. (2015). Language-based communication strategies that support person-centered communication with persons with dementia. *International Psychogeriatrics 27*(10): 1707-1718.	Canada	46 conversation between staff-residents were audio-recorded during routine care tasks over 12 weeks	To examine whether language-based strategies for effective communication with persons with dementia overlapped with the indicators of person-centred communication.	The findings identify specific language-based strategies that support person-centred communication, but the staff need training to use more diverse language strategies that support personhood of residents with dementia
Smit, D., et al. (2012). The relationship between small-scale care and activity involvement of residents with dementia. *International Psychogeriatrics 24*(5): 722-732.		Data were derived from the Living Arrangements for people with Dementia study, 136 long term care facilities, care staff completed questionnaires, involving 1327 residents	To describe how small-scale care is related to the overall activity involvement of residents with dementia and their involvement in different types of activities.	Residents of care facilities with more group living home care characteristics were more involved in overall and preferred activities. They were also more involved in more diverse activities
Smit, D et al (2017) Predictors of activity involvement in dementia care homes: a cross-sectional study. *BMC Geriatrics 17*:175 DOI.10.1186/s12877-017-0564-7	The Netherlands	Data were derived from the Living Arrangements for people with Dementia study, 139 long term care facilities, care staff questionnaires, involving 1218 residents. Multilevel regression analysis	What are the factors that predict higher activity involvement among residents with dementia in care homes?	The most important predictors of higher involvement were: Absence of agitation, less ADL dependency, and a higher cognitive status of the residents, higher staff educational level, lower experienced job demands by care staff and smaller number of residents living in the dementia care wards.
van Weert, J. C. M., et al. (2005). Effects of snoezelen, integrated in 24h dementia care, on nurse–patient communication during morning care. *Patient Education & Counseling 58*(3): 312-326.	The Netherlands	A quasi –experimental pre and post-test design comparing wards implanting Snoezelen	Studying the effectiveness of Snoezelen integrated in 24-hour care on the communication of Nursing assistant and residents in dementia care, morning care	The implementation of Snoezelen improved the actual communication during morning care

(*Continued*)

Table 1. Continued.

Author information, publication year, title, and journal	Country	Design, methods, and sample	Aims	Extract of findings
Ward, R., et al. (2008). A different story: Exploring patterns of communication in residential dementia care. *Ageing & Society* *28*(5): 629-651.	UK	A three-year investigation 2000-2003. The residents were filmed in communal day rooms where also researchers observed and recorded interactions and daily events. Films supplemented with diary observations, combined with efforts to interview the participating residents.	Exploring patterns of communication in residential care. The project set out to identify the constituent element of dementia care practice and the patterns that characterise day-to-day relations through the interactions between the staff and the residents	Care-speak in a particular form of 'institutional talk' that is used by care staff to manage the tasks and requirements of their work. Encounters between staff and residents in care homes become standardised through such repetition and are normalised. Workload pressures prohibit communication, but also communication skills, a low priority and varies between care workers. Findings show that people with dementia are both capable of communication and invest much effort in seeking to engage those around them, but are excluded from the monitoring, planning and provision of care in ways that are discriminatory.

based on Braun and Clarke (2006), the following main themes were identified: characteristics of nursing home residents with dementia, characteristics of staff and their practices, characteristics of relatives' experiences, tools and methods of promoting participation, and environmental and organisational characteristics. We compared the main themes against the data in the included articles and attempted to identify the relationships between them.

Results

Characteristics of nursing home residents with dementia

The literature provides descriptions of persons with dementia as frail, with a lost sense of self and few opportunities to make decisions (Haugen et al., 2019). Very few of the studies in our sample depicted nursing home residents as informants to gain knowledge of the residents' condition and experiences regarding autonomy and participation. Fain et al. (2015) conducted a survey comprised of nursing home residents to investigate the association between a range of resident characteristics and impaired decision-making. They found several independent markers of impaired decision-making in the nursing home residents, including being depressed, sad, or having an anxious mood; dementia; and a greater need for activity of daily living assistance. They concluded that some of these factors, particularly mood, are modifiable, and addressing them may help improve decision-making. Heggestad et al. (2015) investigated how life in Norwegian nursing homes may affect experiences of dignity among persons with dementia. They found that residents felt that their freedom was restricted, also describing feelings of homesickness. Not being seen as an individual autonomous person by the staff was a threat to the residents' personal dignity. In another study of Norwegian nursing homes, 25 residents were interviewed about what they perceived as ethical challenges in their everyday lives. Also in this study, a lack of autonomy and self-determination represented a threat to the sense of dignity (Bollig et al., 2016). Mondaca et al. (2018) conducted a fieldwork-designed case study that focused on the influence older adults living in nursing homes possess over everyday activities. The findings illustrated how influence is situated contextually as well as how it emerges through activities, and is being negotiated.

Characteristics of staff and their practices

Nursing home staff play an important role in facilitating resident participation. The characteristics of the health personnel are related to their education and participation in competence-enhancing interventions, their practices, and their cultural background. Clifford and Doody (2018) explored nurses' views on supporting people with dementia and responsive behaviours in long-stay facilities. Staff access to on-going education and the ability to provide one-to-one care was valued as options that could change the overall nursing practice. A mixed method study of an education intervention aimed to reduce the use of restraint and implement person-centred dementia care in nursing homes comprised 24 nursing home personnel and was conducted by Jacobsen et al. (2017). As a result, training programmes were found to be an important precondition for person-centred care in nursing homes.

Another experimental study aimed to develop person-centred care competences (Barbosa et al., 2015). Four aged care facilities were randomly assigned to either a psychoeducational or education-only intervention (control). Data was collected from 56 direct care workers. The direct care workers participating in the psychoeducational intervention exhibited enhanced group cohesion, emotional management, and self-care awareness.

The provision of one-to-one care seems to be crucial in supporting persons with dementia (Clifford & Doody, 2018). Two Norwegian studies (Helgesen et al., 2014; Norheim & Vinsnes, 2008) examined different forms of participation practices. These practices were described as 'letting the resident make their own decisions', 'adjusting the choices', 'making decisions on behalf of the residents', and 'forcing the residents to act'. Additionally, the education and commitment were described by the study participants as impacting the residents' participation, often combined with the ability of the residents to make decisions and organisational conditions, such as care culture, leadership, and staff ratio. Patient participation had to be adjusted to the individual resident, but it was usually adjusted to suit the nurse's preferences regarding how to carry out the daily care and only secondly to suit the individual resident's needs and wishes (Helgesen et al., 2014).

Participation for residents in nursing homes essentially seems to be about everyday events. The role of the various physical and verbal behaviours of professional caregivers in the onset of restiveness to care (RTC) and the collaborative behaviours of nursing home residents with dementia was assessed in a daily hygienic care routine context (Belzil & Vezina, 2015). Two hundred and forty hygienic care routines, observed in eight nursing home residents, were analysed. The results showed that caregiver and care recipient behaviours were interdependent in the hygienic care routine context. Task-oriented behaviour; neutral, negative, and positive statements; positive and negative instructions; and verbal distraction emitted by caregivers were significantly and moderately associated with the onset of RTC in persons with dementia, but the strength of relationship was found to depend on the care recipient's behaviour prior to the caregiver's action. Staff's positive instructions were moderately associated with collaboration among residents with preserved language abilities; however, for residents with severe language impairments, these same instructions were linked to RTC behaviours. Additionally, Ward et al. (2008) explored patterns of communication in residential care. They found a significant degree of 'institutional talk'(a type of communication taking place between professionals and clients in institutional settings when the asymmetry of the relation is maintained) – excluding persons with dementia – as associated with the provision of care and the promotion and support of communication as a key skill for care workers.

Participation seems to be linked to one-to-one care and relational practices, but, in nursing homes, it is also linked to groups of residents with common interests. In order to explore the possibilities of enhancing such resident communities in common spaces in dementia special care units, 15 healthcare personnel were interviewed (Aasgaard et al., 2017). The analysis indicated that, to enhance the social community, it was essential for the healthcare personnel to be able to cultivate physical, narrative, and moral proximity (i.e. acting and looking out for patients' interests) to the residents.

Nursing homes are multicultural workplaces. Bentwich et al. (2018) explored whether gaps exist between carers from different ethno-cultural groups regarding their perceptions of the autonomy and human dignity of patients with dementia. Twenty formal caretakers participated in the qualitative part of this study, and approximately 200 caretakers were included in the quantitative part. Participants were recruited from three nursing homes and one hospital in the Galilee region of Israel. The results showed that Arab caretakers fostered more thorough conceptions of dignity and autonomy irrespective of institutional setting when compared with the Israeli participants. This could imply that the ethno-cultural background of the staff may have an influence on the extent to which they facilitate resident participation.

Characteristics of relatives' experiences

Sørly (2017) described user participation in dementia care from a triadic perspective, and relatives are central in this sense. Carter et al. (2018) conducted a study consisting of interviews with twenty relatives of nursing home residents, with the aim of exploring the experience and preparedness of family carers in their caregiving role as best-interest decision-makers. Much of the stress experienced by these relatives was explained by a lack of support and competence among the dementia care staff in situations where they were involved in decisions concerning the residents. Another study revealed that the 15 spouses included, adopted different visiting modes to provide continuity in their relationship with their partner throughout the phases of dementia. The visiting modes described as: 'maintaining involvement and intimacy to preserve continuity in their relationship', 'structuring visits to facilitate interaction and communication', and 'pursuing moments of mutuality to preserve continuity in a deteriorating relationship' (Forsund et al., 2016).

Heggestad et al. (2013) interviewed seven relatives of residents with dementia. They found that it was important for the relatives that their family member was confirmed by staff as a relational human being; however, the relatives experienced a lack of resources and task-centred care as threats to confirmation, relational care, and the patients' dignity. Helgesen et al. (2013) interviewed relatives about their role in the participation process. They described their roles with phrases like 'being a visitor', 'being a spokesperson', 'being a guardian', and 'being a link to the outside world'. Different situations and conditions triggered different roles for them, and their trust in the staff was a crucial factor in their roles. The relatives also explained that they had to take on an active role to secure the well-being of their residents.

In-depth interviews with 25 nursing home residents and focus-group interviews with 18 relatives were conducted to study what residents and their relatives perceive as ethical challenges in Norwegian nursing homes (Bollig et al., 2016). One of the main ethical challenges was related to autonomy and self-determination. Relatives' relationship with the staff was of utmost importance and was experienced as both rewarding and problematic. Challenges were mostly connected to 'everyday ethical issues.'

Environmental and organisational characteristics

From the included studies on everyday life-oriented participation, in taking a triadic perspective, many of the results are related to factors outside everyday life and triadic interaction. A recent study (Smit et al., 2017) found important predictors of higher involvement for residents to include higher staff educational levels, lower experienced job demands by care staff, and a smaller number of residents living in the dementia care wards. Clifford and Doody (2018) study on supportive and responsive behaviours showed that the availability of staff, adequate time, and financial restraints were identified as barriers to nurses' ability to provide person-centred care. Physical environment and design of nursing home are other barriers. Cohen-Mansfield, Thein, et al. (2010) examined the impact of environmental characteristics in a community of 193 nursing home residents with dementia. They found that the participants were more often engaged with moderate levels of background noise as well as in the presence of a small group of people. They argued that these findings have implications for the way in which caregivers structure the environment in nursing homes and how they could present stimuli to residents with dementia to optimise engagement in persons with dementia.

One case study on communication with a person with dementia (Lindholm, 2016) concluded that communication challenges can increase in care home settings when a person with dementia is exposed to a setting characterised by multiple simultaneous stimuli. Moreover, Smit et al. (2012) investigated how small-scale care is related to the overall activity involvement of residents with dementia as well as their involvement in different types of activities. Residents in care facilities with smaller units were more involved in both overall and preferred activities.

Both Heggestad et al. (2015) and Mobley et al. (2017) examined participation in terms of the socio-material context and physical environment. The residents interviewed by Heggestad et al. (2015) expressed that a homey nursing home provided the residents with a greater sense of dignity and helped them be seen as an individual, autonomous person. Mobley et al. (2017) found in their case study that the physical environment was of great importance for staff in realising the goals of person-centred care.

In the context of resident participation, leadership is an organisational characteristic. Managers must consider the interests of the staff, the interests of the residents, and the overall structural preconditions. Value-based leadership, in general, is seen as a prerequisite for implementing person-centred care (Bramble et al., 2011; Jacobsen et al., 2017). Evans et al. (2018) interviewed 18 managers from care homes offering dementia care in the Northwest of England to determine how care home managers negotiate the conflict between maintaining a safe environment while enabling the autonomy of residents with dementia. There were three areas in which the managers reported balancing safety and risk against the individual needs of their residents. First, the physical environment created a tension between safety and accessibility to the outside world. Second, the managers described a balancing act between an individual's autonomy and the need to protect all residents' dignity. Finally, they highlighted the ways in which a resident's needs were framed by the needs of other residents to the extent that, on some occasions, the individual's needs were subjugated to the needs of the general population of the home. This highlights that environmental factors are both physical and social.

Tools and methods of promoting participation

In our sample of the literature on participation and nursing home residents with dementia, there were many papers describing various tools or methods that affect residents' participation in everyday life activities in different ways.

Dementia Care Mapping (DCM) is a mapping tool based on principles from person-centred care. When using the method, the staff can gain more insight and knowledge into the resident as a unique person as well as obtain knowledge and awareness of their own therapeutic behaviour. Argyle (2012) used DCM to assess the utilisation and efficacy of a person-centred approach within a group of care home residents. The care home appeared to provide a stimulating and inclusive range of activities, with leisure pursuits and exercise sessions being the most commonly occurring activities. Also, several studies have examined the importance of systematically using life history work to maintain memories and identity and establish relationships between residents, their family, and staff (Berendonk & Caine, 2017; Kellett et al., 2010). Cohen-Mansfield, Marx, et al. (2010a) claimed that activities and stimuli based on a person's past and current preferences will result in their greater participation than other activities/stimuli. To be seen in light of one's life history is an asset intertwined in different methods. Cooney et al. (2014) conducted in-depth interviews with residents with dementia, their relatives, healthcare assistants, nurses, and nurse managers in order to understand different perspectives on reminiscence, its impact on their lives, and the experience of care and care giving. Reminiscence enabled staff to see and understand the person underneath the dementia. Dassa (2018) created an individualised music and other types of memory cues database to promote communication between spouses of people with dementia during their visits to a nursing home. The spouses reported that using the individualised database helped them find ways to communicate with their partners, re-live shared past experiences, and alleviate the stress and feelings of disconnection during visits. Dobbs et al. (2005) described the characteristics associated with activity involvement in 400 residents with dementia in 45 assisted living facilities and nursing homes. Activity involvement was related to family involvement in care and staff encouragement after adjusting for resident age, gender, race, cognitive and functional status, and comorbidity. Bramble et al. (2011) sought to explore the effect of family involvement in care (FIC) intervention on family and staff well-being over a nine-month period in a nursing home for persons with dementia. Overall, participation in the FIC intervention improved family caregiver knowledge in terms of how to involve the resident in decisions and activities.

Edvardsson et al. (2014) explored the prevalence of participation in everyday activities among residents with dementia in Swedish nursing homes. They questioned whether the residents participating in everyday activities lived in more person-centred units and/or had higher quality of life compared to the residents not participating in everyday activities. The residents that participated in the everyday activities lived in more person-centred units, had significantly higher quality of life, and exhibited higher cognitive scores compared to those who had not participated in everyday activities. Fetherstonhaugh et al. (2016) reported from a qualitative study conducted in the states of Victoria and Queensland, Australia, with 80 direct care staff members. The findings revealed that the participants utilised several strategies (e.g. knowledge of preferences, negotiation, and persuasion) in their intention to support decision-making for people with dementia and possessed an overall perception of learning by doing.

A two-year action research project aimed to improve the interaction between care workers and patients with dementia in a nursing home by means of sensory stimulation (Lykkeslet et al., 2014). The analysis revealed that the participating care workers experienced a change in their attitudes toward their patients. These changes emerged gradually through a combination of supervision in practice, continuous reflection, and the acquisition of knowledge, as the staff came to gradually view their residents' symptoms as meaningful expressions and realised the importance of human relationships. van Weert et al. (2005) documented that the implementation of Snoezelen (specific sensory stimulation) improved the communication during morning care. Savundranayagam and Moore-Nielsen (2015) analysed 46 conversations between staff-residents audio-recorded during routine care tasks over 12 weeks to examine whether language-based strategies for effective communication with persons with dementia were associated with the person-centred communication: recognition, negotiation, facilitation, and validation. The findings identified specific language-based strategies that supported person-centred communication, but the staff needed training to use more diverse language strategies to support individual care of the residents with dementia.

Perry et al. (2005) conducted a conversational analysis of residents participating in nurse-led socialisation groups in three residential units. The effectiveness of the nurse-led conversational strategies was reflected in the high resident participation rates, suggesting that with effective support and prompting, patients with advanced dementia can engage in social conversations beyond what would be expected given their diagnosis.

Tools and standardised methods seem to be debated in terms of an individualised, discretionary practice. Kontos et al. (2010) raised a critique of the standardisation of care planning through The Resident Assessment Instrument-Minimum Data Set; RAI/MDS (a standardised assessment process that informs care plan development in nursing homes), claiming that institutional reliance on methods like RAI/MDS undermines the quality of care in care homes, because it overlooks the residents' preferences.

Discussion

Many factors seem to influence user participation among residents in nursing homes with dementia. The residents' current state of mind, health status, perceived freedom, and self-determination seem to be important preconditions of their own participation. Moreover, the education and commitment of the staff was found to impact how they facilitate residents' participation. This was often combined with organisational conditions, such as overall care culture, leadership, and staff to resident ratio. User participation as a triadic process implies relatives' involvement in a variety of roles based on knowledge sharing and support from the staff. The size and hominess of nursing homes, as well as the leadership care of all stakeholders, seem important in promoting participation. The interaction between the human resources and various tools and methods aims to map resident history and preferences, for example, and empower staff in their knowledge and skills to develop a broad repertoire of approaches to promote user participation.

In our review, we found that an important factor facilitating participation is that both staff and relatives understand how to involve the residents. Various forms of continuous education are recommended (Clifford & Doody, 2018; Smit et al., 2017; Ward et al., 2008), and ongoing education of staff must comprise both theory and skills training (Jacobsen et al., 2017). Communication skills have been identified as key competencies for staff to include residents with dementia to take part in the provision of care. The relatives depend on the staff's knowledge and skills as well as on their dissemination of knowledge so that they can assist the residents in participation and decision-making (Bollig et al., 2016; Carter et al., 2018; Heggestad et al., 2013; Helgesen et al., 2013).

Another important factor in participation found in our review is the physical environment and how the care home is designed. Hominess in the nursing home, smaller groups of residents, moderate noise levels, and limited simultaneous stimuli were described as ideal for optimising participation (Cohen-Mansfield, Thein, et al., 2010b; Heggestad et al., 2015; Lindholm, 2016; Mobley et al., 2017; Smit et al., 2012, 2017).

Our selection of literature highlights many tools and methods that can support participation, although in other contexts criticised for other side effects; dementia care mapping, life history and preference-oriented methods, different types of sensory stimulation, and communication strategy training (Argyle, 2012; Berendonk & Caine, 2017; Bramble et al., 2011; J. Cohen-Mansfield, Marx, et al., 2010a; Cooney et al., 2014; Dassa, 2018; Dobbs et al., 2005; Edvardsson et al., 2014; Kellett et al., 2010; Lykkeslet et al., 2014; Perry et al., 2005; Savundranayagam & Moore-Nielsen, 2015; van Weert et al., 2005). With reference to the Actor-Network Theory (ANT), tools, like DMC, can be seen as actors in interactions about social learning and the development of social communities. According to Engeström's Activity Theory (2001), an activity system is a community of multiple points of view, and the tools are elements that impact practices. This corresponds with the findings of a recent study that suggested that nurses use a wide range of tools to support their practice to enable them to perform their multifaceted work (Jensen et al., 2019).

Findings from this review indicate that the triadic perspective on user participation should include more perspectives. Tools and methods shown in this review may appear to be a fourth 'actor' in these processes, and the influence of co-residents may be the fifth (Aasgaard et al., 2017). In addition, the participatory process and the actors within it must be viewed in terms of the identified environmental and organisational characteristics identified in this paper. To integrate these findings, we have developed a figure (Figure 2) that illustrates a broader picture of the factors that may facilitate user participation among residents with dementia in nursing homes.

We did not find studies addressing user participation on a collective level. We question whether people with dementia who live in nursing homes are too ill to participate in a collective context or whether it is assumed that they cannot act as citizens influencing service development – for example together with their next of kin. Another interesting finding from our literature review was the fact

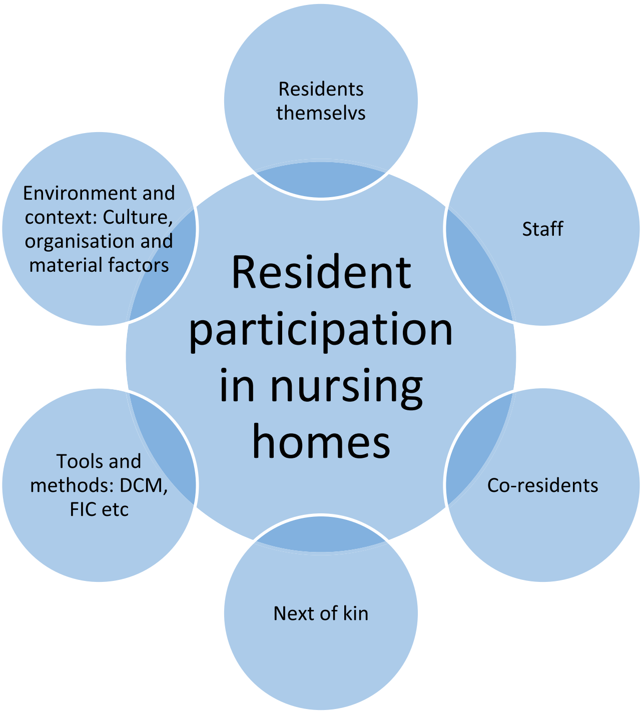

Figure 2. A 'sextet perspective' on user participation for nursing home residents with dementia.

that, with the exception of the study by Helgesen et al. (2014), hardly any of the studies conducted an analysis of whether user participation among persons with dementia in nursing homes provides them with the power to influence the shape and delivery of services. Therefore, we are left questioning whether participation in nursing homes represents what Arnstein describes partnership or tokenism. However, we do not have enough data to provide us with the opportunity to transfer our findings to practice. As far as we know, nursing homes may facilitate collective participation, and hopefully they also facilitate a real distribution of power among the residents. When challenging the nursing home services for lack of real power redistribution and lack of collective participation, we might as well challenge our fellow researchers for having a narrow focus on individual participation. Regarding residents with dementia living in nursing homes as citizens could open new perspectives in both practice and research.

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