Review

Dementia
2024, Vol. 23(8) 1382–1415

DOI: 10.1177/14713012241267122
journals.sagepub.com/home/dem

Enabling work for people with dementia - Recommendations for interventions: A mixed-methods review

Hanne Peoples
Health Sciences Research Centre, UCL University College, Denmark

Jesper Larsen Maersk
Centre for Health and Rehabilitation, University College Absalon, Denmark

Hanne K Kristensen
Health Sciences Research Centre, UCL University College, Denmark
Centre for Innovative Medical Technology, Department of Clinical Research, University of Southern, Denmark

Abstract

Worldwide, 50 million people are living with dementia. As more individuals develop dementia while still working, dementia will increasingly become a workplace issue and a societal concern. Interventions targeted at work retainment, can reduce, and postpone the loss of cognitive functioning following dementia. However, there is a small body of research focused on recommendations for work interventions for people with dementia. The aim of this mixed-methods review was to investigate experiences of work following a dementia diagnosis from the perspective of people with dementia, their relatives, employers, co-workers and HR-professionals, with the objective of formulating recommendations for work interventions for people with dementia. A mixed-method approach guided the review. 16 original studies published between 1989 to 2023 were included, with a collective sample of 684 participants. The review shows that it is possible to live and work well with dementia, if collaborative solutions are continuously negotiated to meet the needs of the person with dementia and the workplace, and with attention to possible contextual enablers and barriers. The review highlights four key elements for successful work interventions for people with dementia: 1) Person-centered Approach, 2) Contextual Relevance, 3) Knowledge-based and 4) Dynamic Approach.

Corresponding author:
Hanne Peoples, Health Sciences Research Centre, UCL University College, Niels Bohrs Alle 1, Odense 5230, Denmark.
Email: hape1@ucl.dk

Keywords
work rehabilitation, citizenship, Alzheimer's dementia, inclusion, employment

Introduction

In Denmark, almost 89,000 people are living with dementia, while worldwide, the figure reaches 50 million. Although dementia is not a result of normal aging, the risk of developing dementia increases with age. Consequently, the number of people living with dementia is expected to grow due to increased longevity (Danish Dementia Research Centre, 2023; WHO, 2017).

It is often thought that work involving people with dementia, concerns those under 65. However, due to an aging workforce with a rising statutory retirement age, dementia during work-life is likely to affect more people over 65 in the coming years, becoming an increasing workplace issue and societal concern (Alzheimer's Society, 2015; Basu, 2019; Evans, 2019; Evans et al., 2021; Johannessen & Möller, 2013). Yet, it is difficult to determine how many people continue to work when they experience early symptoms or are diagnosed with dementia, as these symptoms are often mistaken for depression, stress, or burnout or not even suspected due to the relatively young age (Nygard et al., 2023; Spreadbury & Kipps, 2019). For people with dementia in their working years, the diagnosis often occurs when they are fully engaged in their work life and perhaps at the height of their careers. Early signs of dementia, such as deteriorating emotional and cognitive abilities, often manifest in the workplace, where job tasks require higher cognitive demands than routine everyday activities. These can include memory loss, problems with concentration, difficulty with problem-solving, and challenges in using technology (Busted et al., 2020; Chaplin & Davidson, 2016; Harris & Keady, 2004a; Johannessen et al., 2018; Johannessen & Möller, 2013; Ritchie et al., 2015; Robertson & Evans, 2015; Spreadbury & Kipps, 2019; Wawrziczny et al., 2016).

For most adults, work is one of the most essential aspects of being an adult citizen. It provides structure, valuable social relationships in their everyday life, contributes to the family's income, and enhances a sense of citizenship (Bartlett & O'Connor, 2010; Bartlett, 2021; Peoples et al., 2022). Work is closely connected to a person's identity and quality of life (Maersk et al., 2024). Citizenship for people involves a rights-based approach to support them to live as active, participating and contributing citizens for as long as possible (Farina et al., 2017; Nygard et al., 2023; O'Connor & Nedlund, 2016; Peoples et al., 2022). This perspective represents a human rights model of disability that advocates for inclusion and participation, ensuring that people with dementia have the same rights as everyone else in society, and that society has a role to play in safeguarding these rights (Peoples et al., 2022). However, due to a lack of awareness and misconceptions about dementia, and fear of stigmatization, people experiencing early symptoms often try to conceal their difficulties to avoid fear of negative response and social stigma (Low & Purwaningrum, 2020; Nygard et al., 2023; Peoples et al., 2022). Voluntary or involuntary retirement due to dementia often leads to reduced income, and the loss of worker-identity and relationships with colleagues (Chaplin & Davidson, 2016; Harris & Keady, 2004b). Some people experience transitioning from employment to un-employment as abrupt, traumatic, and forced upon them (Rabanal et al., 2018; Swaffer, 2015). Being excluded from work can seriously impact people with dementia personally, financially and socially. Research shows that people with dementia who are still working have different needs than those who are retired by the time of their diagnosis (Beattie et al., 2004; Carone et al., 2016; Greenwood & Smith, 2016; Hoppe, 2019; Johannessen et al., 2018; Region Sjælland, 2015; Steeman et al., 2006).

People with dementia require interventions and services to manage the immense challenges of maintaining their work-life (Harris & Keady, 2004a; Johannessen & Möller, 2013; Spreadbury & Kipps, 2019). However, in Denmark where this review was conducted, the services provided by municipalities

for people with dementia are primarily limited to counselling and leisure activities (Thuesen et al., 2018). Additionally, a report from the Danish Dementia Research Centre (2023) shows that only 32% of the included 64 municipalities had services specifically designed for people under 65 with dementia. The report does not indicate whether these services are related to work rehabilitation. Consequently, many people with dementia must cope individually with challenges of maintaining their work-life, often leading to involuntary retirement and reduced quality of life (Holdsworth & McCabe, 2018; Johannessen et al., 2018; Richardson et al., 2016; Thorsen et al., 2020).

Interventions aimed at enabling people with dementia to continue or engage in work have reported several positive outcomes, such as feeling useful, having a purpose, enjoyment, relationship, and increased quality of life (Richardson et al., 2016; Robertson & Evans, 2015). Evidence suggests that such interventions reduce the personal consequences of dementia and enhance the quality of life in both work- and everyday life (Richardson et al., 2016; Robertson & Evans, 2015; Thomson et al., 2019). Moreover, some evidence suggests that engaging in cognitively challenging activities, such as work-related tasks, can reduce and postpone the loss of cognitive functioning associated with dementia (Bahar-Fuchs et al., 2019).

There is limited research on supporting employment for people living with dementia, especially regarding how workplaces can manage, and support employees diagnosed with dementia. A preliminary literature search found several reviews on dementia and employment, but none of these focused on recommendations for work interventions (Andrew et al., 2019; McCulloch et al., 2016; Richardson et al., 2016; Ritchie et al., 2015). A systematic review by Thomson et al. (2019) on the management of employees with dementia provides guidance for employers on retaining these employees in the workplace. Although the review is relatively recent, the most recent study included is from 2016 (Thomson et al., 2019). Given the increasing societal focus on work retention and attachment for people with dementia, and the publication of several important studies since 2016, a renewed review in this area is justified.

Consequently, there is a need to understand the essential elements, including social and societal factors, related to work interventions aimed at supporting people with dementia to continue or regain employment and how these are perceived by those involved. Therefore, this mixed-methods review aimed to investigate experiences of work following a dementia diagnosis from the perspective of people with dementia, their relatives, employers, co-workers and HR-professionals, with the objective of formulating recommendations for work interventions for people with dementia. In this study, a work intervention refers to any intervention, approach, solution, or support aimed at retaining people with dementia in the workplace.

Design

This review employed a mixed-method approach, designed to generate knowledge of relevance to citizens, policy makers and practitioners (Pearson, Alan et al., 2015). A segregated design was utilized, as recommended when qualitative and quantitative findings are considered complementary (Lizarondo et al., 2020; Sandelowski et al., 2006).

A search strategy was developed in collaboration with an experienced research librarian. Several test searches were conducted to ensure the relevance and effectiveness of search terms and databases for this review. The search was systematic and exhaustive, covering the following databases: Scopus, Embase, Cinahl Complete and APA PsychINFO. The main search terms were: Dementia, work and intervention, combined with their possible synonyms (e.g. ‘Alzheimer’, ‘people living with dementia’, ‘work rehabilitation’ or ‘vocational intervention’) and supplemented by all applicable descriptors and subheadings.

Ethics

Since this review was based on peer-reviewed published articles, no ethical approval was needed and informed consent was neither relevant nor required. However, during the review process we reflexively engaged in considerations regarding ethical issues associated with potential conflicts of interest and issues of voice and representation in the primary studies (Suri, 2020).

Inclusion and exclusion criteria

In- and exclusion criteria were defined using the structured SPIDER method (Table 1) (Cooke et al., 2012). In- and exclusion criteria were tested on a small sample (200 citations) and subsequently discussed between the first and the last author to ensure that the screening was conducted in a structured and uniform manner. The search was limited to title and abstract and accepted any reported methodology. Parameters were set to include studies written in English, Swedish, Norwegian, or Danish. The timeframe was set from 1989 to 2023, as a preliminary search did not reveal relevant studies published earlier than 1989. The electronic search was supplemented with manual searches of reference lists of included full-text studies. Entries were managed in Refworks, which was also used to identify and remove duplicates.

Data collection and analysis

A total of 7935 citations were identified through database search and organized using Refworks Citation Manager. After duplicates were removed, 5048 citations were screened independently by the first author and a research assistant at the title and abstract level against in- and exclusion criteria, resulting in an additional 5003 citations to be excluded. The same two reviewers screened the remaining 45 primary studies at full-text level, excluding those that did not meet the defined criteria, which resulted in 29 studies being excluded, and thus resulting in 17 studies being included for quality appraisal (Moher et al., 2009; Pearson, A. et al., 2011) (Figure 1. Flow diagram).

Table 1. Inclusion and exclusion criteria (Cooke et al., 2012).

	Specifications	
Spider	Inclusion	Exclusion
Sample	People with dementia (PwD), relatives, employers, co-workers, social workers	
Phenomenon of interest	Work intervention for PwD, work rehabilitation, voluntary work.	
Design	Named types of qualitative, quantitative or mixed data collection and analysis	Opinion papers, studies with unsubstantiated findings .
Evaluation	All reported outcomes/themes	
Research type	Qualitative, quantitative or mixed-method studies	Studies where findings concerning work interventions for PwD could not be separated from the rest, literature reviews.

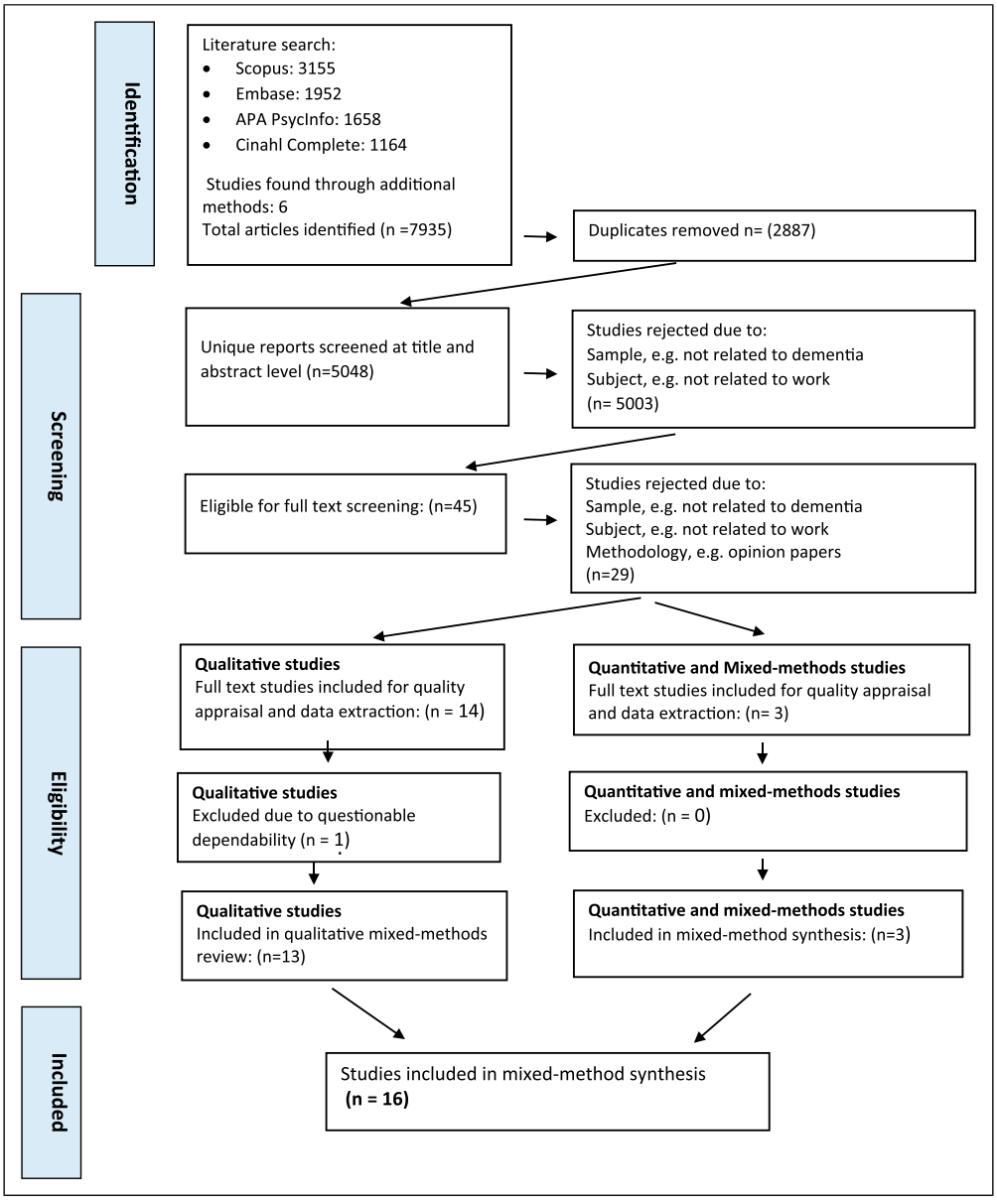

Figure 1. PRISMA flow diagram of search process (50-51).

Quality appraisal

The Joanna Briggs checklist for qualitative research was used for 14 qualitative studies (Briggs, 2017), the Mixed Methods Appraisal Tool was used for two mixed methods studies (Hong et al., 2018) and the Critical Appraisal of a Cross-Sectional Study (Survey) was used for one survey study (CEBMa, 2024). These checklists were chosen since they are

well-established for critical appraisal of systematic reviews. The first and last author independently performed the quality assessment, resulting in one study being excluded based on questionable dependability. One qualitative study was excluded due insufficient description of the research methods (Table 3). Finally, 16 studies were included in this mixed-method review (Chaplin & Davidson, 2016; Cox & Pardasani, 2013; Ebbitt et al., 1989; Egdell et al., 2021; Evans, 2019; Ikeuchi et al., 2022; Kinney et al., 2011; Ritchie et al., 2018, 2021; Roach & Drummond, 2014; Robertson et al., 2013; Robertson & Evans, 2015; Russell, 2020; Stott et al., 2017; Öhman et al., 2001).

Transformation of quantitative data

A survey was used in three studies (Cox & Pardasani, 2013; Ebbitt et al., 1989; Egdell et al., 2021) in combination with qualitative data, for example interviews, workshops or open-ended questions. The results from these three studies were all descriptively presented in the form of themes by the authors of these studies. In the present review, the themes from the three quantitative and mixed (Ritchie et al., 2018)methods studies were regarded as equivalent to the themes that resulted from the qualitative studies, and they combined formed the basis of the analysis of the final mixed-methods review.

Data extraction, integration, and analysis of findings

The Joanna Briggs Institute (JBI) method of meta-aggregation was used to extract, categorize and finally synthesize the findings (Lockwood et al., 2015). The included studies were organized in a matrix with the oldest listed first to show the temporal development in relation to the review purpose (Table 2). Findings from qualitative and quantitative/mixed-methods studies were extracted and critically appraised separately before the final mixed-methods synthesis. The following domains were extracted: Publication year, country of origin, objective, methodology, methods, sample, findings, and recommendations. In this review, a 'finding' is defined as a theme, a category or a result concerning recommendations for work interventions for people with dementia, as stated by the authors of the 16 included studies. Three levels of evidence were considered for these findings: (1) unequivocal, (2) credible, and (3) unsupported (Pearson, Alan, 2004). The three levels indicate if the findings were supported with directly reported evidence and how credible these were, considering the empirical data provided in the primary studies. Unsupported findings were not included in this review.

In accordance with the segregated design, a clear distinction was kept between the qualitative and the quantitative/mixed methods studies until the final mixed meta-synthesis. This involves a comparative analysis of the findings from the included studies. The initial stages involved familiarizing with the data by reading and re-reading each study, generating meaningful units related to the aim of this review, and identifying preliminary themes. Subsequent stages comprised generating themes across the different studies by searching for and reviewing these. Groups of preliminary themes with similar meanings were independently identified and then discussed between first and last author, resulting in the reorganization, merging, and renaming of some themes. After several iterations, three themes were identified and discussed between the authors in relation to the aim of the review.

Results

The 16 studies were conducted in seven countries: UK (Chaplin & Davidson, 2016; Egdell et al., 2021; Ritchie et al., 2018, 2021; Stott et al., 2017), Australia (Evans, 2019; Robertson et al., 2013;

Table 2. Literature matrix of included primary research studies.

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
1.	**Ebbitt, et al.** Work therapy: Intervention for community-based Alzheimer's patients	1989	USA	To investigate the feasibility and potential therapeutic effects of an adapted work program offering paid work experiences in a supervised setting.	Mixed method Pre-/post study (workshop) Survey, Interview and participant observation	7 people with dementia and 7 relatives (workshops) +33 persons with dementia (survey)	3 themes: 1) Attendance and work adaptation 2) Patient depressive symptoms and self-esteem 3) Caregiver burden and depressive symptoms	The data showed that the work-program was a feasible and potentially beneficial intervention for community-based people with early-stage dementia. Important to screen work tasks for complexity, 1–2 years participation in work setting is realistic for most. A need for formal exit criteria due to individual disease progression.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
2.	**Öhman et al.** "The vocational situation in cases of memory deficits or younger-onset dementia"	2001	Sweden	To describe how persons with memory deficits or younger-onset dementia (subjects) perceived and met their problems, regarding present and future vocational situation.	Qualitative Interviews	9 people with dementia + 7 from workplace)	6 subject themes: 1)Experiencing changes 2) The experienced consequences 3) Compensatory solutions initiated by the subjects 4) Attitudes towards work 5)The relationship between IADL, cognitive screening and working possibilities. 6)The meaning of work and other solutions 4 workplace themes: 1) Observing changes 2) Expressed consequences 3) Alternative solutions organized by employer 4) Attitudes towards work	Adaptive solutions from employers reduced number of tasks, time pressure, and support from coworkers. A supportive social environment enables people with dementia to remain in work. Employers had a positive attitude to continued work, but also took an expectant stand regarding the future. Decisions regarding work for people with dementia must incorporate a multifactorial approach, including the experiences of people with dementia and of coworkers.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
3.	**Kinney, et al.,** "'That's me, the Goother': Evaluation of a program for individuals with early-onset dementia"	2011	USA	To document participants' perception about a supervised volunteer program at the local zoo	Qualitative Interviews	6 people with dementia	Participation in the program has benefits that extend beyond the actual time spent in the program. The participants: 1) strongly identified with the program 2) Developed a bond with fellow participant 3) Derived socialization benefits from the program 4) had a shared understanding that the program allowed them to help others and feeling pride/self-esteem 5) Showed insight about their own and others' experiences with the program.	Experienced characteristics of the program: Attention to gender when planning groups. The program was "layered" in that it took place in a relaxed, interactive environment away from the home. Each participant had the opportunity to work/ volunteer, learn and socialize. The participants interacted with each other and the helpline Coordinator, members of the zoo community, and zoo animals, all of which require different skill sets. The program provides people with dementia the opportunity to experience "normalcy". Participants get insights about their own and others' experiences with the program.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
4.	**Cox & Pardasani** "Alzheimer's in the workplace: A challenge for social work"	2013	USA	To examine employers' responses to dementia in the workplace.	Survey with two open-ended questions	103 human resources professionals	The findings were presented in three themes: 1) Experience with employee caregivers. 2) Employees with symptoms of people with dementia or related disorder. 3) Organizational policies	Human resources professionals are interested in having more training and receiving more information on dementia and how to discuss it with employees. Important to become "proactive," rather than reactive, when dealing with an aging work force and dementia. A need for policies and practices, specifically developed in relation to employees with dementia and caregivers. Support services to employers who are struggling with meeting the needs and rights of employees with dementia.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
5.	**Robertson et al.** "Side by side - a workplace engagement program for people with younger onset dementia"	2013	Australia	To describe the initial evaluation of the feasibility of the Side-by-side program (a community-based buddy program)	Qualitative pilot study of the intervention Interviews Journaling Photos	6 people with dementia	The Side-by-Side program demonstrated it was feasible to offer people with dementia and provided: - Opportunities to re-connect with the community - Meaningful activities - Regular breaks for family carers - Increase community awareness of younger onset dementia	As participants became more skilled, they were able to do much more and started making a worthwhile contribution to the workplace. The project provided participants with the opportunity to re-connect with the community. The program was located in the real world of a hardware store and thus not just 'busy-work' to fill empty hours. The program highlighted the benefits that can be gained through innovate practice development that challenges the traditional models of dementia care.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
6.	**Roach, et al.** 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity."	2014	Canada	To explore the transition out of employment or voluntary work.	Qualitative Interviews	8 people with dementia + 10 relatives	Meaningful activity emerged as a major theme with two subthemes: 1) The traumatic cessation of work 2) The need for purposeful activity.	The findings highlight the need for increased education and awareness in the workplace about dementia. Increased awareness may allow for employers to consider modified or alternative duties to enable the person with dementia to remain in work and feel more involved in the decision about their working career and maintaining a sense of dignity and personhood. Volunteer work may fulfil a need to contribute to society and help to feel useful and productive.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
7.	**Robertson & Evans** "Evaluation of a workplace engagement project for people with younger onset dementia"	2015	Australia	To explore the feasibility and safety of engaging people with dementia in workplace activities if an appropriate framework of support was provided.	Qualitative Interviews	9 people with dementia	The study showed: Participants were able to gain the skills needed to complete their respective work duties. They started with simple work tasks, but could over time manage more complex tasks. Participants achieved improved well-being, engaging in worthwhile activities, contributing to society and socialization.	This evaluation has demonstrated that it is possible to provide younger people with dementia with the opportunity to engage in a real workplace and meet real people if an appropriate framework of support is provided. The Side-by-side model of workplace engagement provides a more age-appropriate engagement opportunity for this group, and a better model for community dementia practice.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
8.	**Chaplin & Davidson** "What are the experiences of people with dementia in employment?"	2016	UK	To investigate the experiences of people who develop a dementia while still in employment	Qualitative Interviews	5 people with dementia	4 themes were identified: 1) The realization that something is wrong. 2) Managing the situation in the workplace 3) trying to make sense of change 4) Coming to terms with retirement or unemployment.	The study highlights the need for more effective specialized advice and support regarding employment issues: Support to develop strategies to compensate and manage impairments in the workplace. Accommodation to be created to benefit both sides of the employer-employee relationship. A need for dismissal conversation and follow-up between employee and workplace in case of work termination. A dialogue (between employer and employee) which considers the employees' wishes when considering future plans and utilization of residual skills in the workplace.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
9.	**Stott et al.** "People with dementia as peer workers, challenges, and benefits: a Thematic analysis and nominal groups study"	2017	UK	To explore the challenges and benefits to staff and peers involved in program for people with dementia as peer support workers.	Qualitative. Focus groups	3 People with dementia 6 staff members 6 people with dementia and staff members combined).	Three "benefit themes": 1) Quality of life 2) Peers adding value to the service 3) Reduction of stigma associated with dementia Four "challenge themes": 1) Lack of role definition 2) The challenge of working with clients as colleagues 3) Resource limitations 4) Considering disease progression among people with dementia	Reported benefits of increased QOL, stigma reduction, 'life beyond diagnosis', sense of meaning, and contribution to service delivery. In terms of challenges, the difficulty of working with clients as colleagues, and the lack of clear roles. People with dementia wanted more opportunities. Both staff and people with dementia reported concerns about how to adjust or end peer role upon significant deterioration. Power emerged as an issue which may be because stigmatized groups who have less power have difficulty speaking up.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
10.	**Ritchie, et al.** Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers	2018	UK	To explore the employment-related experiences of people with dementia, and attitudes of employers and/or co-workers towards supporting people with dementia, in order to identify the potential for continued Employment post-diagnosis.	Qualitative Case study research	16 people with dementia, 8 relatives, 18 professionals	Three themes: 1) dementia as experienced in the workplace 2) work keeps me well 3) Wider impact of dementia in the workplace	The findings have the potential to initiate changes to policy and practice related to supporting employees with dementia. The implications of this research are multifaceted and need to be considered in terms of the individuals' wellbeing, organizational support, as well as the wider theoretical, economic and societal consequences of supporting an employee with dementia.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
11.	**Evans, D.** "An exploration of the impact of younger-onset dementia on employment"	2019	Australia	To describe the experience from the onset of dementia-related symptoms to the time when the person left the workforce.	Qualitative life course approach Interviews	10 people with dementia	Five themes: 1) Experiencing problems at work 2) Becoming a poor worker 3) being vulnerable at work 4) Leaving work 5) re-engaging.	The study highlight: Investigating changes in job performance may assist in the early identification of dementia in older working people. The importance of education for occupational health professions about how changes in cognitive health can assist in the early identification of dementia in the workplace. The importance of support for workers with dementia. It involves determining whether cognitive impairment is present *and* investigating which cognitive domains are affected in relation to the requirements of the person's job. Organizations need expert advice to support a worker diagnosed with dementia.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
12.	**Ikeuchi et al.** "Work-related experiences of people living with young-onset dementia in Japan"	2020	Japan	To clarify the experiences of people with dementia during employment in order to gain insights into the appropriate support that can be provided.	Qualitative descriptive study Interviews	11 people with dementia	Four categories of 'crisis from continuing to work': 1) 'Seeking support' 2) 'Overcoming challenges to work' 3) 'Reaffirming a sense of purpose by resuming work 4) Social participation'	Appropriate support is needed when continuing employment or during the transition phase of becoming socially active after leaving work. People living with dementia feel disempowered due to excessive decreases in workload and reassignment to simpler tasks without being consulted. They need support that empowers them. Continued employment, reemployment, and transition to socially active lives after leaving work involved considerable support from coordinators, job coaches and family support groups.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
13.	**Russell, C.W.** "People with dementia, contributing to learning and teaching in higher education: Innovative practice"	2020	Ireland	To explore how people with dementia could contribute to improving educational initiatives about dementia.	Qualitative Semi-structured interviews	4 people with dementia	Four themes: 1) Ambition to continue to make a positive contribution to society. 2) Aspiration to share knowledge about their own experience of dementia so students could learn. 3) Opportunity to enhance their own confidence, which had diminished following diagnosis. 4) Chance to improve personal learning about dementia, and to reflect upon their experience of dementia.	The study provided valuable insight into educational initiatives involving people with dementia that can inform future projects. The project was successful and will form part of the ongoing educational provision on the Foundation degree in dementia studies. It also contributed to learning about matters of contemporary relevance to the wider dementia context, e.g. Personhood, and maintenance of personhood Challenging and moving beyond the standard paradigm of dementia.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
14.	**Ritchie, et al.** "Dementia, work and Employability: Using the Capability approach to Understand the Employability potential for People living with dementia"	2021	UK	To explore the potential for supporting and promoting the employability of people with dementia.	Qualitative Interviews	2 people with dementia 37 others (e.g. health – and HR professionals, trade union representatives, policy-makers	The study showed that while people with dementia have the personal resources to work, employment policy/ practice and access to support services may undermine their abilities and compromise their employability. That is, access to material resources to support employability, and the physical and social environment in which people with dementia operate in, can impinge the individual's ability to continue working or to seek alternative employment.	Importance of an open and supportive work place was cited as key in facilitating continued employment, as well as relationships with, and attitudes of, line managers and colleagues. Stigma and lack of understanding of dementia can impact on employability at the societal, organisational and individual level. Employers may not fully consider adjustments to support the continued employment; healthcare professionals may advise individuals to leave work; and individuals themselves may not realize their abilities because of 'adaptive formation' responses.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
15.	**Egdell, et al.** "Dementia in the workplace: Are employers supporting employees living with dementia?"	2021	UK	To investigate whether employers consider dementia as a workplace concern; and the policies and/or practices available to support employees with dementia.	A sequential mixed-methods approach and online survey Interviews	331 employers	Three themes: 1) Dementia as a workplace concern 2) Support for employees living with dementia 3) Employer policy development and awareness raising. The findings demonstrate dementia awareness, but this knowledge is not applied to employment situations. Dementia is not framed as something that could affect colleagues and stereotyping and infantilizing attitudes are present.	Employers need to support employees living with dementia and understand at a practical level what this entails. The importance of timely in-work support should not be underestimated; as well the creation of working environments where those with (and without) a diagnosis can speak to their employer. Employer guidance and awareness raising regarding reasonable adjustment and dementia is needed. Employers have experience of supporting workers with other health conditions and existing policies could be adapted for people with dementia. Robust training interventions are required to ensure that employers are meeting their legal, equality and human rights obligations.

(continued)

Table 2. (continued)

#	Publication	Year	Country	Objective	Methodology and method	Sample	Results	Recommendations
16.	**Nygard et al.** What happens when people develop dementia whilst working? An exploratory multiple case study	2023	Sweden	To explore how people with dementia and relatives experienced the actions and decisions taken with respect to work, and what the consequences meant to them.	A qualitative longitudinal case study design with multiple cases	5 people with dementia, 4 family members, 1 colleague, 5 employers, 1 social worker	Two intertwined themes: 1) The significance and consequences of a dementia diagnosis: a double-edged trigger 2) Sensemaking and agency.	The dementia diagnosis is alien in work-life, but once diagnosed, it may trigger self-fulfilling expectations based upon stereotypical understanding of dementia. A shift is needed from a deficit-focused perspective, to viewing people with dementia as citizens capable of agency.

Table 3. Critical appraisal of included studies.

Qualitative studies

Tool: JBI Critical appraisal checklist for qualitative research

	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10
Öhman et al. (2001)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	No	Yes
Kinney et.al., 2011	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes
Robertson et al. (2013)	Unclear	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes
Roach et al., 2014	Unclear	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Chaplin & Davidson (2016)	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
Robertson & Evans, 2015	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Stott et al. (2017)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Evans (2019)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Ikeuchi et al., 2022	Yea	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Russell (2020)	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Ritchie et al., 2021	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes
Nygard et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes

Mixed methods Studies

Tool: The Mixed Methods Appraisal Tool

	Screening questions		**Qualitative questions**					**Quantitative descriptive questions**					**Mixed methods questions**				
	S1	S2	1.1	1.2	1.3	1.4	1.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	6.4	5.5
Ebbitt et al. (1989)	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
Egdell et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes

Survey study

Tool: The Critical Appraisal of a Cross-Sectional Study (Survey)

	Question 1	Question 2	Question 3	Question 4	Question 5	Question 6	Question 7	Question 8	Question 9	Question 10	Question 11	Question 12
Cox & Pardasani (2013)	Yes	Yes	Yes	No	Yes	No	Yes	Can't tell	No	No	Can't tell	Yes

Robertson & Evans, 2015), USA (Cox & Pardasani, 2013; Ebbitt et al., 1989; Kinney et al., 2011), Canada (Roach & Drummond, 2014), Ireland (Russell, 2020), Sweden (Nygard et al., 2023; Öhman et al., 2001) and Japan (Ikeuchi et al., 2022) published over a 34-year period (1989–2023). The sample size of the primary studies ranged from three to 331, with a collective sample of 684 participants distributed with 140 people with dementia (ages ranging from 44 to 74), 29 relatives, and 515 professionals (e.g., HR professionals, employers, and social workers).

The analysis identified three themes: 1) Discrete changes in work performance, 2) Support of work retention, and 3) Terminating and/or re-engaging in work-life. The themes reflect an inside (people with dementia) and an outside (relatives and professionals) perspective regarding work and dementia. Although the themes are separated to present the results, they are interrelated and, at times, overlapping.

Discrete changes in work performance

Dementia entered work life slowly with insidious cognitive problems. It was difficult to identify the starting point of the challenges since it was a gradually subtle change in work performance that was easy to miss or discount as stress or depression or explained by contextual factor (Evans, 2019; Ritchie et al., 2018; Öhman et al., 2001). It brought about discrete changes with gradual moments of short-term memory loss, which especially influenced work situations that required the ability to remember names, work routines, appointments, or adjust to new tasks (Chaplin & Davidson, 2016; Ritchie et al., 2018). Some were able to manage the symptoms they experienced as they did not directly influence their ability to continue their job (Ritchie et al., 2018). For most participants, this was an ambivalent time since they had a strong wish to continue their work but were afraid of not being able to live up to their co-workers' and employers', expectations if they could no longer maintain the role of being fully competent employees. The latter was attempted by means of self-developed strategies to overcome challenges, for example, by starting earlier, working overtime, or bringing work tasks home each day to complete their work and keep up with their own and others' expectations (Chaplin & Davidson, 2016; Evans, 2019; Ritchie et al., 2018; Öhman et al., 2001). These strategies were used to conceal their difficulties from managers and co-workers and to maintain a sense of control. However, these strategies were often insufficient (Chaplin & Davidson, 2016). As the condition progressed, their work performance continued to decline, complex work tasks became more difficult, and the need for support increased. Colleagues noticed changes in the personality of the person with dementia, for example, lack of engagement, loss of spirit, and how they made mistakes and needed more time to finish usual tasks (Evans, 2019; Ikeuchi et al., 2022). These difficulties caused increased workloads, irritation and conflicts that negatively influenced the collegial relationship (Ritchie et al., 2018; Öhman et al., 2001).

None of the workplaces in the included studies had a strategy for work support for the person with dementia and fear of disclosing their diagnosis was motivated by not knowing their options and worries about losing their jobs. Employers and colleagues were often aware of the problems the person with dementia was having, but without recognizing the possibility of a serious underlying cause. Also, limited attention was given to the risks involved and insufficient support provided, which could potentially endanger both the individual and co-workers (Ritchie et al., 2018). When the employee disclosed their diagnosis and employers and co-workers learned the reason for the decline in work performance, several experienced support from the workplace and a willingness to find alternative ways to maintain them in their jobs (Cox & Pardasani, 2013; Ebbitt et al., 1989; Ikeuchi et al., 2022; Ritchie et al., 2018, 2021; Stott et al., 2017; Öhman et al., 2001). The lack of a formal strategy also made it difficult for employers and co-workers to initiate a relevant support

process. The workplaces had different support systems available to them. Larger organizations had access to HR professionals who could assist with necessary adjustments and provide support. However, many expressed a need for more guidance and information about dementia (Chaplin & Davidson, 2016; Cox & Pardasani, 2013; Egdell et al., 2021; Ritchie et al., 2018, 2021; Roach & Drummond, 2014). In smaller businesses often lacked organized support system, but smaller teams could provide the necessary collegiate support. Financial challenges were noted for smaller companies in maintaining employees on full wages if they could not fully manage their work duties (Kinney et al., 2011; Ritchie et al., 2018). Despite these challenges some workplaces expressed a willingness to support people with dementia to continue working for as long as possible. However, this was not universally the case, as some employees were dismissed as soon as they disclosed their diagnosis (Chaplin & Davidson, 2016; Evans, 2019; Nygard et al., 2023; Roach & Drummond, 2014).

Support of work retention

Understanding the cause of the employee's possible changed work performance, helped the workplaces to understand what kind of adjustments and support were needed (Nygard et al., 2023; Ritchie et al., 2018). The workplaces launched various initiatives to support and enable work retention, such as simplifying tasks and screening work them for complexity (e.g., regarding the level of abstract thinking) to adapt to the person's level of functioning, reduction in work hours and various degree of support, as well as supervision from co-workers and change of job role. The latter could be stepping down from a leadership position to a less complex position. Other examples were; shorter work sessions, an appointed work-buddy among colleagues, scheduled time for coffee and lunch to enable social interaction with colleagues and permission to rest during the work day (Chaplin & Davidson, 2016; Ebbitt et al., 1989; Ikeuchi et al., 2022; Nygard et al., 2023; Russell, 2020; Stott et al., 2017; Öhman et al., 2001). However, some employers highlighted the difficulties of managing the support for employees with dementia while maintaining the successful operation of their company (Ritchie et al., 2018).There was a difference in how the adjustment process was experienced and to what extent people with dementia were involved. For some people with dementia, it was a relief to be free from the demands of complex work tasks. In contrast, for others, the adaptation process was experienced as an 'all or nothing' approach from their workplace with little attention to ways of using their remaining skills. Some described how they felt they were being watched covertly by their colleagues, taken off their regular work duties and assigned to work in pairs with one of their colleagues, without being involved in these decisions. In cases where adjustments were not discussed openly with the person with dementia or they thought that excessive assistance was provided, they felt humiliated, degraded, and punished, which negatively influenced their work performance and resulted in an inappropriate power imbalance between them and their colleagues (Chaplin & Davidson, 2016; Ikeuchi et al., 2022; Stott et al., 2017). On the other hand, the employers described that adjustments were made to make work life easier for the employees with dementia (Egdell et al., 2021; Ritchie et al., 2018). In cases where people with dementia were actively involved in exploring solutions for their cognitive difficulties, they expressed a greater approval of the results, which enhanced feelings of doing something meaningful and useful and positively influenced their work satisfaction (Ebbitt et al., 1989; Egdell et al., 2021; Ikeuchi et al., 2022; Ritchie et al., 2018; Russell, 2020).

Many workplaces were ill-equipped to handle and cope with the challenges it entailed when an employee or colleague was diagnosed with dementia. Employers and staff expressed a need for

knowledge about the symptoms of dementia to identify these and differentiate them from stress symptoms, enabling them to respond appropriately and supportively while respecting the individual's autonomy (Cox & Pardasani, 2013; Egdell et al., 2021; Evans, 2019; Ikeuchi et al., 2022; Ritchie et al., 2018; Roach & Drummond, 2014). Employers furthermore stressed the importance of supporting the resources of the person with dementia to build on these instead of focusing on what the person could no longer do.

Since dementia is a progressive disease, there comes a point where it becomes too difficult for the person with dementia to compensate for their difficulties, or for the workplace to continue employing them. Therefore, termination of their employment becomes necessary.

Terminating of and/or re-engaging in work-life

For people with dementia, terminating their work-life was particularly difficult, and felt largely beyond their control, especially when it was experienced as unexpected and traumatic (Ritchie et al., 2018; Roach & Drummond, 2014). Termination of work-life influenced their overall life situation, for instance, regarding the role in the family and financial hardship that affected their entire family (Kinney et al., 2011; Roach & Drummond, 2014). Several people with dementia described how, after their termination, they lacked a sense of purpose in their daily lives. They struggled with being at home all day without something meaningful to fill their days with, and often spent their days in isolation at home (Kinney et al., 2011; Roach & Drummond, 2014). This was especially pertinent for those living alone or whose relatives were still working and away most of the day (Evans, 2019; Ikeuchi et al., 2022; Kinney et al., 2011; Roach & Drummond, 2014; Robertson et al., 2013; Robertson & Evans, 2015; Öhman et al., 2001).

In general, the workplaces were, ill-equipped to handle the termination of an employee with dementia. Both the persons with dementia and their employers expressed a need for formal termination criteria as the illness progressed (Ebbitt et al., 1989; Stott et al., 2017). Although the reasons and the circumstances surrounding the termination were different, the loss of work influenced the sense of purpose, identity, and role fulfilment of the persons with dementia (Evans, 2019; Roach & Drummond, 2014). Some felt compelled to resign immediately after they received their diagnosis to avoid stigma and loss of work status, while others continued to work for as long as possible with support from their workplace. There were also some who were made redundant or fired as soon as the workplace learned about their diagnosis, even though people with dementia do not lose their abilities 'overnight' and most of them had worked full-time until the day of their diagnosis (Chaplin & Davidson, 2016; Evans, 2019; Roach & Drummond, 2014). Several people with dementia expressed disappointment and frustration at the lack of opportunities following their diagnosis. They emphasized the difference between being unable to do a job and not being able to work. By this, they meant that even though they could no longer maintain their current work role, they felt able to continue working in an adapted form or in another work role (Ikeuchi et al., 2022; Russell, 2020). Although some people with dementia were able and wanted to continue working, stigma and prejudices from people around them made it difficult and discouraging to fight for their job and resulted in feelings of resentment in the way their working life ended (Evans, 2019; Ikeuchi et al., 2022; Ritchie et al., 2018, 2021; Öhman et al., 2001).

Although, people with dementia appreciate the value of being involved in 'real' work rather than 'busywork', a work environment specifically designed for them also offers opportunities to meet others beyond their immediate network and share thoughts and feelings (Kinney et al., 2011; Roach & Drummond, 2014; Robertson & Evans, 2015). They also expressed that being connected to work-

life again enabled a sense of "normalcy" in the face of an illness that had made them give up many activities that once defined them (Evans, 2019; Kinney et al., 2011). Working not only challenged social discourses regarding the capabilities of employees living with dementia but also reinforced the belief that life remained valuable after the diagnosis (Egdell et al., 2021; Stott et al., 2017). However, for those who worked alongside other people with dementia, if could also provide a glimpse into a future they feared, especially if they witnessed colleagues experiencing rapid deterioration in their dementia.

Some studies show how people with dementia who have lost their jobs can be re-engaged in employment. For example, this can involve appointing a support person at the workplace to facilitate integration, or employers initiating discussions and planning future employment with the employee (Robertson et al., 2013; Robertson & Evans, 2015; Öhman et al., 2001). Re-engaging in work-life provides the opportunities for social relationships with co-workers and contribute to both the workplace and to society at a large, positively impacting the well-being of people with dementia's well-being (Ebbitt et al., 1989; Evans, 2019; Kinney et al., 2011; Roach & Drummond, 2014; Robertson et al., 2013; Russell, 2020). For those with dementia, returning to work allows them to expand their daily activities and explore their abilities in new work environments. They describe how this experience reignited their zest for life (Ebbitt et al., 1989; Robertson et al., 2013). Moreover, the positive effect on work engagement extend to their relationship with their relatives. Family members note that the person with dementia returns home from work with renewed energy, improved sleep, and increased activity, positively influencing the entire family's everyday life (Ikeuchi et al., 2022; Ikeuchi et al., 2022; Ritchie et al., 2018; Robertson & Evans, 2015; Robertson & Evans, 2015; Stott et al., 2017; Stott et al., 2017).

Discussion

The aim of this mixed-methods review was to investigate recommendations for work interventions for people with dementia. The review identifies that being able to continue working greatly influences the way people with dementia perceive themselves as contributing citizens in their everyday lives. The findings further show that it is possible to live and work well with dementia if collaborative solutions are continuously negotiated to meet the needs of both the person with dementia and the workplace. The findings show that employers who used a person-centered approach to assess the needs and abilities of employees with dementia facilitate work retention. Additionally, workplace education and dementia-awareness sessions are essential in this regard. Moreover, successful work interventions also require close attention to contextual barriers, such as power dynamics within the work environment and stigmatization that may cause untimely work termination (Low & Purwaningrum, 2020). This is in line with Issakainen et al. (2023), who identified that stigma associated with dementia negatively influenced work retention. The review also identifies that continuing employment may help address preconceptions about the abilities of people with dementia and thereby reducing the stigma they experience in the workplace. Attention to what enables successful work interventions is equally important, for example, how collaboration between the person with dementia and the workplace can promote more sustainable solutions for work continuation. This is also reported in a systematic review by Thomson et al.' (2019) who found that shared decision-making enables employees with dementia to make informed choices regarding their work life.

The findings of this review support research showing that the fear of losing one's job and not being able to live up to own and other's expectations may cause some individuals to resign shortly

after a dementia diagnosis (Roach & Drummond, 2014; Sakata & Okumura, 2017; Thomson et al., 2019). Moreover, research indicate that the stigma and preconceptions people with dementia face regarding work may also negatively affect their job retention (Low & Purwaningrum, 2020)

Dementia carries strong connotations of immediate incapacity, which may cause people with dementia to conceal their difficulties for as long as possible by applying self-developed strategies, such as meeting earlier and staying longer at work to finish their tasks. However, these strategies are often ineffective and counterproductive, being only effective for a limited time, and they may add to the overall pressure the person with dementia is experiencing at work. Early disclosure of a dementia diagnosis is shown as crucial for workplace to understand the causes of an employee's changed work performance, enabling timely interventions for work retention. However, people with dementia expressed a need to understand their rights before disclosing their diagnosis. Despite this, none of the workplaces had a formalized strategy to support employees with dementia and many of the employers and HR-professionals expressed a need for knowledge about dementia, for example, regarding early symptoms and possible ways to provide the best support for the person with dementia and employers often rely on existing disability management policies in the absence of policies specifically addressed dementia. As a result, companies are often uncertain about how to best support the work retention of an employee with dementia and manage a dignified conclusion to the person's working life. Moreover, stigmatization and a general lack of knowledge about how dementia can manifest itself in work situations may prevent employers and co-workers from taking the initiative to discuss options with the person. Consequently, in the early stages, many people with dementia are forced to cope with their challenges on their own, which research has shown may lead to involuntary retirement and a reduced quality of life (Nygard et al., 2023; Thorsen et al., 2020). Explicit guidelines for work retention following a dementia diagnosis can encourage employees with dementia to disclose their diagnosis early in the process and guide the workplace in initiating timely and collaborative work intervention. The findings furthermore showed that guidelines should include strategies for terminating employment, as both staff and people with dementia reported concerns about how to end work life in an ethical and dignified manner as the illness significantly progresses.

Methodological considerations

The review included a relatively small number of studies, which demonstrates the limited availability of evidence, highlighting the limited availability of evidence and making the gathering and dissemination of the findings even more relevant for guiding practice. It also indicates a need for further research.

Due to the mixed-method format, the review draws on multiple sources, methods, and theories to capture a wide range of data, thereby enhancing the finding's potential to inform the development of work interventions for people with dementia. Mixed-methods research can provide a more comprehensive understanding of complex social phenomena such of this review. However, mixed-methods research has been criticized for its conceptual and methodological challenges, since it requires balancing the depth of qualitative data with the breadth of quantitative data, which may lead to compromises during the analysis process. In this review, we aimed to analyze the data by adhering closely to the methodological approaches reported by the authors of the primary studies. However, balancing the depth of qualitative data and the breadth of quantitative data is challenging, and there may be findings that we have not fully capture.

To enhance the credibility of this review, several strategies were implemented in collaboration with an experienced research librarian. We tested the inclusion and exclusion criteria on a small

sample and conducted a preliminary search to determine the appropriate search terms and timeframe. This led us to use a relatively wide timeframe in the final search, resulting in many hits and a time-consuming screening process. However, this proved to be a sound decision, as it identified two early relevant studies. Despite these efforts, we may have missed some relevant studies, particularly those in gray literature.

Conclusion

As more people are diagnosed with dementia earlier and with an increase in the compulsory retirement age in many countries, more workplaces will need to adapt to support workers living with the condition. This mixed-methods review aimed to investigate recommendations for work interventions for people with dementia, including how these interventions are experienced by people with dementia, their relatives, employers, co-workers, and HR professionals. The review shows that it is possible to live and work well with dementia if collaborative solutions are continuously negotiated to meet the needs of both the person with dementia and the workplace, with attention to contextual enablers and barriers. None of the workplaces in the included studies had a formal strategy for employees with dementia, although having such a strategy might encourage earlier support-seeking and disclosure, contributing to a more timely and effective retention process.

Implication for policy and practice

The included studies reported experiences and results from developing and testing various types of work interventions for people with dementia. These included adapted and supervised work settings, a community-based buddy program, and roles for people with dementia as peer support persons and teachers in health and educational institutions. Overall, the review highlights four key elements for successful work interventions for people with dementia:

1) Person-centered Approach: Dementia affects individuals differently, yet they are often perceived as a single group, overlooking the diverse skills and competencies they possess. To address this, interventions should prioritize continuous collaboration among people with dementia, the workplace, and other relevant stakeholders, such as dementia specialists. This ensures that the individual's wishes, abilities, and skills are considered in efforts to retain employees with dementia. While work is crucial for most adults, providing income, structures, and social connections, its meaning varies from person to person. For work to be perceived as meaningful, alternative roles or tasks must feel genuine and relevant for the individual.
2) Contextual Relevance: Traditionally, work interventions have focused on fitting individuals into existing environments, where individuals are expected to develop certain skills before being placed into a work environment. However, each person's situation is unique. Work environments are dynamic and subject to constant change, making them unsuitable for static fitting processes. Instead, there is a constant need to consider ways to optimize the fit between the workplace, the individual, and the task at hand. This requires critical reflection on the 'conditions of possibility' within the environment, including exploration of the underlying forces such as power dynamics, social relations, and dementia discourses that may impact a successful fit.
3) Knowledge-based: Research shows that lack of knowledge and misconceptions about dementia are some of main reasons for stigmatization and the cause of exclusion from work for people with dementia. Research-based knowledge about dementia is wanted and needed for those involved to be able to recognize early signs of dementia, to initiate a collaborative retainment process, and to plan

a dignified termination of work-life for people with dementia. Workplace education and dementia-awareness sessions may help employers and colleagues to recognize and understand the abilities and challenges of employees with dementia, which may provide guidance on how best to support them. **4) Dynamic Approach:** Since dementia is a progressive and, at times, fluctuating illness, the intervention must be dynamic and consist of a wide range of elements that can be continuously adjusted regarding timeframe, type of support, complexity of work tasks, and relational considerations. This could be shorter work sessions, assigning tasks one at a time, rather than all at once, the possibility of a support person and support sessions, fewer cognitively demanding work tasks, and scheduled time for breaks to enable social interaction with colleagues. The progressive nature of dementia, also require a respectful and inclusive approach when deciding how the termination of work-life should take place, to enable the best fit between the individual person's work and everyday life situation.

Acknowledgement

The authors wish to thank research librarian Anne-Marie Fiala Carlsen and research assistant Sif Højmark Vobbe for their valuable contribution to this review. We would also like to thank the Danish Occupational Therapist Association, for funding this study.

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) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Ergoterapeutforeningen (FF1/21-R169-A3936).

Ethical statement

Ethical approval

Since this review was based on peer-reviewed published articles, no ethical approval was needed and informed consent was neither relevant nor required.

ORCID iDs

Hanne Peoples https://orcid.org/0000-0002-2630-2870
Jesper Larsen Maersk https://orcid.org/0000-0002-5290-7937
Hanne K Kristensen https://orcid.org/0000-0002-9596-5571

References

Alzheimer's Society. (2015). *Creating a dementia-friendly workplace. A practical guide for employers*. https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/creating_a_dementia-friendly_workplace.pdf

Andrew, C., Phillipson, L., & Sheridan, L. (2019). What is the impact of dementia on occupational competence, occupational participation and occupational identity for people who experience onset of symptoms while in paid employment? A scoping review. *Australian Occupational Therapy Journal*, *66*(2), 130–144. DOI: 10.1111/1440-1630.12535.

Bahar-Fuchs, A., Martyr, A., Goh, M. A., Sabates, J., & Clare, L. (2019). Cognitive training for people with mild to moderate dementia. *Cochrane Database Syst Rev*, *3*(3), CD013069. DOI: 10.1002/14651858.CD013069.pub2.

Bartlett, R. (2021). Inclusive (social) citizenship and persons with dementia. *Disability & Society*, *2*(7), 1129–1145. DOI: 10.1080/09687599.2021.1877115.

Bartlett, R., & O'Connor, D. L. (2010). *Broadening the dementia debate: Toward social citizenship*. Policy Press.

Basu, O. (2019). Early onset dementia (EOD) and its impact on employment of young adults. *Archives in Neurology & Neuroscience*, *4*(5), 1–4.

Beattie, A., Daker-White, G., Gilliard, J., & Means, R. (2004). 'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia services. *Health & Social Care in the Community*, *12*(4), 359–368. DOI: 10.1111/j.1365-2524.2004.00505.x.

Briggs, J. (2017). *Joanna Briggs critical appraisal checklists*. https://joannabriggs.org/research/critical-appraisal-tools.html

Busted, L. M., Nielsen, D. S., & Birkelund, R. (2020). "Sometimes it feels like thinking in syrup" - the experience of losing sense of self in those with young onset dementia. *International Journal of Qualitative Studies on Health and Well-Being*, *15*(1), 1734277. DOI: 10.1080/17482631.2020.1734277.

Carone, L., Tischler, V., & Dening, T. (2016). Football and dementia: A qualitative investigation of a community based sports group for men with early onset dementia. *Dementia (London, England)*, *15*(6), 1358–1376. DOI: 10.1177/1471301214560239.

CEBMa. (2024). *Critical appraisal of a cross-sectional study (survey)*. CEBMa Center for Evidence-Based Management. https://cebma.org/resources/tools/critical-appraisal-questionnaires/

Chaplin, R., & Davidson, I. (2016). What are the experiences of people with dementia in employment? *Dementia (London, England)*, *15*(2), 147–161. DOI: 10.1177/1471301213519252.

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research*, *22*(10), 1435–1443. DOI: 10.1177/1049732312452938.

Cox, C. B., & Pardasani, M. (2013). Alzheimer's in the workplace: A challenge for social work. *Journal of Gerontological Social Work*, *56*(8), 643–656. DOI: 10.1080/01634372.2013.821693.

Danish Dementia Research Centre. (2023). *Incidence of dementia in Denmark*. Danish Dementia Research Centre – patient care, research and education. https://videnscenterfordemens.dk/en/incidence-dementia-denmark

Ebbitt, B., Burns, T., & Christensen, R. (1989). Work therapy: Intervention for community-based Alzheimer's patients. *The American Journal of Alzheimer's Care and Related Disorders & Research, September/October*, *4*(5), 7–15.

Egdell, V., Cook, M., Stavert, J., Ritchie, L., Tolson, D., & Danson, M. (2021). Dementia in the workplace: Are employers supporting employees living with dementia? *Aging & Mental Health*, *25*(1), 134–141. DOI: 10.1080/13607863.2019.1667299.

Evans, D. (2019). An exploration of the impact of younger-onset dementia on employment. *Dementia*, *18*(1), 262–281. DOI: 10.1177/1471301216668661.

Evans, D., Murray, C., Berndt, A., & Robertson, J. (2021). Supporting people with dementia in employment. In I. L. Low & K. Laver (Red) (Ed.), *Dementia Rehabilitation. Evidence-based interventions and clinical recommendations* (pp. 149–170). Elsevier Inc.

Farina, N., Page, T. E., Daley, S., Brown, A., Bowling, A., Basset, T., Livingston, G., Knapp, M., Murray, J., & Banerjee, S. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. *Alzheimer's & Dementia*, *13*(5), 572–581. DOI: 10.1016/j.jalz.2016.12.010.

Greenwood, N., & Smith, R. (2016). The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas*, *92*, 102–109. DOI: 10.1016/j.maturitas.2016.07.019.

Harris, P. B., & Keady, J. (2004a). Living with early onset dementia: Exploring the experience and developing evidence-based guidelines for practice. *Alzheimer's Care Quarterly*, *5*(2), 111.

Harris, P. B., & Keady, J. (2004b). Living with early onset dementia: Experiences and developing evidence-based guidelines. *Alzheimer's Care Today*, *5*(2), 111–122.

Holdsworth, K., & McCabe, M. (2018). The impact of younger-onset dementia on relationships, intimacy, and sexuality in midlife couples: A systematic review. *International Psychogeriatrics*, *30*(1), 15–29. DOI: 10.1017/S1041610217001806.

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boatdman, F., Cargo, M., Dagenais, P., Gagnon, M., Griffiths, F., Nicolau, B., O'Cathain, A., Rousseau, M., & Vedel, I. (2018). *Mixed methods appraisal tool (MMAT)*. https://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf

Hoppe, S. (2019). Shifting uncertainties in the pre-diagnostic trajectory of early-onset dementia. *Dementia (London, England)*, *18*(2), 613–629. DOI: 10.1177/1471301216687436.

Ikeuchi, S., Omote, S., Tanaka, K., Okamoto, R., Morikawa, Y., & Iritani, O. (2022). Work-related experiences of people living with young-onset dementia in Japan. *Health & Social Care in the Community*, *30*(2), 548–557. DOI: 10.1111/hsc.13157.

Issakainen, M., Mäki-Petäjä-Leinonen, A., Heimonen, S., Nedlund, A., Astell, A., Boger, J., Rissanen, S., & Nygård, L. (2023). Experiences of influencing one's own life when living with working-age dementia. *Ageing and Society*, *43*(8), 1934–1953. DOI: 10.1017/S0144686X21001525.

Johannessen, A., Engedal, K., Haugen, P. K., Dourado, M. C. N., & Thorsen, K. (2018). "To be or not to be": Experiencing deterioration among people with young-onset dementia living. *International Journal of Qualitative Studies in Health and Well-Being*, *13*(1), 607–617.

Johannessen, A., & Möller, A. (2013). Experiences of persons with early-onset dementia in everyday life: A qualitative study. *Dementia*, *12*(4), 410–424. DOI: 10.1177/1471301211430647.

Kinney, J., Kart, C., & Reddecliff, L. (2011). "That's me, the Goother": Evaluation of a program for individuals with early onset dementia. *Dementia*, *3*, 361–377.

Lizarondo, L., Stern, C., Carrier, J., Godfrey, C., Rieger, K., Salmond, S., Apostolo, J., Kirkpatrick, P., & Loveday, H. (2020). Chapter 8: Mixed methods systematic reviews. I. E. Aromataris & Z. Munn (Red), *JBI manual for evidence Synthesis*. JBI. DOI: 10.46658/JBIMES-20-09

Lockwood, C., Munn, Z., & Porritt, K. (2015). Qualitative research synthesis: Methodological guidance for systematic reviewers utilizing meta-aggregation. *International Journal of Evidence-Based Healthcare*, *13*(3), 179–187. DOI: 10.1097/XEB.0000000000000062.

Low, L., & Purwaningrum, F. (2020). Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, *20*(1), 477. DOI: 10.1186/s12877-020-01754-x.

Maersk, J. L., Peoples, H., Kristensen, H. K., & Praestegaard, J. (2024). A meta-ethnography of identity formation among people with early-onset dementia. *British Journal of Occupational Therapy 2024*. (Early online).

McCulloch, S., Robertson, D., & Kirkpatrick, P. (2016). Sustaining people with dementia or mild cognitive impairment in employment: A systematic review of qualitative evidence. *British Journal of Occupational Therapy*, *79*(11), 682–692. DOI: 10.1177/0308022616665402.

Moher, D., Tetzlaff, J., & Altman, D. (2009). Preferred reporting Items for systematic reviews and meta-analyses: The PRISMA Statement. *PLoS*, 6(7), 234. DOI: 10.1371/journal.pmed.1000097.

Nygard, L., Nedlund, A., Mäki Petäjä Leinonen, A., Astell, A., Boger, J., Issakainen, M., Engvall, A., Heuchemer, B., Rosenberg, L., & Ryd, C. (2023). What happens when people develop dementia whilst working? An exploratory multiple case study. *International Journal of Qualitative Studies on Health and Well-Being*, *18*(1), 2176278. DOI: 10.1080/17482631.2023.2176278.

O'Connor, D., & Nedlund, A. (2016). Editorial introduction: Special issue on citizenship and dementia. *Dementia (London, England)*, *15*(3), 285–288. DOI: 10.1177/1471301216647150.

Öhman, A., Nygård, L., & Borell, L. (2001). The vocational situation in cases of memory deficits or young-onset dementia. *Scandinavian Journal of Caring Sciences*, *15*, 34–43.

Pearson, A. (2004). Balancing the evidence: Incorporating the synthesis of qualitative data into systematic reviews. *JBI Reports*, *2*(2), 45–64. DOI: 10.1111/j.1479-6988.2004.00008.x.

Pearson, A., Robertson, S., & Rittenmeyer, L. (2011). *Synthesising qualitative evidence*. Lippincott & Wilkins.

Pearson, A., White, H., Bath-Hextall, F., Salmond, S., Apostolo, J., & Kirkpatrick, P. (2015). A mixed-methods approach to systematic reviews. *International Journal of Evidence-Based Healthcare*, *3*, 121–131.

Peoples, H., Varming, J., & Kristensen, H. K. (2022). Social citizenship when living with dementia: A qualitative meta-study. *Journal of Occupational Science*, *30*(3), 453–471. DOI: 10.1080/14427591.2022.2061040.

Rabanal, L. I., Chatwin, J., Walker, A., O'Sullivan, M., & Williamson, T. (2018). Understanding the needs and experiences of people with young onset dementia: A qualitative study. *BMJ Open*, *8*(10), e021166. DOI: 10.1136/bmjopen-2017-021166.

Region Sjælland. (2015). *Forløbsprogram for Demens. Sundhedsaftale 2015-2018*. https://www.regionsjaelland.dk/Sundhed/samarbejde-og-indsatser/DemensSjaelland/Fagpersoner/Documents/17052016_ForlobsprogramDemensRegionSjaelland.pdf

Richardson, A., Pedley, G., Pelone, F., Akhtar, F., Chang, J., Muleya, W., & Greenwood, N. (2016). Psycosocial interventions for people with young onset dementia and their carers: A systematic review. *International Psychogeriatrics*, *28*(9), 1441–1454. DOI: 10.1017/S1041610216000132.

Ritchie, L., Banks, P., Danson, M., Tolson, D., & Borrowman, F. (2015). Dementia in the workplace: A review. *Journal of Public Mental Health*, *14*(1), 24–34. DOI: 10.1108/JPMH-04-2014-0015.

Ritchie, L., Egdell, V., Danson, M., Cook, M., Stavert, J., & Tolson, D. (2021). Dementia, work and Employability: Using the capability approach to understand the Employability potential for people living with dementia. *Mental Health Weekly Digest, December*, *1*, 1–19. DOI: 10.1177/0950017020961929.

Ritchie, L., Tolson, D., & Danson, M. (2018). Dementia in the workplace case study research: Understanding the experiences of individuals, colleagues and managers. *Ageing and Society*, *38*(10), 2146–2175. DOI: 10.1017/S0144686X17000563.

Roach, P., & Drummond, N. (2014). 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing*, *21*, 889–895. DOI: 10.1111/jpm.12154.

Robertson, J., & Evans, D. (2015). Evaluation of a workplace engagement project for people with younger onset dementia. *Journal of Clinical Nursing*, *24*(15-16), 2331–2339. DOI: 10.1111/jocn.12852.

Robertson, J., Evans, D., & Horsnell, T. (2013). Side by Side: A workplace engagement program for people with younger onset dementia. *Dementia (London, England)*, *12*(5), 666–674. DOI: 10.1177/1471301212473881.

Russell, C. W. (2020). People with dementia, contributing to learning and teaching in higher education: Innovative practice. *Dementia (London, England)*, *19*(2), 447–452. DOI: 10.1177/1471301216685460.

Sakata, N., & Okumura, Y. (2017). Job loss after diagnosis of early-onset dementia: A Matched Cohort study. *Journal of Alzheimer's Disease*, *60*(4), 1231–1235. DOI: 10.3233/JAD-170478.

Sandelowski, M., Voils, C. I., & Barroso, J. (2006). Defining and designing mixed research synthesis studies. *Research in the Schools*, *13*(1), 29. https://www.ncbi.nlm.nih.gov/pubmed/20098638

Spreadbury, J. H., & Kipps, C. (2019). Measuring younger onset dementia: What the qualitative literature reveals about the 'lived experience' for patients and caregivers. *Dementia*, *18*(2), 579–598. DOI: 10.1177/1471301216684401.

Steeman, E., De Casterlé, B. D., Godderis, J., & Grypdonck, M. (2006). Living with early-stage dementia: A review of qualitative studies. *Journal of Advanced Nursing*, *54*(6), 722–738. DOI: 10.1111/j.1365-2648.2006.03874.x.

Stott, J., Sweeney, J. M., Koschalka, L., O'Connor, L., & Mwale, A. (2017). People with dementia as peer workers, challenges, and benefits: A thematic analysis and nominal groups study. *International Psychogeriatrics*, *29*(7), 1185–1192. DOI: 10.1017/S1041610216002519.

Suri, H. (2020). Ethical considerations of conducting systematic reviews in educational research. In I. O. Zawacki-Richter, M. Kerres, S. Bedenlier, et al. (Ed.), *Systematic reviews in educational research - methodology, perspectives and Application* (pp. 41–54). Springer.

Swaffer, K. (2015). Dementia and prescribed disengagement. *Dementia (London, England)*, *14*(1), 3–6. DOI: 10.1177/1471301214548136.

Thomson, L., Stanyon, M., Dening, T., Heron, R., & Griffiths, A. (2019). Managing employees with dementia: A systematic review. *Occupational Medicine (Oxford)*, *69*(2), 89–98. DOI: 10.1093/occmed/kqy161.

Thorsen, K., Dourado, M. C. N., & Johannessen, A. (2020). Developing dementia: The existential experience of the quality of life with young-onset dementia - a longitudinal case study. *Dementia*, *19*(3), 878–893.

Thuesen, J., Kristensen, F., Frausing, S., Kruse, R. E., Johansen, H., & Millesen, B. T. (2018). Rehabilitation for mild to moderate dementia: A national survey of understandings, initiatives, and organization in regions and municipalities [Rehabilitering ved demens i let til moderat grad. National kortlægning af forståelser, indsatser og organisering i regioner og kommuner]. Nyborg, DK: REHPA.

Wawrziczny, E., Antoine, P., Ducharme, F., Kergoat, M., & Pasquier, F. (2016). Couples' experiences with early-onset dementia: An interpretative phenomenological analysis of dyadic dynamics. *Dementia (London, England)*, *15*(5), 1082–1099. DOI: 10.1177/1471301214554720.

WHO. (2017). *Global action plan on the public health response to dementia 2017-2025*. WHO. https://www.alzint.org/what-we-do/partnerships/world-health-organization/who-global-plan-on-dementia/

Author Biographies

Hanne Peoples is a senior lecturer and researcher at the Health Sciences Research Centre, UCL University College, Denmark. In her research, Hanne Peoples focuses on exploring various aspects of dementia and everyday life, including age-inclusive environments, an aging workforce, and citizenship, to understand and develop interventions that improve inequalities, promote healthy aging, and enable meaningful lives. Hanne's research targets user involvement and co-creation and takes place within the fields of occupational science, occupational therapy, and cross-sectional and interdisciplinary rehabilitation.

Jesper Larsen Maersk is a senior lecturer and researcher. In his research, Jesper focuses on developing rehabilitation and palliative care interventions to reduce inequality in health concerning people with chronic and life-threatening illnesses. Moreover, to generate conceptual and theoretical understandings of the intersection between everyday life with chronic and life-threatening illness and subjective phenomena such as self-care, identity, understanding of illness, and health literacy.

Hanne Kaae Kristensen, The research of Hanne Kaae Kristensen takes place in the research fields of occupational science, occupational therapy, cross-sectional, and interdisciplinary rehabilitation, e.g., within dementia and stroke rehabilitation. It concerns the implementation of science and research, generating new knowledge in interdisciplinary and international perspectives, stressing user involvement, knowledge sharing, and high quality. The research has developed and implemented health services approaches and rehabilitation interventions that enable functioning, emphasizing activity and participation in meaningful everyday life.