

Sustaining people with dementia or mild cognitive impairment in employment: A systematic review of qualitative evidence

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Abstract

Introduction: The World Health Organization estimates that 10% of the 35.6 million people worldwide with dementia are aged under 65 years. In an ageing workforce this has implications for employers, employees, and statutory and third sector services. Limited research has been conducted into this emerging global issue.

Method: This systematic review, employing the methodology of the Joanna Briggs Institute, aimed to identify and synthesise the best available qualitative evidence regarding the needs, experiences and perspectives of people with early onset dementia or mild cognitive impairment who were either in employment or wished to gain employment.

Results: Of 69 studies identified, eight met the inclusion criteria. From these, four themes emerged: disease progression and recognition; the emotional impact of change; the employer's management of the worker; and changes to the worker role.

Conclusion: There are health benefits to the individual with dementia or mild cognitive impairment of continuing to engage in meaningful occupation. Retirement policy changes have resulted in an ageing workforce with concurrent risk factors for dementia. A lack of understanding of reasonable adjustments and sheltered employment opportunities was evident from the literature. This review highlights the potential for occupational therapists to engage this client group in vocational rehabilitation.

Keywords

Dementia, cognitive impairment, vocational rehabilitation

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Introduction

This systematic review is focused on the qualitative evidence regarding people with dementia or mild cognitive impairment (MCI) who are employed, wish to gain employment or be sustained in employment. The impact of people with dementia or MCI continuing to engage in productive remunerative employment is an emerging public health issue (FitzGerald et al., 2013). The potential for occupational therapy to address the vocational aspirations of this important emerging population is clear. Government policy demands allied health professionals include 'the work question' when assessing individuals of working age within health care settings. Engagement in employment by younger people with dementia has attracted little attention from the research community worldwide. While epidemiological projections vary, it is thought that dementia will increasingly affect low- and middle-income countries (World Health Organization (WHO), 2012), and it is anticipated that 115 million people will be affected worldwide by the year 2015. The prevalence of dementia is predicted to double in the United Kingdom (UK) in the next 40 years (Alzheimer's Society, 2014) and to more than triple worldwide in the next 50 years (WHO, 2012). Dementia is a progressive

condition that affects the brain, and it may have any of a number of underlying pathologies, the most common being Alzheimer's disease (WHO, 2012). MCI is associated with an increased risk of developing Alzheimer's disease and other forms of dementia.

There are drivers that may impact on the number of people with dementia or MCI who are employed or seeking employment. Firstly, earlier diagnosis of dementia due to the discovery of markers associated with the development of the syndrome means that more people of working age will be identified.

Secondly, working life is being extended in many countries and ageing is associated with the development of dementia (Fundarò & Casale, 2012). The older the working population, the greater the likelihood of people

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with dementia or MCI in the workplace. In 2013 there were approximately 3000 people of working age with dementia in Scotland (Alzheimer's Scotland, 2013). Beattie et al. have highlighted 'the need for specialist, flexible, age-appropriate, and dedicated services' (Beattie et al., 2002).

Thirdly, throughout the world the incidence of type 2 diabetes is increasing. It is projected that due to an ageing and increasingly obese population this figure will rise in coming decades (Danaei et al., 2011). There is an association between type 2 diabetes and Alzheimer's disease and other common forms of dementia; in particular, vascular dementia (Danaei et al., 2011). People with type 2 diabetes are at least twice as likely to develop Alzheimer's disease as the general population (Ohara et al., 2011).

Finally, governmental policies worldwide encourage people with disabilities to remain in employment wherever possible. There is agreement that employment is good for people economically and has physical and mental well-being benefits (Roach and Drummond, 2014). As Robertson et al. (2013) have suggested, younger people with dementia may withdraw from engagement in activities of daily living, their community, and from engagement in employment as a consequence of the cognitive manifestations of the disease.

A recent systematic review by Then et al. (2014) suggested that psychologically complex and challenging work may have a preventive effect, reducing the impact and/or delaying the cognitive and functional decline associated with dementia. This view is supported by Seidler et al., who summarised that Alzheimer's disease is 'negatively associated with diversity of activities and intensity of intellectual activities and positively associated with psychosocial inactivity and unproductive working' (Seidler et al., 2004: 962).

Given these predictions, it is critical that an understanding is developed of factors that determine the ability of an individual with dementia or MCI to succeed in employment. Some research has demonstrated qualitative evidence of successful programs for younger people with dementia in either supported or open employment (Robertson et al., 2013). While it is evident from the existing research that little has been published with regard to maintaining employment for people with dementia, current literature considering other mental health conditions impacting on cognition have demonstrated the value to patients and clients of continuing engagement in the work role (Arbesman and Logsdon, 2011; Gibson et al., 2011; Wimpenny et al., 2014).

With the introduction of the Allied Health Professional (AHP) Advisory Fitness for Work Report (Hynie, 2014) it is imperative to ask service users the 'work question', providing an opportunity to develop AHP vocational rehabilitation services for people with MCI and dementia. Additionally, as health and social care services integrate, there is a potential for AHP skills to be applied to health and functional issues in employability, an area of life that is of profound importance to many, individually and at a societal level.

Method

A Joanna Briggs Institute (JBI) (2015) methodology was employed to conduct a systematic search for qualitative research literature published in the period January 2001 to January 2015. (The comprehensive search strategy is available on request from the authors.) The systematic review aimed to identify and synthesise the best available qualitative evidence regarding the needs, experiences and perspectives of people with early onset dementia (EOD) or MCI who were either in employment or wished to gain employment.

Search strategy

The search process is summarized in Figure 1. The databases reviewed included AMED, Cinahl, EMBASE, Medline, PsycArticles, Psycinfo and Web of Science. The search terms dementia, mild cognitive impairment, Alzheimer* and confus* were combined using an 'OR' command. Search terms work*, employ*, occupation*, labour, job and vocation were combined using an 'OR' command. These two searches were combined using an 'AND' command. The number of quantitative studies was reduced by using the filter 'NOT trial NOT randomi*' and target publication dates were determined by the filter 'AND Limiters (Published Date: Published Date: 20010401-20150131)'. See Appendix 1: Sample Search Strategy, in the supplemental material available at <http://bjo.sagepub.com/content/by/supplemental-data>.

This resulted in 23,292 articles being identified for potential inclusion. On the face of it, this might suggest a lack of specificity in the search strategy; however, we chose to have no upper age limit for study participants as we were conscious that there is now no longer a universal retirement age.

A total of 6235 duplicates were excluded. A total of 16,988 were excluded on evaluation of title and/or abstract (see Appendix 2: Exclusion criteria prior to obtaining full text articles, in the supplemental material available at <http://bjo.sagepub.com/content/by/supplemental-data>). Of the 69 remaining papers, 61 were excluded on reading the full text.

Each title and abstract was reviewed by two of the authors independently, and the process was audited by the third author. The methodological quality of the studies was rated using the Joanna Briggs Institute (JBI) System for the Unified Management, Assessment and Review of Information (SUMARI) Qualitative Assessment Review Instrument (QARI) (Figure 2).

Figure 3 and Table 1 are the instruments that we used to analyse and rate the papers to determine which should be included in the final review.

From the systematic review of the 69 papers, eight met the criteria for inclusion in this review, and are listed in Table 2, which summarises the authors' critique of the selected papers.

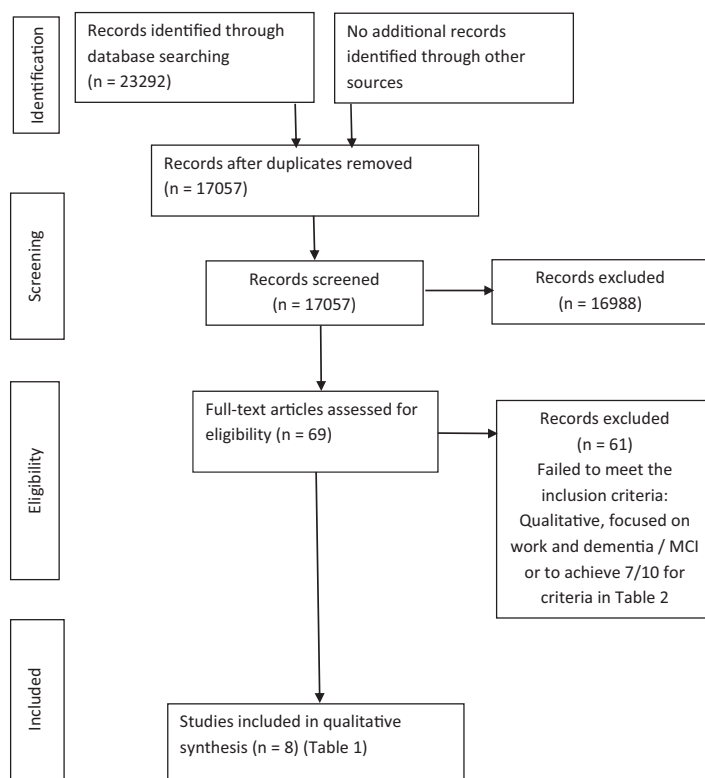


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher et al., 2009).

Findings

A significant number (1039) of the original papers identified by the search strategy, superficially matching the criteria outlined in the JBI protocol (Robertson et al., 2015), related to frail elderly people and the impact of dementia on their carers. Of the 69 papers included for full review, 61 were excluded because they failed to focus on dementia/MCI, employment or were not qualitative research. These were anecdotal or opinion pieces, surveys, literature reviews and quantitative studies and, where relevant, they have been included in the background to this paper.

All of the studies employed qualitative methods that the authors reported as including grounded theory (3, Braudy Harris, 2004; Braudy Harris and Keady, 2009; Johannessen and Moller, 2013), interpretative phenomenological analysis (1, Chaplin and Davidson, 2014), repeated interview (1, Roach and Drummond, 2014), interpretive qualitative methodology (2, Gallagher et al., 2013; Hopcroft et al., 2013) or exploratory approach (1, Robertson and Evans, 2015). As expected, data collection was predominantly by means of semi-structured interviews in seven of the eight studies (Braudy Harris, 2004; Braudy Harris and Keady, 2009; Chaplin and Davidson, 2014; Gallagher et al., 2013; Hopcroft et al., 2013; Johannessen and Moller, 2013; Roach and Drummond, 2014); the remaining study used workplace observation, workplace journals and focus groups (Robertson and Evans, 2015). In addition to semi-structured interviews,

Braudy Harris (2004) and Braudy Harris and Keady (2009) used focus groups.

Description of the literature included for full narrative analysis

Of the eight papers included (Table 2), one paper was from an occupational therapy perspective, and the participants of two of the other published studies (Gallagher et al., 2013; Hopcroft et al., 2013) had HIV-related dementia. It was apparent that there was a dearth of research literature relating to this topic.

The papers included in this review were published by teams from different global locations; thus, the findings may not all be applicable to the health, social care and legislative context of the UK. There was variety in terms of the participants selected, for example some researchers were examining data gathered from people resident in two different continents (Braudy Harris and Keady, 2009), while one study detailed the experiences of participants in one localised, supported-employment initiative (Robertson and Evans, 2015). Not all the papers focused entirely on employment, but all included employment within their scope. Chaplin's (2014) paper was the one that perhaps reflected most closely the aims of this literature review. A variety of qualitative research methods were employed, including grounded theory, interpretative phenomenological analysis and exploratory analysis. Seven of the eight papers used semi-structured interviews to gather

Reviewer.....Date.....

Author.....Year.....

Journal.....Record Number.....

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes No

Figure 2. JBI SUMARI QARI data extraction form for interpretive and critical research. Permission to use this figure has been provided by The Joanna Briggs Institute.

participant and carer subjective experiences of transitioning from employment.

Description of the thematic analysis

On review and thematic analysis of the eight papers that met the criteria for inclusion the authors identified and grouped key themes. The process adopted for thematic analysis was that authors 1 and 2 separately identified key elements within each paper that related to the focus of the review. Author 3 acted as a moderator in this process, and as a team a consensus was reached to agree the validity and representativeness of the four super-ordinate themes identified. These four themes are discussed in the light of the existing literature:

1. Disease progression and recognition;
2. The emotional impact of change;
3. Employer’s management of the worker;
4. Changes to the worker role.

Exploration of the super-ordinate themes

Disease progression and recognition. An important theme was lack of awareness or denial of the underlying dementia pathology by the individual, recognition of these pathological changes by co-workers, family members and carers, and the difficulty in obtaining a formal diagnosis.

It has been recognised that lack of insight into pathological change is a common consequence of dementia, a feature that can compound the difficulty in obtaining a dementia diagnosis, a theme discussed by Braudy Harris (2004). Participants also reported being easily distracted by environmental factors, such as background noise, poor memory and an inability to multi-task, which had an impact on the ability to function at work. Gallagher et al. quote a participant as reporting ‘I’ve got to either listen [during work presentations] or do the writing. I cannot do both’ (Gallagher et al., 2013: 40). Johannessen and Moller’s participant identifies that ‘it

Reviewer	Date	Record Number			
Author	Year	yes	no	unclear	Not applicable
1.	Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall appraisal <input type="checkbox"/> Include <input type="checkbox"/> Exclude <input type="checkbox"/> Seek further info. <input type="checkbox"/>					
Comments (Including reason for exclusion)					

Figure 3. JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research. Permission to use this figure has been provided by The Joanna Briggs Institute.

Table 1. Appraisal of eight selected papers (using the JBI QARI checklist). Questions 1-10 relate to the 10 questions posed in the JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research (Figure 3).

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Braudy Harris (2004)	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Braudy Harris (2009)	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Chaplin (2014)	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Gallagher (2013)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Hopcroft (2013)	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Johanssen (2013)	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Roach (2014)	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Robertson (2015)	Y	Y	Y	Y	Y	N	U	Y	Y	Y

Y = yes, N = no, U = unsure

started when I was doing a lot of things wrong at work. . . My colleagues at work . . . told me that it seemed as if I was struggling and they asked me if I was tired' (Johannessen and Moller, 2013: 414). Subjects in a number of studies described how they had been forced to decrease their workloads or change professions entirely because of

neurocognitive challenges, such as atypical, uncharacteristic, angry outbursts at co-workers.

A number of participants described strategies that they had utilised to enable them to remain in employment. These included spending more time and effort in planning and organising tasks, and the use of memory

Table 2. Summary critique of the eight papers selected.

Paper	Criteria	Result
Brady Harris (2004)	Study type	Qualitative grounded theory.
	Population n/M/F/mean age	23 participants, age range 43–68, mean age 56 years. All participants were Caucasian.
	Setting	USA. Local Alzheimer Association. Focus groups – health centre; interviews – participant's home.
	Aim	Subjective experience of EOD.
	Method	Face-to-face in-depth interviews, on-line interviews and focus groups.
	Results	Eight themes were synthesised: difficulty obtaining a dementia diagnosis, marginalisation, changing relationships within the family, workforce/retirement issues, dependency, lack of meaningful occupation, issues of self esteem and awareness of changes in self.
	Conclusions	More workshops focusing on the issues of younger people with dementia need to be developed.
	Key strengths	Well-recognised and appropriate methodology.
Brady Harris (2009)	Limitations	The sample is small and may not comprise a representative sample of people with EOD. Such a sample limits the generalisability of the findings.
	Study type	Qualitative, grounded theory.
	Population n/M/F/mean age	USA – young Caucasian people with dementia, age 43–68, mean age 56. All participants living in own home. UK – carers, age range 21–64, living in North Wales community.
	Setting	USA – voluntary agencies. UK – participant's home.
	Aim	Meaning and construction of selfhood and identity.
	Method	Semi-structured interviews, on-line interviews and focus groups.
	Results	Identity as a worker, identity of abandoned individual, sexual identity, family identity and identity as an individual engaged in living.
	Conclusions	Raise public and employer awareness through targeted health education and promotion centred on recognising the early signs of younger onset dementia and the needs of families. Reducing stigma and promoting normalising services for younger people with dementia would positively support each of the identity themes. Future studies should recognise the importance of longitudinal research to provide data for quality service provision.
Chaplin and Davidson (2014)	Key strengths	Well-recognised and appropriate methodology. Data was collected from both the US and the UK.
	Limitations	Study not explicitly focused on employment although a comprehensive account of the experiences of people with younger onset dementia and their carers. Limited acknowledgement of the differences in the healthcare systems.
	Study type	Interpretative phenomenological analysis.
	Population n/M/F/mean age	Five people, age range 58–74.
	Setting	UK – participants home.
	Aim	Experience of people with dementia in employment.
	Method	Semi-structured interviews.
	Results	People with dementia fail to receive reasonable adjustments in the workplace and are poorly treated and have distressing experiences in the workplace.
Gallagher et al. (2013)	Conclusions	This study highlights the need for staff working in services for people with EOD to have some knowledge of employment law and to build up relationships with useful agencies in the field of employment. Employment of people with EOD is a growing and imminent problem augmented by the removal of the statutory retirement age in 2012.
	Study type	Interpretive, qualitative study.
	Population n/M/F/mean age	16 women, age range 21–62. Majority of participants were born in East/South Africa.
	Setting	Toronto, Canada. Neurobehavioural research unit.
	Aim	Experiences of self-identified HIV-associated neurocognitive change.
	Method	In-depth semi-structured interviews. Structured using a episodic disability framework.
	Results	Conceptualising neurocognitive challenges through a disability lens focuses attention on how impairments interact with other realities in these women's lives.

(continued)

Table 2. Continued

Paper	Criteria	Result
Hopcroft et al. (2013)	Conclusions	Cognitive impairment restricts participation in a range of activities, including work.
	Key strengths	The use of a disability framework. Advocates the role of a disability-oriented approach.
	Limitations	Due to small sample size, saturation may not have been achieved. There was variation in participants' ages as well as time since HIV diagnosis. Approximately half of the participants were born in Southern or Eastern Africa, which is likely to create a different life experience, in contrast to women born in Canada, where the study was located.
	Study type	Qualitative, interpretive study.
	Population n/M/F/mean age	12 men, age range 50–62, born in Canada.
	Setting	Toronto, Canada. Neurobehavioural research unit.
	Aim	Experiences of men ageing with HIV-associated neurocognitive changes.
	Method	Semi-structured interviews using an episodic disability framework.
	Results	Advocates the role of disability-oriented approach in managing impairments, difficulties with day-to-day activities and challenges to social inclusion.
	Conclusions	Links social inclusion issues to impairments. Individuals adopt living strategies to address their neurocognitive challenges, demonstrating creativity and resilience.
Johannessen and Moller (2013)	Key strengths	The use of a disability framework to illustrate linkage of issues of social inclusion to impairments and to focus attention on the living strategies employed by individuals. Advocates the role of a disability-oriented approach in managing impairments, difficulties with day-to-day activities and challenges to social inclusion.
	Limitations	Study participants were male and born in Canada, a high-income country with a comprehensive social welfare system, including universal health care. Experiences of participants may have differed from those not engaged with the formal health care system.
	Study type	Qualitative grounded theory.
	Population n/M/F/mean age	20 participants, age range 54–67, mean age 62. Eight female participants.
	Setting	Norway. Recruited from old age psychiatric hospitals. Living at home.
	Aim	Experiences of people with EOD.
	Method	Semi-structured interviews.
	Results	Opinions of people with EOD should be included as an integral part of the treatment plan; services should focus on keeping persons with EOD connected to others and to society. Employers should be encouraged to do more to facilitate alternative work solutions in collaboration with the person and with health care professionals in the early phase of the disease.
	Conclusions	There is a need for more knowledge about EOD in order to reduce the difficulties that people and their families experience in the process towards a dementia diagnosis.
	Key strengths	Focused on the informant's point of view and acknowledges that the informants' own descriptions and stories are worth taking into consideration when trying to understand the situation of persons with EOD.
Roach and Drummond (2014)	Limitations	Inconsistencies with existing literature may be explained by confabulation or impaired insight within the experiences related by the participants.
	Study type	Qualitative repeated interview study.
	Population n/M/F/mean age	Nine families, 20 participants, age range 56–64 years.
	Setting	Canada. Family unit recruited through Alzheimer Society. Interviews took place in the individual's home with family present.
	Aim	Maintaining purposeful activity, work or volunteering.
	Method	Semi-structured research interviews.
	Results	Themes were transition out of work, the need for purposeful activity and traumatic cessation of work.
	Conclusions	Programmes whether funded by charities or by health are a potential way to address the transition from paid employment by providing a safe and purpose filled environment for younger people with dementia.
	Key strengths	Coherent search strategy. Conclusions flow from the findings.
	Limitations	The persons with dementia who participated in this study were exclusively male, and this limited the analysis and findings to a sex-stratified sample.

(continued)

Table 2. Continued

Paper	Criteria	Result
Robertson and Evans (2015)	Study type	Qualitative exploratory approach.
	Population n/M/F/mean age	Nine participants with supportive carers. Mean age 58.8 years, all under 65 years old.
	Setting	Australia. Clients of a respite cottage and community-based dementia support networks. Hardware store Side by Side project.
	Aim	Feasibility and safety of engagement in work activities.
	Method	Observation, interview, work journal and focus group.
	Results	No adverse workplace events, good outcomes in wellbeing, engagement, contribution to society and socialisation. The workplace programme provided the participants with the opportunity to engage in a real workplace environment, meet people and make new friends.
	Conclusions	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 authors argue for the value of this model of social inclusion for dementia services for young people.
	Key strengths	Very comprehensive in-depth interviews gaining both individual and carer perspectives.
	Limitations	This reported on one initiative in one discreet location with resultant limited generalisability.

aids such as diaries and files. Self-employed participants were more able and likely to obtain support from significant others to facilitate this. An illustration of this is given in a study by Chaplin and Davidson, where a participant reported ‘when we went to meetings she would whisper the name of the person particularly if it is someone who is a client of the company’ (Chaplin and Davidson 2014: 6).

Emotional impact. Participants described the emotional impact of their neurocognitive decline on their ability to continue to work. Self awareness and management practices left participants feeling under scrutiny, which resulted in reported feelings of stress, guilt, depression, fatigue and boredom, and questioning their competence at work. Limited opportunities to share fears and feelings were identified by study participants, most attempting to manage these complex emotions alone.

Where managers or colleagues noted difficulties in participants performing tasks, the manager or co-worker appeared to manage this by increased observation of the employee but failing to discuss this heightened vigilance with the employee. Participants would have preferred to have been consulted about being observed covertly. A participant in one study reported resentment from colleagues; ‘they didn’t think I was pulling my weight, which I was, I just wasn’t doing it right’, when a work adjustment had been initiated by management (Chaplin and Davidson, 2014: 7).

Neurocognitive challenges were worsened by stress arising from sources such as finances, personal relationships and work. Stress was identified by participants in the studies as particularly affecting memory, concentration and clarity of thought processes, thereby making the management of the effects of stress hugely challenging. Participants in all studies reported feelings of depression in some form or another, regardless of a formal diagnosis of depression and, in addition, reported how depression

worsened their memory or concentration, and decreased their participation in work activity. The fatigue reported by participants was disproportionate to the efforts demanded in the work situation, and activities requiring intense concentration resulted in high levels of fatigue. For example, a participant in a study by Gallagher et al. reported ‘[After] three or four hours of [a] meeting, I began to feel almost brain dead . . . I . . . felt physically and mentally exhausted from feeling bombarded by a lot of information I couldn’t really understand’ (Gallagher et al. 2013: 40). The duration of the working day impacted on fatigue levels in a number of participants, who reported impaired decision-making and information retention later in the day (Hopcroft et al., 2013)

Employer’s management of the worker. For many, diagnosis meant early retirement, something that was not planned, resulting in boredom and a lack of meaningful occupation. Participants described the importance of having a meaningful occupation and how it provided them with a strong sense of self. For example, a participant in one study stated ‘I have been forced to take early retirement and for a person who has worked since he was seven years old, retirement and financial dependency upon your wife is very difficult to accept’. (Braudy Harris, 2004: 30). Participants who had the opportunity to resume work in sheltered environments engaged in purposeful, worthwhile activities, and perceived themselves, and were perceived by others, to have improved wellbeing, resulting in a more positive outlook for the future (Robertson and Evans, 2015). Robertson and Evans’ (2015) study evaluated a supported employment initiative designed for younger people with dementia, and received encouraging feedback from participants with regard to the perceived positive, worthwhile nature of work that utilised previous knowledge and skills, permitted participants to develop new skills and decreased family discord. Family members perceived improved health in their relative with dementia,

reporting, for example, of one participant, 'it's been fantastic. He's had people come back [to the store] the following week when he's on duty to praise what he's suggested so that's been a real boost for his confidence' (Robertson and Evans, 2015: 6).

Four sub-themes detailed the experiences of people with dementia who were in the worker role at the time of diagnosis. Participants perceived a lack of consultation about management decisions. A minority were given adjusted duties, none were offered 'reasonable adjustments' under the *Equality Act 2010* or referred to a Disability Employment Advisor. The majority were advised to take sickness leave post diagnosis, and one participant reported immediate termination of employment: 'the situation was taken behind closed doors and... it was a case of "yes he's got it and we're not prepared to even look for anything"' (Chaplin and Davidson, 2014: 8).

A second sub-theme focused on feeling abandoned by the workplace and consequent feelings of resentment towards the workplace, and was particularly identified by participants on sickness leave. Financial hardship was exacerbated as human resources departments failed to warn about cessation of sickness pay. Participants questioned the will of employers to find a more suitable role or acknowledge remaining skills. When asking about other jobs in the workplace, rationalisations such as a lack of insurance or competence now that a diagnosis of Alzheimer's disease had been made (which is an incorrect statement in most countries with disability rights legislation) were used by employers (Chaplin and Davidson, 2014).

Traumatic cessation of work was not an uncommon experience. Participants reported walking out of their jobs, being made redundant or getting fired. This sudden and traumatic end to a person's working life had financial, emotional and interpersonal consequences. It also increased the pressure felt by the spouse of the person with dementia as the now sole income provider. A family member in Roach and Drummond's study summed up this perception.

They were laid off without empathy... without even trying to see... where we can put you... in a less stressful job, even shuffling papers, even copying papers. Keep that person in a job for as long as you can, because when he loses his job, the whole family loses their income... He was extremely anxious... felt like people were attacking him... like he was really being cornered at work and everywhere. He was suspect of people... of them wanting to get rid of him, push him out... nobody realising what the underlying problem was... (Roach and Drummond, 2014: 892)

Families in other studies supported this perception, feeling as though the employers of the person with dementia were treating them unfairly, assuming that their job performance was slipping, and not exploring possible physical or mental health conditions that may be underlying such performance (Johannessen and Moller, 2013).

Changes to worker role. With a diagnosis of dementia, it is usually this identity (work role) that is fractured first, especially in younger-onset dementia, for it is often in the workplace where the symptoms are first noticed. For all, forms of work were reported as being a very positive aspect of their lives. Participants, often at the height of their careers, struggled to make sense of how quickly their work situation was changing. Some believed in their continued competence, despite the realisation of impairment, if an adjusted work role could be negotiated. Some highlighted the importance of fighting for dignity at work, while others were relieved not to have to work; a big transition. Participants expressed this realisation and the financial impact of work cessation in a variety of ways. 'I lost everything that defined me as a productive and meaningful man when I had to stop working... it's such a challenge yet to work out finances. How are we gonna live out the rest of our lives until retirement?' (Brady Harris and Keady, 2009: 439). 'Having to take a 40% reduction in income has had a severe impact' (Brady Harris, 2004: 28).

A number of participants received employment benefits; for others, early retirement or semi-retirement were options, though frequently these caused severe financial hardship. Volunteering was described as a way of being productive, however participants emphasised the importance of finding an organisation flexible with structuring routine and accommodating neurocognitive challenges. 'I feel like my job [volunteering] is my coping skill... I feel happy... I feel that joy of helping other people' (Gallagher et al., 2013: 41). Several of the participants had considered returning to education, but expressed concern about their ability to focus on course work. Those taking courses felt their performance was adversely affected.

Participants believed that engagement in work helped to reduce some of their loneliness and isolation; others who reflected on the meaning of work in their lives expressed an acceptance of the final outcome of the loss of employment. 'I was quite happy with the outcome, for my health, but it was a bit long, 12 months, I think it should have been sooner but never mind' (Chaplin and Davidson, 2014: 9).

Discussion

The original aim of this review was to identify and synthesise the best available qualitative evidence regarding the needs, experiences and perspectives of people with EOD or MCI who were either in employment or wished to gain employment. From review of the evidence it became clear that what little literature had been published was done so in developed societies and the distribution of researchers failed to reflect the projected distribution of the disease that is thought to threaten emerging economies to a far greater extent than Western economies.

A significant proportion of the studies (5, Brady Harris, 2004; Brady Harris and Keady, 2009; Chaplin and Davidson, 2014; Robertson and Evans, 2015; Roach

and Drummond, 2014) identified the critical importance of promoting the normalisation of provision of a range of services, including those focused on employment for younger people with dementia. It could be suggested that normalising these services might reduce stigma and promote social inclusion.

People with EOD often fail to receive reasonable adjustments in the workplace (Chaplin and Davidson, 2014), resulting in the traumatic cessation of the worker role (Braudy Harris, 2004; Braudy Harris and Keady, 2009; Johannessen and Moller, 2013; Roach and Drummond, 2014; Robertson and Evans, 2015). Transition from paid employment to work programmes that provide a safe and purposeful environment and an opportunity to participate in meaningful occupation (Robertson and Evans 2015; Roach and Drummond, 2014), which in one study (Robertson and Evans, 2015) meant a real workplace programme, highlight the importance and value to the individual and their family (Braudy Harris, 2004; Braudy Harris and Keady, 2009; Robertson and Evans, 2015) of an employment routine and worker role.

It could be suggested that increasing awareness and knowledge of employment law (Chaplin and Davidson, 2014) might serve to improve the retention of people with dementia or MCI in the workplace, which would preserve both the potentially valuable contribution that may be made to society as well as maintain good outcomes in the wellbeing of the individual. It is undoubtedly true that, given the predicted increase in the prevalence of people with MCI or dementia in the workplace, efforts should continue to establish good practice guidelines (Braudy Harris, 2004); and the importance of longitudinal research to provide data for quality service provision and development cannot be underestimated (Braudy Harris and Keady, 2009).

Occupational therapy has a role within vocational rehabilitation (College of Occupational Therapists, 2010) in maintaining people with EOD in work-related activity, alleviating prescribed disengagement (Swaffer, 2015). For example, occupational therapists using the Model of Human Occupation (MOHO) standardised assessment tools such as the Assessment of Work Performance (AWP) 2010, Worker Role Interview (WRI) 1998 and Work Environment Impact Scale (WEIS) 1998 (Kielhofner, 2002) could help identify reasonable work adjustments for supporting the employee to remain in work, thus enhancing their role within the family and society. Sheltered employment supported by occupational therapists should offer a continuation of the worker role, whilst improving wellbeing and volition, and providing meaningful occupation, structure and routine. The existing literature has identified that neither employers nor employees have the ability to identify the manifestations of early dementia in the workplace. The Allied Health Professionals (AHP) Fit Note (2013) may be the tool that enables occupational therapists to influence employers and other stake holders in maintaining people with EOD in vocational occupation.

One of the limitations of this review is that the studies were predominantly from first-world countries where health care is freely available and research funding is embedded in the culture. This bias obscures the experiences of significant worldwide populations with, or at risk from, EOD, and cultures that may also value familial and carer or non-vocational roles. The limitations of qualitative research in respect of these papers are detailed in Table 2.

In summary, four themes emerged from the review. It was surprising that there was relatively little emphasis on disease progression. This may be a manifestation of the syndrome, as insight is frequently impaired. Far more important to the individual appeared to be the loss of established roles, in particular the worker role, and resultant consequences to the individual and family. The transition out of employment appeared to lead to resentment towards the employer, distress to the individual and family, depression and anxiety and loss of status within their social network.

Supported employment offered a continuation of the worker role, whilst improving wellbeing, volition and providing meaningful occupation, structure and routine. In theory and in an ideal situation the person with dementia or MCI could be offered an opportunity to discuss 'reasonable adjustments' (Department for Work and Pensions, 2015) within their current role. However, the evidence from the reviewed literature suggests that a barrier to this work adjustment under the *Equality Act 2010* is the delay in people obtaining a diagnosis (Chaplin & Davidson, 2014).

Conclusion

This systematic review aimed to identify and synthesise the best available qualitative evidence regarding the needs, experiences and perspectives of people with EOD or MCI who were either in employment or wished to gain employment. The opinions of carers and significant others were incorporated where possible.

Current services are structured around the needs of older people with dementia. In the UK, since 2012 people have no longer been required to retire at age 65 (Chaplin & Davidson, 2014). An ageing workforce may have a greater proportion of people with dementia or MCI.

Key findings

- Significance of the loss of the worker role.
- Benefits of supported employment.
- Lack of awareness of legislation in relation to work adjustments for people with cognitive impairment.

What the study has added

This review highlighted the need for research involving the employment of younger adults with dementia and the paucity of occupational therapy literature regarding this emerging public health issue.

Research ethics

This study did not require research ethics approval.

Declaration of conflicting interests

The authors confirm that there is no conflict of interest.

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Supplemental material

The Appendices are available online at <http://bjo.sagepub.com/content/by/supplemental-data>

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