

Dementia in the workplace: are employers supporting employees living with dementia?

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Objectives

As working lives extend and there is better recognition of early-onset dementias, employers need to consider dementia as a workplace concern. With suitable support, people living with dementia can continue employment – although this is not appropriate for all. The requirement for employers to support employees living with dementia has human rights and legal foundations. This paper considers whether employers consider dementia as a workplace concern; and the policies and/or practices available to support employees living with dementia. Thus, it develops understanding of whether employers are meeting their human rights/legislative obligations.

Method

A sequential mixed-methods approach was employed, with data collection undertaken in Scotland (United Kingdom). An online survey was sent to employers across Scotland, with 331 participating. 30 employer interviews were conducted, with the survey results informing the interview approach.

Results

The survey and interview data were analyzed separately and then combined and presented thematically. The themes identified were 1) Dementia as a workplace concern 2) Support for employees living with dementia and 3) Employer policy development and awareness raising. The findings demonstrate dementia awareness, but this knowledge is not applied to employment situations. There was little evidence suggesting that the rights of employees living with dementia are consistently upheld.

Conclusion

This research sends out strong messages about the rights and legal position of person living with dementia which cannot be ignored. The continuing potential of employees living with dementia and their legal rights are not consistently recognized. This highlights the need for robust training interventions for employers.

Key words: dementia, workplace, employers, human rights, employment legislation

Introduction

Dementia is a workplace concern. Between 2-10% of all cases of dementia start before the age of 65 (World Health Organization, 2012). If the OECD (Organisation for Economic Co-operation and Development) (2018) **international standard of working age** (15-64 years) is assumed, this means that in many countries a significant number of individuals may experience symptoms of dementia whilst in employment. **Moreover, extending working lives; better recognition of early-onset dementias and mild cognitive impairment; and earlier diagnosis are part of this evolving picture** (Phillipson, 2013; Robertson, Kirkpatrick, & McCulloch, 2015).

In the UK, the requirement to support employees living with dementia has legal and human rights foundations ([Author, 2018a]). Dementia falls under the protection of the Equality Act 2010 which provides a framework for persons with disabilities to request that their employer make ‘reasonable adjustments’ to support continued employment (Section 6 and Schedule 8) (HM Government, 2010). If one takes a fundamental human rights perspective (Cahill, 2018), recognizing dementia as a disability (Gove et al., 2017), the United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD), provides an enhanced opportunity for **persons living with dementia** to claim their right to work in an accessible environment (United Nations, 2006).¹ It emphasizes that persons with disabilities must be genuinely able to enjoy human rights on an equal basis with others, including in the workplace, and that reasonable accommodation must be provided to achieve this equality (Article 27).² **The CRPD makes it clear that the traditional approach to equality and non-discrimination can no longer apply if genuine equality of rights is to be universal. Differences in treatment of persons with disabilities, justified as being reasonable and objective, are not permissible** (United Nations, 2018).

Consequently, from a legal and human rights perspective, employers need to be prepared to support employees living with dementia and understand what this requires. However, dementia literacy is poor (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Low & Anstey, 2009) and employees living with dementia are not supported ([Author, 2018b]; Chaplin & Davidson, 2016; Thomson, Stanyon, Denning, Heron, & Griffiths 2019). Age Scotland (2016) and the Alzheimer's Society (2015) have developed practical employer guidance. Examples of reasonable adjustments are provided (e.g. noise reduction, 'buddy' systems and refresher training); the importance of communication and ongoing support reflecting dementia's progressive nature is emphasized; and the need for dignified workplace exits is highlighted. However, the extent to which employers are making these adaptations is unclear. Thus, the exploratory research conducted in Scotland (one of the four countries making up the United Kingdom (UK)) that is presented in this paper asks, 'whether employers are meeting their legal and human rights responsibilities and supporting employees living with dementia?'

Given the development of the rights-based dementia movement (Cahill, 2018) there is surprisingly little research on workplace experiences of dementia. The post-diagnostic support with employment offer is also under-researched (Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2018). This knowledge gap is symptomatic of the pervasive stereotyping and infantilizing views that undermine the capabilities of people living with dementia (e.g. to work) (Gove, Downs, Vernooij-Dassen, & Small, 2016; Milne, 2010; Nedlund & Nordh, 2015; Swaffer, 2014). There is a developing research base around the workplace experiences of people living with dementia – including research on employer experiences (Cox & Pardasani, 2013). This work suggests that symptoms of dementia are often first noticeable at work ([Author, 2015]; [Author, 2018b]; Chaplin & Davidson, 2016; Evans, 2019; Ohman, Nygard, & Borell, 2001). Although for many the impact of dementia is negative and

continued employment is inappropriate, there is evidence that, with suitable and timely support from employers and co-workers, people living with dementia can continue employment ([Author, 2018b]; Evans, 2019; Ohman et al., 2001; Stephen, 2015). However, many employers might not consider making adjustments to make the best use of, and retain, an employee's skills ([Author, 2018b]; Chaplin & Davidson, 2016). As performance deteriorates and tasks become more difficult, an employee living with dementia can be perceived as a 'poor worker' (Evans, 2019; Thomson et al., 2019).

While the requirement to support employees living with dementia has human rights and legal foundations, difficulties often arise in establishing that an individual with a mental illness/impaired cognitive abilities comes within the definition of disabled (Bell, 2015; James, 2004; Lockwood, Henderson, & Thornicroft, 2014). In the UK, while not having a medical diagnosis of dementia should not act as a barrier (Equality and Human Rights Commission, 2011), case-law suggests that those without a diagnosis of dementia could face significant obstacles in establishing themselves as a person with a disability ([Author, 2018a]). This could be exacerbated by the lengthy diagnosis process associated with early-onset dementia (Carter, Oyebode & Koopmans, 2018; Greenwood & Smith, 2016). Indeed many exit the labour market before receiving a diagnosis ([Author, 2018b]; Evans, 2019; Ohman et al., 2001; Thomson et al., 2019).

The workplace exits experienced by people living with dementia are often poor, and can negatively effect the social, emotional and financial wellbeing of persons living with dementia and their families ([Author, 2015]; [Author, 2018b]; Carter et al., 2018; Chaplin & Davidson, 2016; Evans, 2019; Greenwood & Smith, 2016; Harris & Keady, 2009; Ohman et al., 2001; Roach & Drummond, 2014; Roach, Drummond, & Keady, 2016; Thomson et al., 2019). Thus, it is imperative that employers treat workplace exits sensitively.

Given the complex and precarious position of **persons living with dementia**, this paper considers whether employers consider dementia as a workplace concern; and whether they currently have policies and/or practices in place, or are developing policies and/or practices, to support **employees living with dementia**. **In considering these issues, this paper develops understanding of whether the current UK human rights and legislative framework ensures that employees living with dementia are supported at work**. Not only does this paper seek to add to the small, but developing, evidence base on dementia in the workplace, it also adds to the knowledge base regarding (disability) rights-based approaches to dementia. **While the paper focuses on the Scotland/UK context, the arguments have international relevance.**

Methods

A sequential mixed-methods approach was employed (Teddlie & Yu, 2007). **An online employer survey (May-November 2017) and employer interviews (October 2017-January 2018) were conducted**. The survey results were used to inform the approach taken in the interviews.

Online employer survey

An online survey was sent to employers across Scotland. The survey was directed to human resources (HR) departments (or equivalents) and gathered information on policies in place that address dementia and linked issues such as employee health and wellbeing, disability, and age management. Questions were asked about understandings of Equality Act 2010 and CRPD duties, as well as awareness of dementia symptoms. The survey was predominantly composed of closed-questions, although in some parts, participants were able to provide additional written information if they wished to expand on their responses. Informed consent was taken via participants answering a compulsory question that they agreed to take part in the survey.

A (primarily) purposive sampling technique was used (Teddlie & Yu, 2007). The aim was to achieve a sample of 200 employers given the research's exploratory nature. In order to identify individual businesses and to ensure that a range of organizations were represented, local business databases and directories were mined. Sampling was focused on 15 of the 32 Scottish Local Authority areas to ensure a mix of employers from urban and rural areas were represented. There was also some less geographically targeted recruitment with business directories only available at the Scotland level used. As a result of this mining, over 4,500 employers were sent an email invitation to complete the survey. The survey link was also shared through Twitter to increase the sample size. The team closely reviewed survey responses to mitigate geographical bias.

There were 331 valid responses. Participants did not always answer every question, although there was a core of 165-170 employers completing the survey. Reflecting the research's exploratory nature, the survey's information section detailed that participants did not have to answer any questions that they did not want to, and that if they could not answer a question this was not a problem.

Sample characteristics are presented in Table 1. Cities, commuting suburbs, towns and rural and island locations were represented adequately to be able to make reasonable and scalable conclusions. The industries and sectors represented broadly reflected the employment structure of the Scottish economy (Scottish Government, 2017).

[Table 1]

Most workplaces were the sole premises of the business, although over a third were part of a larger organization. There was a good range of workplace sizes (e.g. micro enterprises, small and medium sized enterprises, and large employers). Over half (56.6%) had staff on non-standard contracts.

Employer interviews

Semi-structured interviews were conducted with 30 employers to explore in detail employer approaches to dementia and employer understandings of their legal and human rights duties. Questions addressed issues such as perceptions of how easy it would be to support an employee living with dementia, and whether employers thought that people living with dementia in the workplace fell within the protection of the Equality Act 2010. The interviews both expanded on the quantitative findings and allowed for issues raised in the survey to be explored in more depth.

In recruiting participants both snowball and purposive sampling techniques were applied (Teddlie & Yu, 2007). With regards to the snowballing approach, employers participating in the survey were asked to indicate if they were happy to take part in follow-up interviews. Most of the sample were recruited this way. While the research cannot claim to be representative, the research team also applied purposive sampling by drawing on existing links with employers to ensure that a range of sectors and organizational sizes were represented. Most participants had HR experience and included HR heads and managers, chief officers, business partners and advisers; as well as directors and owners (see Table 1).

The interviews were conducted face-to-face or via telephone. Interviews lasted 30 to 60 minutes. Most interviews were audio recorded with the participants' permission. Where an audio recording was not made, detailed notes were taken. Informed consent was taken.

Data analysis

The survey data were used to produce descriptive statistics. This analysis was conducted using SPSS Statistics 25. All interviews were transcribed, and thematic analysis was applied (Saunders, Lewis, & Thornhill, 2016), with the assistance of NVivo11 software, to identify key themes in the responses to each question. As exploratory research, the interview analysis

followed an inductive approach, with themes emerging from detailed question-by-question study of the transcripts. Several themes emerged which were synthesized into larger cross-cutting themes. While the data analysis for these two data sources was undertaken separately, the data from both research stages are presented together in the following sections as a further step of the data analysis involved reviewing key findings and themes across the datasets.

Research integrity

The research received ethical approval from [University].

Results

This section draws upon the survey and interviews and focuses attention on key cross-cutting themes. These data are presented in three sections that, together, address the question asked in this paper. First, the issues of whether employers believe that dementia is a workplace concern is considered. Second, how employers would, or are, supporting employees living with dementia is discussed. There is then consideration of employer policy development and awareness raising.

Dementia as a workplace concern

Both the survey and the interviews sought to understand whether dementia in the workplace was currently a concern for participants, or would be in the future. Most survey participants did not feel that employees living with dementia were a concern for their organization; and policies were not in place to support them, nor were they being developed (Table 2).

However, employer concern was not clear-cut. A large minority of 168 survey participants were aware of the need to support employees living with dementia (9.5% strongly agreed and 33.3% agreed) (Table 2). While, some interviewees felt that dementia in the workplace was a concern now, or would be in the future, it was not always clear whether they thought

dementia was a concern for their organization or for workplaces more generally. Thus, in general it can be surmised that dementia is not a concern for employers.

[Table 2]

Perhaps one reason for this lack of concern was that employers did not have experience of employees living with dementia (only 13% of interviewees and 7% of survey participants had experience). The interviews suggested that the age profile of some workplaces could also explain this lack of concern. Dementia was not on the 'radar' of those with a younger workforce. However, while prevalence does increase with age, dementia can affect younger people (Alzheimer's Disease International, 2015; World Health Organization, 2012). Therefore, employer awareness raising, or dedicated signposting to support, is required.

Dementia hasn't been thought about within this organization ... the bulk of our employees are early 20s to mid-30s (Interviewee, Professional, scientific and technical activities)

There was some employer awareness that, because of demographic change and extended working lives, dementia could be a future workplace concern.

It's not saying definitely 'no' forever, because in 10 years' time we might find that people are retiring that bit older in our business, and therefore we'll need to consider it further (Interviewee, Construction)

However, not all employers who were considering the implications of demographic change and extended working lives considered that this might mean a need to support employees living with dementia.

Despite these findings, employers demonstrated dementia literacy. Some interviewees conceded that, while they could not identify cases of employees living with dementia, this did not necessarily mean there was not, or had never been, someone living with dementia

employed in their workplace. This might suggest employer awareness that employees may not disclose a diagnosis and/or may have left work by the time they have received diagnosis ([Author, 2018b]; Evans, 2019; Ohman et al., 2001).

To my knowledge there's not been a live example of dealing with dementia in the workplace. Though that doesn't mean that of [our] employees that we don't have people who have dementia (Interviewee, Education)

There was understanding of the symptoms associated with dementia and the progressive nature of the condition. 79.6% of survey participants self-rated themselves as having 'good' or 'very good' awareness of symptoms. Most survey participants identified common dementia symptoms, apart from 'issues with visual perception' (Table 3).

[Table 3]

The interviews revealed that some of this understanding was gleaned from personal experiences, reflecting previous research findings (Cox & Pardasani, 2013).

I've experienced it personally with my [family member], and [family member] can remember what happened 50 years ago, but [family member] can't remember what [family member] had for lunch, for example (Interviewee, Public administration and defence/compulsory social security)

Amongst survey participants, a significant minority were aware that their organization had engaged with dementia awareness training/activities (27.2% of those answering the question) (Table 4) although it is not known whether these focused-on dementia in the workplace.

[Table 4]

Health and social care providers had an understanding, although this did not translate to framing dementia as a workplace concern.

[Dementia in the workplace is] certainly not something that's been on our agenda, although I'd like to think we've all got a good grasp of the subject... (Interviewee, Human health and social work activities)

In sum, while dementia is not framed as a workplace concern, **the participants** demonstrated dementia literacy. Knowledge is gleaned through personal and professional experiences but may not be applied to the workplace.

Supporting employees living with dementia

Data were gathered to gauge employer understanding of how to support **employees living with dementia**. Participants detailed how they thought that dementia might affect an employee's ability to do their job. Interviewees suggested that dementia would affect an employee's attention to detail and accuracy; cognitive and communication skills; and abilities to cope with an unstructured routine and pressure. **For some, difficulties in using technology were a concern that could compromise a person's ability to remain in work.** While highlighting dementia literacy, these views indicate stereotypical assumptions about the abilities of **people living with dementia**.

In terms of the extent to which dementia might compromise an individual's ability to remain in work, the context of the job role was important. **One interviewee was concerned that dementia might invalidate an individual's professional registration, making continued employment impossible.**

There are certain things like registration with a registered body, and if somebody isn't able to register with that registered body, then there's a chance that they wouldn't be able to be employed legally (Interviewee, Human health and social work activities)

Other interviewees had reservations about the abilities of an employee living with dementia to manage customer facing roles.

A large majority of roles here are **front-facing**, the biggest critic we have are the people who come here...goodness knows what they would be like with somebody who had an illness that maybe made them a bit slower, or made them forget something (Interviewee, Accommodation and food service activities)

However, survey participants and interviewees were relatively positive about **supporting employees living with dementia**. Over 70% of 166 survey participants reported positive attitudes towards reasonable adjustments being offered (50.6% strongly agreed and 34.9% agreed that employers should make 'reasonable adjustments' for **employees living with dementia**) (Table 5).

[Table 5]

Interviewees discussed adjustments. Although most had no direct experience of **employees living with dementia**, they did have experience of other health conditions which were seen to be either similarly progressive or had similar cognitive and memory impairments. They drew on experiences of supporting these employees. The most frequently mentioned adjustments were changing roles/responsibilities, providing additional support and supervision, flexible working, re-deployment, and providing IT support. Interviewees who had direct experience of dementia in the workplace discussed how such employees were supported e.g. by supportive and accepting colleagues.

The willingness of employers to support **employees living with dementia** could be attributed to recognition of dementia as a disability. Over half (53.6%) of 168 survey participants responding to the question saw dementia as a disability, although a third (34.6%) did not know if this was the case. A majority (60.1%) of these 168 survey participants considered **employees living with dementia** to be protected under the Equality Act 2010; however, 37.5% did not know whether this was the case. However, interviewees were hesitant about whether dementia fell within the protection of this Act. When asked whether

they would see dementia as a disability, there was more certainty that it was a disability which fell within the protection of the Equality Act 2010, as well as the CRPD.

We would certainly class dementia as a disability, because it has a long-term impact, as well as day-to-day (Interviewee, Agriculture, forestry and fishing)

Not having a medical diagnosis of dementia should not act as a barrier to coming within the protection of the legislation (Equality and Human Rights Commission, 2011). The majority (84%) of 162 survey participants indeed 'strongly agreed' or 'agreed' that employers should support an employee if they showed symptoms of dementia but had not yet received a diagnosis. The interviewees detailed that, where an employee had not (yet) received a diagnosis or did not disclose one, they had systems in place to support them, including: monthly supervisory meetings, one-to-one supervisions, and dedicated health and well-being HR advisors, who had a remit to coach managers and develop their skills regarding supporting employee well-being and conducting difficult conversations with employees (regardless of the existence of health issues).

The possibility of employees living with dementia being dismissed through a loss of capability was recognized by some interviewees. Some smaller organizations either had no or only basic policies in place. They would therefore follow a generic capability assessment process instead. Some larger employers mentioned these processes, although the existence of health issues would not necessarily prevent performance procedures from being followed. Nonetheless, some employers did recognize that looking at reporting procedures, and asking the right questions, was vital.

Many of the interviewees felt that they had an open culture and close-knit teams, which meant that employees would be confident about disclosing a diagnosis.

Here, there is quite an open culture ...it's maybe an environment where somebody with dementia would be able to come and say look I'm struggling with that, but I'm still managing that (Interviewee, Human health and social work activities)

Some interviewees cited that changes in an individual's performance would be treated sensitively, and that diagnosis alone would not be the catalyst for reasonable adjustments being made. One interviewee felt that managers also could identify any changes.

We would instantly know, because our managers are trained, and spoken to about picking up any differences, and we work in a very, very caring organization, which looks after its employees...a lot of organizations, go 'oh, performance' and out. We absolutely take care of our employees...if there's any change we would always, always look into it (Interviewee, Manufacturing)

However, rather than employers being expected to diagnose dementia, the preferred approach would be fostering a working environment where those who have received a diagnosis feel able to disclose this, and those who may be experiencing difficulties but do not have a diagnosis, can speak to their employer (Age Scotland, 2016; Alzheimer's Society, 2015).

Despite narratives of support, there were misgivings from sizable numbers of survey participants when investment in equipment, reductions or alterations in hours, increased support from colleagues, training, and other intrusions into work arrangements were suggested (Table 5). The interviews confirmed many of these sentiments. The financial implications of providing additional support, a focus on the 'bottom-line', and health and safety implications all would limit the adjustments made.

One thing we could do was add higher levels of supervision, where that becomes an issue is when it's not cost effective to do...But, we would certainly add levels of support like that to start with (Interviewee, Financial and insurance activities)

Our client group are very vulnerable...So, if we put a vulnerable person in a vulnerable situation to help a vulnerable person, society might not thank us for that (Interviewee, Human health and social work activities)

Employer policy development and awareness raising

The research considered possible future policy developments. While few survey participants indicated that policies were in place to support **employees living with dementia**, nor were they being developed (Table 3), this did not mean that there were no policies to support **employees living with dementia**. Twenty interviewees stated that their organization had other, all-encompassing policies which would support someone **living** with dementia. Employers generally did not think dementia-specific policies were required, as they might lead to a proliferation of diluted policies.

The challenge is for having a specific policy in place for a particular condition, is that there are so many other conditions...the more you have the more overwhelmed people become and less attention they pay (Interviewee, Education)

Most believed their general health and well-being policies were broad enough, and needed to be, to accommodate many kinds of conditions including dementia.

We try as far as possible, to keep things broad and fair, and not hone in on anything...I've managed to cope with a fair number of different illnesses as they are (Interviewee, Financial and insurance activities)

However, the authors of this paper would highlight that, because of the limited experience of dementia in the workplace, whether these general policies are appropriate in practice is not clear; nevertheless, there was evidence that policies would be adapted if necessary.

There were also some instances where a 'reactive' rather than 'proactive' approach was indicated. In one small business, taking a 'common sense' approach was cited. This

raises concerns that, if the employer was not dementia literate, then **employees living with dementia** might not be adequately supported.

While employers generally did not think a dementia-specific policy was required, they did believe that they would benefit from guidance. Some had already taken part in dementia awareness training/activities. Several interviewees mentioned interest in managing an ageing workforce and saw dementia awareness fitting into this. Others saw it fitting into a wider mental health awareness.

Discussion and Conclusions

Dementia is increasingly recognized as a workplace concern (Age Scotland, 2016; Alzheimer's Society, 2015; ([Author, 2018a]; [Author, 2018b])). The requirement to support **employees living with dementia** has, amongst other things, human rights and legal foundations (([Author, 2018a])). Employers need to be prepared to support **employees living with dementia** and understand at a practical level what this entails. Drawing upon mixed-methods research, this paper adds to the small research base on dementia and the workplace, by presenting one of the first empirical studies to consider whether employers understand, and are meeting, their human rights and legal obligations.

Only a small number of participants had experience of employees living with dementia, which is perhaps an indication that many people permanently exit the labour market before receiving a diagnosis ([Author, 2018b]). A (poor) workplace exit has negative financial, social and emotional implications for persons living with dementia and their families ([Author, 2018b]; Carter et al., 2018; Greenwood & Smith, 2016; Harris & Keady, 2009; Ohman et al., 2001; Roach & Drummond, 2014; Roach et al., 2016; Thomson et al., 2019). Therefore, the importance of early diagnosis, and thus the possibility 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 (Age Scotland, 2016; Alzheimer's Society, 2015).

Employers may have a high degree of knowledge of the symptoms and issues associated with living with dementia, gleaned from professional and personal experiences (Cox & Pardasani, 2013). However, such knowledge appears not to have been applied to employment situations. Dementia is not framed as something that could affect colleagues and stereotyping and infantilizing attitudes are present ([Author, 2018b]). Employers might not make adjustments to make the best use of, and retain, the skills of their employees ([Author, 2018b]; Chaplin & Davidson, 2016). Thus, the real continuing potential of employees living with dementia is not generally recognized. As previous research identifies, too many employees living with dementia are exited from, or exit the workplace, although adaptations would allow many to continue working ([Author, 2018b]; Evans, 2019). Employers have experience of supporting workers with other health conditions and existing policies could be adapted for persons living with dementia – with the caveat that the appropriateness of these pre-existing policies has yet to be put to the test. This suggests that further employer guidance and awareness raising regarding reasonable adjustment and dementia is needed. This activity would need to emphasise the need for case-by-case basis support given the individualized nature of the condition (Alzheimer's Society, 2015).

The requirement to support employees living with dementia in the workplace has legal, equality and human rights foundations ([Author, 2018a]), and the participants appeared to recognize in principle that dementia is a disability falling within the scope of the Equality Act 2010 and CRPD. However, their knowledge of the protection potentially provided under such legislation, and therefore their legal responsibilities, is low. The reluctance of some employers to put in place adjustments that incur substantial costs may also limit the ability of a person living with dementia to remain in work. Robust training

interventions are required to ensure that employers are meeting their legal, equality and human rights obligations.

There are research limitations to be acknowledged. The sample size was small and located in one part of the UK. The response rate was low – although it should be noted that the aim of this exploratory research was to achieve a sample of 200 employers. This could reflect employers not acknowledging that dementia is a workplace issue, thus perceiving the research to be irrelevant. It can be assumed that employers with a personal or professional interest in dementia were more likely to have participated and thus be most knowledgeable. The sample was generated via business lists that often only provided generic email addresses; invitations to the email addresses of individuals could have generated a greater response. Survey participants were not required to answer every question – again given the exploratory nature of the research - with a core of 165-170 employers completing the survey. This could reflect lack of dementia literacy for example.

Scaling up, transferring the results and increasing the scope requires supplementary examination. For example, the role that employers do/could play in the multi-disciplinary teams of professionals supporting employees living with dementia needs to be considered. Future research could also address the perspectives of colleagues and their role in supporting employees living with dementia. Research indicates that colleagues may experience increased workload and emotional strain ([Author, 2018b]) which needs to be accounted for.

Acknowledging these limitations, this research still sends out strong messages about the rights and legal position of persons living with dementia which cannot be ignored. Many of the employers did not consider dementia to be a workplace concern, although it would be interesting to see if taking part in the research had subsequently changed their view. The findings indicate basic dementia awareness, but this knowledge is not applied to employment situations. The continuing potential of employees living with dementia is not recognized, and

there is reluctance to put in place costly adjustments. There was little evidence that the rights of employees living with dementia are consistently upheld. This highlights the need for robust training interventions for employers.

Notes

¹ It should be noted that there are slight differences in the approaches taken in the Equality Act 2010 and CRPD (see [Author, 2018a] for an overview).

² CRPD rights cannot be enforced through UK national courts and tribunals. However, the UK has an obligation under international law to comply with it and devolved Scottish legislation and Scottish Government policy risks being blocked by the UK Government for incompatibility with the CRPD (Sections 35 and 58 Scotland Act 1998). Moreover, the increasing influence and recognition of the CRPD within Scotland can be evidenced in the Scottish Government's 2016 CRPD delivery plan (Scottish Government, 2016) and its recent consultation on reform of the Adults with Incapacity (Scotland) Act 2000 (Scottish Government, 2018). However, internationally CRPD is not explicitly incorporated in national dementia plans and strategies (Splain et al., 2017).

References

Age Scotland. (2016). *Dementia and the Workplace. A Guide for Employers in Scotland*. Edinburgh: Age Scotland.

Alzheimer's Disease International. (2015). *World Alzheimer Report 2015. The Global Impact of Dementia. An Analysis of Prevalence, Incidence, Cost and Trends*. London: Alzheimer's Disease International.

Alzheimer's Society. (2015). *Creating a Dementia-Friendly Workplace. A Practical Guide for Employers*. London: Alzheimer's Society.

[Author, 2015]

[Author, 2018a]

[Author, 2018b]

Bell, M. (2015). Mental health at work and the duty to make reasonable adjustments. *Industrial Law Journal*, 44(2), 194–221.

- Cahill, S. (2018). *Dementia and Human Rights*. London: Policy Press.
- Cahill, S., Pierce, M., Werner, P., Darley, A. & Bobersky, A. (2015). A systematic review of the public's knowledge and understanding of Alzheimer's Disease and dementia. *Alzheimer Disease and Associated Disorders*, 29(3), 255–275.
- Carter, J. E., Oyebode, J. R., & Koopmans, R. T. C. M. (2018). Young-onset dementia and the need for specialist care: A national and international perspective. *Aging & Mental Health*, 22(4), 468-473.
- Chaplin, R., & Davidson, I. (2016). What are the experiences of people with dementia in employment? *Dementia*, 15(2), 147–161.
- 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.
- Equality and Human Rights Commission. (2011). *Equality Act 2010: Employment Statutory Code of Practice*. London: The Stationery Office.
- Evans, D. (2019). An exploration of the impact of younger-onset dementia on employment. *Dementia*. 18(1), 262-281.
- Gove, D., Downs, M., Vernooij-Dassen, M. J. F. J., & Small, N. (2016). Stigma and GPs' perceptions of dementia. *Aging & Mental Health*, 20(4), 391-400.
- Gove, D., Andrews, J., Capstick, A., Geoghegan, C., Georges, J., Libert, S., McGettrick, G., Rochford-Brennan, H., Rohra, H., Vehmas, S. & Williamson, T. (2017). *Dementia as a Disability: Implications for Ethics, Policy and Practice. Ethical Discussion Paper*. Luxembourg: Alzheimer Europe.
- Greenwood, N., & Smith, R. (2016). The experiences of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas*(October 2016), 92, 102–109.
- Harris, P. B., & Keady, J. (2009). *Selfhood in younger onset dementia: Transitions and*

- testimonies. *Aging & Mental Health*, 13(3), 437–44.
- HM Government (2010). *Equality Act*. London: HM Government.
- James, G. (2004). An unquiet mind in the workplace: Mental illness and the Disability Discrimination Act 1995. *Legal Studies*, 24(4), 516–539.
- Lockwood, G., Henderson, C., & Thornicroft, G. (2014). Mental health disability discrimination: Law, policy and practice. *International Journal of Discrimination and the Law*, 14(3), 168–182.
- Low, L.-F. & Anstey, K. J. (2009). Dementia literacy: Recognition and beliefs on dementia of the Australian public. *Alzheimer's and Dementia*, 5(1): 43–49.
- Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F., & Goodman, C. (2018). Age-appropriate services for people diagnosed with young onset dementia (YOD): A systematic review. *Aging & Mental Health*, 22(8), 933-941.
- Milne, A. (2010). The 'D' word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health*, 19(3), 227–233.
- Nedlund, A.-C., & Nordh, J. (2015). Crafting citizen(ship) for people with dementia: How policy narratives at national level in Sweden informed politics of time from 1975 to 2013. *Journal of Aging Studies*, 34(August 2015), 123–133.
- OECD. (2018). *Working Age Population*. Retrieved from <https://data.oecd.org/pop/working-age-population.htm>
- Ohman, A., Nygard, L., & Borell, L. (2001). The vocational situation in cases of memory deficits or younger-onset dementia. *Scandinavian Journal of Caring Sciences*, 15(1), 34–43.
- Phillipson, C. (2013). Reconstructing work and retirement: labour market trends and policy issues. In J. Field, R. J. Burke, & C. L. Cooper (Eds.), *The SAGE Handbook of Aging, Work and Society* (pp. 445–460). London: SAGE Publications Ltd.

- 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(10), 889–95.
- Roach, P., Drummond, N., & Keady, J. (2016). 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies*, 36(January 2016), 26–32.
- Robertson, D., Kirkpatrick, P., & McCulloch, S. (2015). Sustaining adults with dementia or mild cognitive impairment in employment: A systematic review protocol of qualitative evidence. *The JBI Database of Systematic Reviews and Implementation Reports*, 13(3), 124-136.
- Saunders, M., Lewis, P., & Thornhill, A. (2016). *Research Methods for Business Students* (Seventh ed.). Harlow: Pearson Education Limited.
- Scottish Government. (2016). *A Fairer Scotland For Disabled People: Our Delivery Plan to 2021 for the United Nations Convention on the Rights of Persons with Disabilities*. Retrieved from www.gov.scot/Resource/0051/00510948.pdf
- Scottish Government. (2017). *Businesses in Scotland 2017*. Retrieved from, www.gov.scot/Topics/Statistics/Browse/Business/Corporate/alltables
- Scottish Government. (2018). *Consultation Paper: Adults with Incapacity (Scotland) Act 2000 Proposals for Reform*. January. Edinburgh. Retrieved from www.gov.scot/Publications/2018/01/4350/downloads#res530800
- Splain, M., Wortmann, M., Seitzer, M., Gordon, K., Kerr, S., & Lynch, C. (2017). *National Dementia Action Plans. Examples for Inspiration*. London: Alzheimer's Disease International.
- Stephen, H. (2015). Research is identifying how employers can help people with dementia stay in work for longer. *Living with Dementia Magazine*, July 2015.

- Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, 13(6), 709–716.
- Teddlie, C., & Yu, F. (2007). Mixed methods sampling: A typology with examples. *Journal of Mixed Methods Research*, 1(1), 77-100.
- Thomson, L., Stanyon, M., Denning, T., Heron, R., & Griffiths, A. (2019). Managing employees with dementia: A systematic review. *Occupational Medicine*, 69(2), 89-98.
- United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. A/RES/61/106, 13 December. New York: United Nations.
- United Nations. (2018). *General Comments No.6 (2018) on Equality and Non-Discrimination*. Geneva: United Nations.
- van Gennip, I. E., Pasman, H. R. W., Oosterveld-Vlug, M. G., Willems, D. L., & Onwuteaka-Philipsen, B. D. (2016). How dementia affects personal dignity: A qualitative study on the perspective of individuals with mild to moderate dementia. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 71(3), 491–501.
- World Health Organization. (2012). *Dementia: A Public Health Priority*. Geneva: World Health Organization.

Tables

Table 1: Online employer survey and employer interview sample characteristics

| Main Activity of the workplace | Online employer survey | | Employer interviews | |
|---|-------------------------------|----------|----------------------------|----------|
| | Number | % | Number | % |
| Agriculture, forestry and fishing | 3 | 1.1 | 1 | 3.3 |
| Manufacturing | 21 | 7.5 | 2 | 6.7 |
| Electricity, gas, steam and air conditioning supply | 1 | 0.4 | - | - |
| Water supply, sewerage, waste management and remediation activities | 2 | 0.7 | - | - |
| Construction | 17 | 6.1 | 1 | 3.3 |
| Wholesale and retail trade; repair of motor vehicles and motorcycles | 3 | 1.1 | 1 | 3.3 |
| Transportation and storage | 5 | 1.8 | - | - |
| Accommodation and food service activities | 7 | 2.5 | 1 | 3.3 |
| Information and communication | 13 | 4.6 | - | - |
| Financial and insurance activities | 9 | 3.2 | 3 | 10.0 |
| Professional, scientific and technical activities | 23 | 8.2 | 3 | 10.0 |
| Administrative and support service activities | 23 | 8.2 | 1 | 3.3 |
| Other private services | 43 | 15.4 | - | - |
| Public administration and defence; compulsory social security | 34 | 12.1 | 5 | 16.7 |
| Education | 19 | 6.8 | 2 | 6.7 |
| Human health and social work activities | 36 | 12.9 | 10 | 33.3 |
| Other (mostly third sector organisations) | 21 | 7.5 | - | - |
| Total | 205 | 100.0 | 30 | 100.0 |
| Workplace type | | | | |
| Public sector organisation (includes local authorities, councils, government departments, civil service, state schools) | 44 | 18.7 | 9 | 30.0 |

| | | | | |
|--|-----|-------|----|-------|
| Private sector organisation (includes partnerships, private limited companies, family-owned businesses, self-employed) | 132 | 56.2 | 13 | 43.3 |
| Third sector organisation (includes charities and not for profit organisations) | 55 | 23.4 | 8 | 26.7 |
| Social enterprise (includes profit and not for profit) | 4 | 1.7 | - | - |
| Total | 235 | 100.0 | 30 | 100.0 |
| Number of employees | | | | |
| Less than 10 | 53 | 26.2 | 1 | 3.3 |
| 10-49 | 59 | 29.2 | 5 | 16.7 |
| 50-249 | 41 | 20.3 | 9 | 30.0 |
| 250-999 | 16 | 7.9 | 3 | 10.0 |
| 1,000 or over | 33 | 16.3 | 11 | 36.7 |
| Total | 202 | 100.0 | 30 | 100.0 |

Table 2: Is dementia a workplace concern (%) (results from the employer survey)?

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Total % | Number responding |
|---|-----------------------|--------------|-----------------------------------|-----------------|--------------------------|----------------|--------------------------|
| Employees with dementia are not considered to be a concern for this organisation | 16 | 29 | 30.2 | 19.5 | 5.3 | 100 | 169 |
| This organisation is increasingly aware of the need to do more to support employees that have dementia | 9.5 | 33.3 | 34.5 | 16.1 | 6.5 | 100 | 168 |
| This organisation already has a policy in place to support employees with dementia | 2.4 | 6.5 | 23.7 | 48.5 | 18.9 | 100 | 169 |
| This organisation is currently reviewing its approach with a view to developing a policy to support employees with dementia | 3 | 12.6 | 38.9 | 30.5 | 15 | 100 | 167 |

Table 3: Level of employer agreement that dementia can cause...(%) (n=166)

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Don't know |
|------------------------------------|-----------------------|--------------|-----------------------------------|-----------------|--------------------------|-------------------|
| Memory loss | 51.2 | 46.4 | 1.8 | 0 | 0 | 0.6 |
| Difficulties in effective planning | 44 | 50 | 3.6 | 0 | 0 | 2.4 |
| Communication problems | 42.8 | 50 | 4.8 | 1.2 | 0 | 1.2 |
| Confusion over times and places | 49.4 | 47.6 | 3 | 0 | 0 | 0 |
| Issues with visual perception | 27.7 | 36.1 | 21.1 | 4.2 | 0.6 | 10.2 |
| Mood changes | 46.4 | 46.4 | 6 | 0.6 | 0 | 0.6 |

Table 4: Are you aware if your organisation has ever undertaken any dementia awareness raising activities with staff?

| | Number | % | Of those answering (%) |
|----------------------------|---------------|----------|-------------------------------|
| Valid Yes | 50 | 15.1 | 27.2 |
| No | 112 | 33.8 | 60.9 |
| Don't Know | 22 | 6.6 | 12.0 |
| Total | 184 | 55.6 | 100.0 |
| Missing | 147 | 44.4 | |
| Total (full survey) | 331 | 100.0 | |

Table 5: To what extent do you agree or disagree with the following statements (%)

| | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree | Don't know | Number responding |
|--|-----------------------|--------------|-----------------------------------|-----------------|--------------------------|-------------------|--------------------------|
| Employers should make 'reasonable adjustments' for employees with dementia | 50.6 | 34.9 | 9.6 | 1.8 | 1.2 | 1.8 | 166 |
| Employees with dementia should be offered a change in hours/flexible working | 27.5 | 47.5 | 22.5 | 1.9 | 0.6 | 0 | 160 |
| Employees with dementia should be offered a change in job to take on lighter or less demanding work | 25 | 46.9 | 26.3 | 1.9 | 0 | 0 | 160 |
| Employees with dementia should be offered a reduction in workload | 23 | 44.7 | 29.2 | 3.1 | 0 | 0 | 161 |
| Employees with dementia should be offered increased IT support/specialist IT equipment to support them with their work | 25.8 | 43.4 | 27 | 3.8 | 0 | 0 | 159 |
| Employees with dementia should be offered extra support from work colleagues | 20.8 | 48.4 | 25.8 | 5 | 0 | 0 | 159 |
| Employees with dementia should be offered re-training to be able to do another job | 17.5 | 45.6 | 30 | 6.3 | 0.6 | 0 | 160 |
| Employees with dementia should be offered time off to attend medical appointments | 44.7 | 39.8 | 13.7 | 1.2 | 0.6 | 0 | 161 |
| Employees with dementia should be offered counselling or mentoring support | 30 | 50 | 17.5 | 2.5 | 0 | 0 | 160 |