Dementia education and training for caregivers supporting older people with intellectual disability: a scoping review of the literature

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1.0 Introduction

Dementia is a chronic and progressive disease which effects cognitive functioning, behaviour, mood and physical health in older adults (Aalten, de Vugt, Jaspers, Jolles, & Verhey, 2005). The consequence of decline often places considerable strain on care givers and can have a significant effect on the quality of life for people with dementia and those who provide care and support (Terum et al., 2017; Williams, Moghaddam, Ramsden, & De Boos, 2019). This is particularly evident in people who have intellectual disability; as progression of the disease increases, the caregivers' ability to support an individual to 'live in place' becomes more difficult and can lead to difficulties in care delivery (Courtenay, Jokinen, & Strydom, 2010; Herron & Priest, 2013).

Increased life expectancy and improvements in health and social care have resulted in generic services to respond more effectively to meet the needs of people with intellectual disability (Cleary & Doody, 2017). Although, health inequalities and disparities continue within this population group (Heslop & Hoghton, 2018). Consequently, more people with intellectual disability are living into later life, with an increased risk of developing age related conditions, such as dementia (Strydom, Chan, King, Hassiotis, & Livingston, 2013). The representative challenge this creates increases the reliance on caregivers to provide specialist care and support to people in older adulthood with dementia (Ryan, Taggart, Truesdale-Kennedy, & Slevin, 2014; Wilkinson, Kerr, & Cunningham, 2005).

The UK Governments commitment to dementia care is outlined in the national strategy and NHS long term plan (Department of Health, 2015; National Health Service, 2019). It pledges to improve dementia services to support people with intellectual disability. National clinical guidance underpins this commitment by recognising the need for specialist services to improve clinical expertise in the assessment, diagnosis, and post diagnostic interventions for people with dementia (National Institute for Health and Care Excellence, 2018a, 2018b; The British Psychological Society, 2015).

Despite the growing need to improve delivery of dementia care there has been limited evidence of post diagnostic education for caregivers of people with intellectual disability~~., evidence of post diagnostic education for caregivers has been limited.~~ ((MacDonald & Summers, 2020)~~ MacDonald & Summers, (2020)~~ explored post diagnostic intervention for people with intellectual disability and~~,~~ underlinedining ~~the disparity and a~~ the~~ ~~ dearth of research in this area.

There is evidence to suggest that more ~~E~~effective assessments and information to help ~~early~~ caregivers to better detect the signs and symptoms of dementia to inform early diagnosis are essential~~. for improving post diagnostic intervention to improve the lives of people with dementia~~ (Elliott-King et al., 2016; Zeilinger, Stiehl, & Weber, 2013). It is important to recognise the difficulty in diagnosing dementia in people with intellectual disability. Research has identified initial signs can be more difficult to recognise as initial signs include changes to personality and behaviour rather than memory loss (McKenzie, Metcalfe, & Murray, 2018). In addition, c~~C~~aregivers can have ~~can often experience~~ difficulties identifying the early signs of cognitive decline, to allow for timely assessment and diagnosis (Dodd, 2014; Wilkinson et al., 2005). Subsequently, post diagnostic treatment and social support are often delayed (Iacono, Bigby, Carling-Jenkins, & Torr, 2014).

A~~a~~ lack of knowledge and awareness of dementia amongst caregivers is a key factor in meeting the age related needs of people with intellectual disability (Iacono et al., 2014). Therefore, it is important to provide caregivers with information about dementia to improve knowledge to be better prepared to manage the effect the disease can have on individuals lives and foster more positive attitudes in those who provide care. There~~herefore, there~~ is a pressing need for age related dementia education awareness to improve understanding in caregivers of older people with intellectual disability (Cleary & Doody, 2017). A lack of clarity in post diagnostic care often creates uncertainty amongst caregivers which can impact on future care provision.

1.1 Aim & Objective

This scoping review aims to investigate the evidence of dementia related education programmes and training needs of caregivers of older people with intellectual disability. Dementia awareness training could be characterised as an intervention to increase the awareness of family and formal caregivers caring for people with intellectual disability. The main objective of this review is to understand the impact of dementia education on caregivers' knowledge and confidence towards the delivery of older adult care. The secondary objective is to identify areas of training development ~~need~~ and interventions which support caregivers to effectively recognise early signs of dementia.

2.0 Method

A scoping review has been selected due to the methodology allowing for an synopsis of diverse and multiple forms of emerging evidence (Munn et al., 2018). This includes synthesising different research methodologies, for example, qualitative and quantitative studies, or primary research, reviews, and non-empirical evidence (Peterson, Pearce, Ferguson, & Langford, 2017). Scoping reviews differ from systematic reviews as quality appraisal of included studies is generally not completed (Munn et al., 2018).

In their seminal paper Arksey & O'Malley (2005) ~~(Arksey & O'Malley, 2005)~~ were early pioneers in illustrating a six stage framework for scoping reviews. Building on this work, the Joanna Briggs Institute extended the framework to provide a wider context to explore the breadth and nature of heterogeneous literature to identify gaps in the existing available evidence to inform future research, policy and clinical practice (Peters et al., 2015). Peters et al (2015) argued that scoping reviews are more effective when research questions are exploratory which identify and map available evidence. Therefore, this scoping review aims to answer two ~~one main~~ questions: 'What is the evidence of dementia education programmes meeting the training needs of caregivers of older adults with intellectual disability' and 'identify areas of development to focus future interventions to support caregivers to more effectively identify early signs of cognitive decline'.

An inclusion and exclusion criteria (table 1) was used to establish a search strategy with overall agreement reached from DA, SLJ and SJ.

Table 1 – inclusion exclusion

Inclusion criteria	Exclusion Criteria
Population **Caregivers/families of people~~Participants~~ with Intellectual disability.** **Diagnosis of dementia or Alzheimer's disease ~~or suspected cognitive impairment~~.**	People without a diagnosis of Intellectual disability. No evidence of diagnosis of dementia ~~or cognitive impairment.~~
Intervention **Dementia or older adult education for families, and carers.** **Delivered by professional groups** **Training and education for care givers to support post diagnostic interventions.** **Focus groups examining ageing and dementia training needs of care givers.**	No evidence of direct dementia or age related training or education for carers. No focus on improving carer confidence in delivery of care.
Study Characteristics **Articles written in English.** **All qualitative & quantitative studies.** **Evidence of evaluation.** **Publication between years of 2005 to 2022.**	Research paper not available in English. Conference and review articles. No outcome evaluation.

2.1 Search Strategy

A comprehensive literature database search was completed by DA in November 2022 using: CINHAL, PsycINFO, MEDLINE, ScienceDirect and google scholar. The search strategy was agreed by the author and co-investigators based on key words. The search terms used explored the topic of intellectual disability and relevant dementia education for caregivers. A scoping exercise of key words was

undertaken to enhance the search criteria. Boolean operator terms “AND” “OR” were used with terms intellectual disability or mental retardation or learning disability or developmental disability or learning disabilities, dementia or Alzheimer’s disease, and education or training or learning and carer or care giver or family or supporter. Reference lists from study papers were used to include articles not identified through the literature search and reviewed for relevance.

Table 2 – search strings

Table 2 Search process

Search	Terms used	Field
S1	intellectual disabilit* OR mental retardation OR learning disabilit* OR developmental disabilit* OR Down’s syndrome	Title OR Abstract
S2	AND Dementia OR Alzheimer’s disease	Title OR Abstract
S3	education OR training OR learning OR post diagnostic OR training needs	Title OR Abstract
S4	carer OR famil* OR caregiver OR supporter	Abstract

3.0 Results

3.1 Included Studies

The methods for this scoping review followed the guidelines for Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA) (figure 1) (Tricco et al., 2018). Approximately 720 abstracts/titles were identified and considered against the inclusion and exclusion criteria (table 1). Following duplicate being removed, 691 articles remained for further stages of analysis. The process for screening titles and abstracts excluded 631 papers as they did not meet the inclusion criteria. Following review of the titles and abstracts 60 papers were included for full text analysis. Following full text analysis 49 papers were excluded. The papers were excluded if the intervention did not provide any direct carer education or training (n=34) or outcome evaluation (n=3). In addition, papers were excluded which did not fit any of the concepts within the eligibility criteria such as, no focus on improving carer confidence in providing care (n=5). Papers were also excluded if they were book review, conference notes or review articles (n=7). The remaining 11 studies were reviewed independently by DA, SLJ and SJ for inclusion in the final analysis.

3.2 Study Characteristics

Table 3 provides a summary of studies included. The 11 papers included in this scoping review were from Ireland (1), United States of America (3), Australia (2), Canada (1), and from the United Kingdom (4). All papers were written in English and published between 2007-2023. Three of the

studies used mixed methods, one used a quantitative method, one paper used a Delphi group method, one study was a clinical audit and five studies used a qualitative design.

3.3 Overview of included studies

Table 3.

Author - Year	Design	Focus	Sample	Summary of key findings
Bayley, Amoako, & El-Tahir. (2017)	Clinical Audit	Review of specialist intellectual disability memory service.	N=20 care staff. N=4 family	The specialist intellectual disability memory service demonstrated overall compliance with national guidelines and best practice recommendations. Positive feedback and improvements to knowledge evident from families and carers who attended bespoke dementia training programme.
Chapman, Lacey & Jervis (2018)	Qualitative study	Evaluation of dementia education	N=8 clinical staff	The evaluation identified the effectiveness of dementia education for families and carers. Top tips information provided increased awareness, dementia knowledge and supported strategies in providing proactive support and reduce crisis situations. .
Dekker, Wissing, Ulgiati, Bijl, van Gool, Groen, Grootendorst, van der Wal, Hobbelen, De Deyn, Waninge. (2021)	Qualitative Study Focus group	To understand the information and training needs of dementia in people with severe/profound intellectual disability.	N=49 A mix of multi-disciplinary care professionals and family members	The study highlighted the need of carers for enhanced education to contribute towards increased knowledge development and supportive organisational policies. Understanding the need for timely diagnosis of dementia to support carers provide a more effective response to people's changing needs.
Fahey-McCarthy, McCarron, Connaire, McCallion (2009)	Qualitative study	Development of dementia education programme in collaboration with end of life care team.	N=16 staff members	Development and delivery of a dementia training programme demonstrated positive feedback from staff members that completed the education programme.
Kalsy, Heath, Adams & Oliver. (2007)	Mixed factorial design	To examine the effects of care staff training in ageing and dementia on controllability	N=97-day centre care staff	Training improved care staff knowledge and identified the experience of staff has a correlating factor in management of behaviour in people with Down's syndrome in early to mid-stages of dementia.
Lane, Reed,& Hawranik (2019)	Qualitative descriptive design	Improve knowledge of dementia and intellectual disability amongst generic nursing staff	N=9 staff members	Identified the importance of education for nurses working within care homes when supporting people with intellectual disabilities. Collaborative sharing of knowledge between staff members and involving families was identified as a principal factor for learning in practice to better meet the needs of people with intellectual disabilities and dementia.
Northway, Jenkins & Holland-Hart. (2017)	Qualitative design	To explore the experiences, training and	N= 14 house managers	A lack of training in healthy ageing for care staff. Training was found to be reactive to peoples changing needs

		support needs of residential support workers.		with limited proactive education to support effective monitoring of changes within health status.
Shirai, Bishop & Kushner. (2021).	Mixed methods design (pre and post survey, questionnaires and semi-structured interviews)	To create and test a shortened version of dementia capability care training programme.	N=368 Family/ carers, professional staff	The study trialled a shortened dementia training programme to reduce the length of the programme and cost but retaining the core components. The education programme demonstrated improved caregivers' knowledge and confidence in providing person centred dementia care.
Walaszek, Schroeder, Krainer, Prichett, Wilcenski, Endicott, Albrecht, Carlsson & Mahoney. (2020).	Mixed methods design (pre and post surveys – telephone interview)	To understand if an education programme increased professional caregivers' ability to screen for dementia in people with intellectual disability.	N=154 professional care givers.	The study demonstrated following training, professional care givers demonstrated an increased confidence in detecting changes to indicate mild cognitive impairment or dementia. Satisfaction of training was high, and participants felt able to use the screening tool with their clients.
Wark, Hussain, & Edwards. (2014).	Delphi method	To identify areas of training need in caregivers of ageing within people with intellectual disability.	N=23 care workers. N=8 care managers	The study findings identified number of training priorities for care staff to improve care delivery to older adults with intellectual disability. Main areas identified included the need for improved dementia, mental health, and physical health awareness training.
Webber, Bowers & Bigby. (2016)	Quantitative survey	To understand the confidence of paid caregivers in supporting the health needs of older people with intellectual disability.	N=76 care staff.	Specific physical health training in older adults with intellectual disability improved caregivers' confidence in delivery of care. Staff demonstrated less confidence in older adult care for people with multiple health conditions. Recommendation for care staff training in ageing and intellectual disability to support people to age in place.

4.0 Purpose of training interventions

The purpose of education in ageing and dementia in people with intellectual disability for those who provide care is multi-faceted. The overarching theme from identified studies was a clear focus on improving knowledge and confidence of caregivers to provide effective person centred care to an ageing population.

Four of the studies included (table 3) provided evidence of dementia training clearly contributing towards improvements in caregivers' knowledge (Bayley, Amoako, & El-Tahir, 2017; Chapman, Lacey, & Jervis, 2018; Fahey-McCarthy, McCarron, Connaire, & McCallion, 2009; Shirai, Bishop, & Kushner, 2021). Three studies provided further insight into additional objectives from training interventions underlining the effectiveness of developing communication skills to improve

management of behavioural distress (Chapman et al., 2018; Kalsy, Heath, Adams, & Oliver, 2007; Lane, Reed, & Hawranik, 2019).

Two studies explored the training needs of formal caregivers to understand level of knowledge and confidence in providing age related care (Northway, Jenkins, & Holland-Hart, 2017; Webber, Bowers, & Bigby, 2016). The studies in this category recognised training was often reactive with less focus on effective monitoring of physical health. The relationship between age related training and improving confidence in supporting co-morbid physical health problems was clearly expressed in both studies. The findings illustrated that a more proactive approach is needed to support healthy ageing in people with intellectual disability.

A study aimed at providing training to formal caregivers reported similar findings and highlighted the need to improve dementia awareness, and physical and mental health needs of people with intellectual disability (Wark, Hussain, & Edwards, 2014). Dekker et al, (2021) identified the enhanced training needs of family and paid caregivers to effectively recognise the changing needs of people with severe intellectual disability. Although, most studies focused on age related training to improve awareness and delivery of care, one study identified the importance of training caregivers to use a screening tool to better recognise the early signs and symptoms of dementia (Walaszek et al., 2020). Participants included caregivers from a range of social care organisations, who reported an increased ability to recognise changes associated with mild cognitive impairment and dementia.

4.1 Result findings

The literature review revealed four key areas which have been grouped as; the impact of dementia training programmes on confidence, training to improve early diagnosis, training needs of caregivers and training needs of caregivers.

4.21 Content of training interventions

Training programmes provided a general focus on improving understanding of dementia and management of associated difficulties. It was evident that studies incorporated communication strategies, behavioural approaches and promoted person centred approaches based on Kitwood & Bredin (1997) theoretical person centred model (Chapman et al., 2018; Fahey-McCarthy et al., 2009; Shirai et al., 2021; Walaszek et al., 2020). Content varied in educational programmes with a small number of studies providing information, for example, the link between Alzheimer's disease and Down's syndrome and different types of dementia (Fahey-McCarthy et al., 2009; Shirai et al., 2021). Bespoke dementia awareness training was a commonly used term to describe programmes within studies by (Bayley et al., 2017; Chapman et al., 2018). wWhilst other programmes provided

information on the pathological processes of dementia, and behavioural and psychological symptoms of dementia (Lane et al., 2019; Shirai et al., 2021; Walaszek et al., 2020).

In some programmes, there was additional focus on non-pharmacological post diagnostic psychosocial interventions (Bayley et al., 2017; Chapman et al., 2018; Shirai et al., 2021). One programme used vignettes to enhance the training and improve behavioural management approaches (Kalsy et al., 2007). Wwhist other programmes incorporated role play into the training programme and used videos to enhance training content (Shirai et al., 2021). There was additional focus on health comorbidities and end of life care in two programmes (Fahey-McCarthy et al., 2009; Webber et al., 2016).

4.32 The impact of dementia training programmes on confidence

The development of a bespoke dementia staff training programme in conjunction with a palliative care team demonstrated the value of co-designing education programmes with key stakeholders within intellectual disability care services (Fahey-McCarthy et al., 2009). A 20-session dementia education manual was used to deliver an eight week training programme. Evaluation of feedback from non-directive interview guides from participants was evaluated using content analysis. The results demonstrated an overall increased confidence in meeting individual's dementia related needs and supporting people to 'live in place'.

The length of training programmes and availability of attendees was considered a factor in providing a cost-effective educational programme for caregivers of people with intellectual disability (Shirai et al., 2021). As a result, the study adapted a pre-existing educational material to develop a shorter dementia training programme, which provided equally effective results in improving caregivers confidence in providing care. The training remained effective in increasing awareness of adapting environments and using effective communication strategies to manage challenging behaviours. Training handouts provided additional information surrounding the recognition of pain and distress, which is an area of need not often recognised by those caring for people with intellectual disability (Dillane & Doody, 2019).

Similarly, a top tips information sheet was included in one evaluation study. Chapman et al. (2019) analysed a focus group of professional staff as part of an intellectual disability service evaluation programme. Findings noted an overall effectiveness of a bespoke dementia education programme coupled with top tips information sheets increased caregiver's knowledge and increased confidence in delivering person centred care. Bayley et al. (2017) service evaluation provided further insight into the value of dementia training for increasing confidence in families and caregivers. The bespoke dementia education programme was found to improve caregivers understanding of dementia and

provide additional strategies to help manage care challenges along with providing a forum for shared learning.

The promotion of shared learning approaches within dementia training programmes were found to transform care delivery and promote modelling procedures between care teams (Lane et al., 2019; Shirai et al., 2021). Lane et al. (2019) observed that training improved caregivers' ability to communicate more effectively with people with intellectual disability and dementia when responding to episodes of behavioural distress. Moreover, Kalsey et al. (2007) found that dementia training was effective in changing formal care givers' approaches to the management of behaviour and enhanced care practices. It is suggested, educating caregivers to effectively manage challenging behaviours is essential to enable people to remain within their home environment for as long as possible (Cleary & Doody, 2017).

A significant consequence of ageing is increased morbidity with a greater burden on those who provide care to people with intellectual disability (McLaughlin & Jones, 2011). However, by incorporating age related physical health information into training programmes, one study found an increased in confidence in providing care (Shirai et al., 2021). A key aspect of education and training was to encourage healthy ageing care practices (Northway et al., 2017). Studies assessing caregivers' confidence in providing age related care to older adults emphasised the educational value of bespoke age related intellectual disability training programmes. Caregivers working within a group home identified that condition specific physical health training had a positive effect on participants confidence in supporting multiple comorbid health conditions of older adults with intellectual disability (Webber et al., 2016).

4.~~3~~ Training to improve early diagnosis

Early diagnosis was identified as a key factor in a study examining the training needs of care professionals and families to more effectively recognise the signs of dementia in people with severe and profound intellectual disability (Dekker et al., 2021). Focus group interviews with participants emphasised that improvements in educational provision were required to improve carers' knowledge of dementia and allow more timely diagnosis. Equally, early diagnosis was considered imperative towards making environmental and care adaptations to support people to age in place.

Compounding, early identification of dementia is a lack of caregiver education programmes which focus on the ageing process to support identification of subtle signs of cognitive decline in people with intellectual disability (Herron & Priest, 2013; Wark et al., 2014; Wilkinson et al., 2005). One study examined the effectiveness of a bespoke screening tool to detect the early signs of cognitive

decline in people with intellectual disability. In their study, Walaszek et al. (2020) delivered a comprehensive educational programme for professional carers to improve knowledge of dementia. Additionally, training was provided in the use a screening tool to identify the early signs of cognitive decline in people with intellectual disability. The programme demonstrated caregivers had an increased level of confidence in using the screening tool to identify potential indicators of functional decline and improved monitoring of health conditions.

4.54 Training needs of caregivers

Examining the training needs of caregivers who support older adults with an intellectual disability identified four studies that reported several training priorities. Wark et al. (2014) identified number of training priorities aimed at improving the knowledge of mental and physical health in formal care givers. Consistent with these findings, several other studies in this review highlight, the challenges care givers experience in meeting the physical health needs of older adults with intellectual disability (Dekker et al., 2021; Fahey-McCarthy et al., 2009; Webber et al., 2016). In evaluating the training needs of formal carers, Northway et al. (2017) argues that despite previous experience and training, formal caregivers often feel unprepared to adequately respond to people's age related health needs.

A common theme in all studies was limited knowledge and awareness of physical health issues in people with intellectual disability (Dekker et al., 2021; Northway et al., 2017; Wark et al., 2014; Webber et al., 2016). Whilst age related co-morbidities were considered a concern, the need for enhanced dementia awareness was viewed more of a priority by caregivers (Dekker et al., 2021; Northway et al., 2017). Although, Webber et al. (2016) found improved knowledge of physical health provided care givers with increased confidence to care to people with intellectual disability.

All studies suggested that to meet the needs of an ageing population caregivers should be provided with multi-component training interventions which include education on ageing, dementia, and mental and physical health (Dekker et al., 2021; Northway et al., 2017; Wark et al., 2014; Webber et al., 2016). Whilst internal training is often available for formal care givers working in larger provider agencies, these programmes generally do not focus on the physical and mental health aspects of ageing and intellectual disability (Northway et al., 2017). Therefore, making age related education available to caregivers of people with intellectual disability is essential to improve quality of life and meet the health needs of an ageing population (Iacono et al., 2014).

5.0 Discussion

The review identified eleven studies which focused on dementia education and training needs for carers of people with intellectual disability. The results highlight contrasting evidence to suggest

both family and formal care givers have the capability to provide high quality of care following a diagnosis of dementia (Furniss, Loverseed, Lippold, & Dodd, 2012). However, limited knowledge of ageing and dementia has a significant impact carer's ability to respond to people's changing needs. This is particularly evident as progression of the disease intensifies (Wilkinson et al., 2005). Therefore, it could be considered there is a disparity between the availability of age related education and level of care delivery which care givers are expected to provide to people with intellectual disability.

It is noteworthy, that a commonality to all papers, was the variability of post diagnostic education for care givers of people with intellectual disability. When dementia training was delivered to families and carers, the result was often aligned with increased care giver confidence in delivering person centred dementia care. However, there was a lack of evidence of any sustained improvement or if training programmes resulted in any improved health outcomes.

It is important for future studies to evaluate the efficiency of dementia training programmes within organisations to understand the effects of improving knowledge and confidence. A model by Kirkpatrick is a widely used training evaluation method, which could be used to understand efficacy of training programmes and whether increased knowledge leads to changes in care practices (Kirkpatrick, 1996; Smidt, Balandin, Sigafoos, & Reed, 2009). Alternatively, comparative studies should examine the effects of training on improving confidence of caregivers in providing care. These should include examining any improvements in care practices and any reduction in levels of psychological distress and burden of care.

Pivotal to developing knowledge is caregivers being 'dementia ready' and provided with valuable education to provide the person-centred dementia care for an aging population. However, it is interesting to note the limited available evidence of any specific content or standardised dementia awareness training which was effective in transferring knowledge into care practices. It is not unreasonable to suggest, that a stepped approach to education and training would seem a sensible approach to accompany the person and their care network.

As such, training would be enhanced by co-designing education programmes with caregivers who have a lived experience of caring for a person with intellectual disability and dementia. These programmes should include information to increase awareness of dementia, but also include instructive elements to allow people to understand how to manage situations and provide person centred dementia care. The use of interactive elements and supportive resources are needed to help direct care delivery and provide information to improve outcomes.

The dementia learning and development framework provides guidance for all people working in health and social care staff to provide high quality care to people with dementia (Dementia Learning and Development Framework, 2016). The framework provides a criterion which outlines core themes to construct dementia education programmes. Bespoke educational programmes have been found to be more effective when care givers have been provided with accompanying course materials to transfer learning into caring practices (Chapman et al., 2018; Shirai et al., 2021). Therefore, it is pivotal educational programmes not only provide advice on practical solutions to support day to day management strategies, but also have a greater focus on people's physical health needs to direct healthy ageing practices (Chapman et al., 2018).

There is a clear value to in providing proactive training for health and social care staff to improve identification of the subtle signs of mild cognitive decline for early diagnosis and support more effective treatments (Walaszek et al., 2020). However, a lack of training programmes which focus on the ageing process of people with intellectual disability identified in this review emphasises the need for improved provision of bespoke education programmes. Particularly, when evidence clearly identifies a barrier to early diagnosis is often due to a lack of care giver knowledge of dementia signs and symptoms (Sommerlad & Dudley, 2013; Strydom et al., 2010).

A more collaborative approach is essential to support early recognition of dementia symptoms which should include education and training as well as effective care planning (Janicki, 2011). In addition, there is a need for the development of dementia screening indicator tools for care givers to be trained to support better identification of the subtle early signs of cognitive decline. The effectiveness of an early detections screening tool was found to improve care givers ability to recognise early signs of cognitive decline and refer for more specialist dementia assessments (Walaszek et al., 2020). However, empirical research is needed to examine any sustained care giver confidence or long term improvements in early diagnosis of dementia using validated detection screening tools with educational guidance, an essential part of this process. Presently there is a distinct paucity of evidence into these domains.

The principles of person centred care are well established within intellectual disability practices (Hakobyan, Nieboer, Finkenflügel, & Cramm, 2020; Mansell & Beadle-Brown, 2004; Smith & Carey, 2013). Key to improving dementia care practice is incorporating person centred approaches within education programmes (McGinley & Knoke, 2018; Schaap, Dijkstra, Stewart, Finnema, & Reijneveld, 2019).

Specific multi-component didactic training programme should be examined to understand the feasibility of this approach and where possible, identify the cost effectiveness of post diagnostic

education. This approach could enable carers to adapt caring practices in response to a person's changing characteristics, as progression of dementia intensifies, thus improve confidence in care delivery in those who provide care. To support such innovations policy and practice guidelines need to make dementia awareness training available for all care givers of people with intellectual disability.

An essential component towards improving dementia knowledge and sustaining person centred dementia care practices is providing accompanying resources (Surr et al., 2017). There is a need for specialist dementia education to be made available to all care givers and designed to support interventions for practical solutions to behavioural management, as well as enable improved physical health outcomes (Herron, Priest, & Read, 2020). The development of a co-produced resource manual could be used to accompany dementia training programmes to capture management strategies and provide information to support effective monitoring of a person's physical health. The ability to adapt and individualise a resource manual would allow caregivers to transfer information from training to inform care practices. It is important to involve caregivers as part of this process.

Future studies are needed to examine the effectiveness of specific management strategies incorporated in training programmes, to establish if these lead to changes in outcomes and attitudes towards managing challenging behaviours. It is important to understand if improved knowledge about dementia leads to improvements in confidence in care delivery.

There is an increased emphasis on supporting people with intellectual disabilities to 'age in place' and improve the level of age related care (Fahey-McCarthy et al., 2009). This should include exploring if educational interventions have any effect on improving the quality of life of people with intellectual disability and equally those who provide care. Key to improving awareness is incorporating ageing and dementia training into routine post diagnostic care practices.

5.1 Limitations

This scoping review provides an overview of the dementia training and education provided to carers of people with intellectual disability. Studies included in the review were not critically appraised for methodological quality or bias as scoping reviews provide an overview of the existing literature (Munn et al., 2018). Although, studies identified positive results, most were single group studies with limited evidence of any sustained carer confidence in providing aged care. Only a limited number of studies used validated outcome measures or examined any improvements in quality of life. There

were no studies which examined the use of eLearning or other digital training media to improve knowledge or early identification of dementia symptoms in people with intellectual disability.

However, we argue this review makes a contribution towards designing training interventions by illustrating a correlation between increased knowledge of dementia and improved confidence in the delivery of care of older people with intellectual disability. It is important that future research examines if training and education has any impact on reducing the levels of psychological distress caused by caring for a person with dementia. In addition, there is a clear need for interventions to improve identification of the sign and symptoms of dementia to enable more timely diagnosis and post diagnostic treatments.

5.2 Conclusion

The review demonstrates a systematic process used to examine post diagnostic education and identify the training needs for caregivers of people with intellectual disability. Despite the variations in approaches and heterogeneity within study designs identified in this scoping review, there are several key areas of further development identified. There is clear evidence to suggest training and education provide carers with increased confidence to support an aging population. Education and training programmes should incorporate information to increase understanding of dementia progression, behavioural management, and post diagnostic psychosocial intervention with a significant focus on monitoring and improving awareness of physical health.

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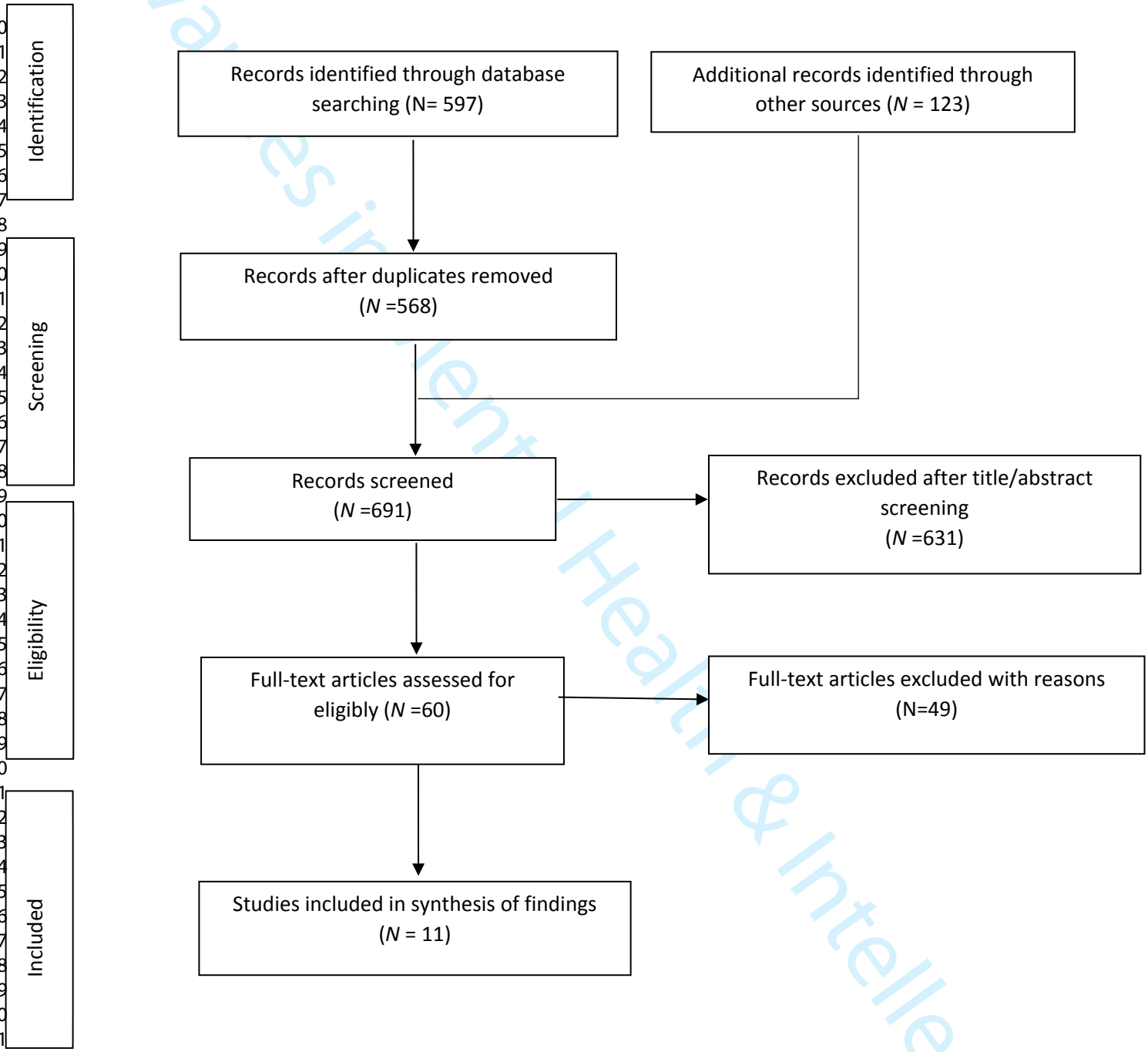
Figure 1.

PRISMA-ScR flow diagram



Adapted from (Tricco et al., 2018).