





REVIEW

Experiences of people with intellectual disability and dementia: A systematic review

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Abstract

Background: Dementia disproportionately affects people with intellectual disability. Most qualitative studies explore their experiences by utilising proxy-reports. A smaller number of studies illustrate the possibility of exploring perspectives directly from people with intellectual disability and dementia.

Method: This systematic review synthesised findings from existing studies ($n = 8$) that involve people with intellectual disability and dementia as participants to understand their experiences of dementia. Searches were conducted using CINAHL, PsychInfo and Social Services Abstracts.

Results: Findings include descriptions of changes in individual functioning, a narrowing of social worlds and of how people made sense of the changes despite often having no knowledge of their dementia diagnosis. Additionally, discussion focuses on how people's experiences are shaped by their environments.

Conclusion: The review recognises the complexities of speaking to people with intellectual disability about dementia, challenges views that people with intellectual and dementia cannot be involved in research and makes recommendations to support inclusion in future studies.

KEYWORDS

dementia, intellectual disability, learning disability, qualitative, systematic review

1 | INTRODUCTION

People with intellectual disability are at increased risk of dementia, particularly people with Down syndrome. Studies have suggested that more than half of people with Down syndrome over 60 will be affected by dementia (Bayen et al., 2018; McCarron et al., 2017). As the life expectancy of people with intellectual disability is increasing (Emerson & Hatton, 2008), the prevalence of dementia is also increasing and older people with intellectual disability have become a group of interest for researchers and policy makers over the past two decades (Chapman et al., 2018; Grant, 2001;

Scottish Government, 2013). While there are similarities in symptoms and care needs for people with dementia with and without intellectual disability, there are also differences. People with intellectual disability experience increased health inequalities compared to others. In the United Kingdom, people with intellectual disability die on average 15–20 years earlier than the general population which has been linked to inequalities in their access to good quality care (Heslop et al., 2014; O'Leary et al., 2018; Truesdale & Brown, 2017). Difficulties in dementia diagnosis and post-diagnosis support for people with intellectual disability have been linked to diagnostic overshadowing, where symptoms and behaviour that suggest dementia

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are seen to be part of the person's intellectual disability (Herron et al., 2020). This extends existing stigma associated with intellectual disability even prior to a diagnosis of dementia (Scior et al., 2020).

There is increasing recognition that personal experiences are valuable alongside professional expertise to help understand what it means to have dementia (Górska et al., 2018). This is reflected in a growing body of qualitative research that is centred around the experiences and views of people with dementia. Such personal experiences can highlight everyday situations and identify facilitators and barriers to social participation. This can provide a more multifaceted view of dementia that sees people with dementia as active contributors to relationships in their lives, challenging perceptions of passivity and vulnerability (Bartlett et al., 2010). However, one group that is missing from existing first-person accounts are people with intellectual disability and dementia. This is despite a long-standing tradition of participatory and inclusive methods within intellectual disability research (Milner & Frawley, 2019; Walmsley, 2001). The exclusion of the experiences and views of people with intellectual disability and dementia from research can partly be explained by ethical concerns around capacity to consent and engage in meaningful research involvement (Forbat & Wilkinson, 2008; Watchman, 2016). Dementia interacts with existing cognitive impairments, which means that people often benefit from additional communication supports prior to a diagnosis and as verbal communication can reduce post diagnosis, research interactions may require further support (Watchman, 2016).

Most systematic reviews within the field of intellectual disability and dementia draw on quantitative or mixed-method studies to summarise early signs of dementia, establish diagnostic pathways, map service-needs or evaluate interventions (Llewellyn, 2011; MacDonald & Summers, 2020; McKenzie et al., 2018; Zeilinger et al., 2013). Systematic reviews of qualitative studies have largely focused on the proxy experiences of caregivers who provide care and support for people with intellectual disability and dementia (Cleary & Doody, 2017b; Dillane & Doody, 2019; Perera & Standen, 2014). To our knowledge, there have been no reviews that explore experiences of dementia from the perspective of people with intellectual disability and dementia. However, studies have shown that it is possible to explore the perspectives of people with intellectual disability and dementia (Lloyd et al., 2007; Sheth et al., 2021; Watchman, 2016). Such studies are often based on a small number of participants with intellectual disability and dementia, typically three to four (Manji & Dunn, 2010; Sheth, 2019; Watchman, 2016). A systematic review and thematic synthesis of the perspectives and experiences of people with intellectual disability and dementia can strengthen existing evidence by integrating knowledge from qualitative projects and case studies.

2 | AIMS

The aim of our review is to synthesise findings across studies to better understand how people with intellectual disability experience dementia. Research questions are:

How do people with intellectual disability experience dementia?

What is known about their everyday lives and how do people's lives change during the course of dementia?

TABLE 1 Search terms

Population	Phenomena of interest	Context
Learning disability* or intellectual disability* or developmental disability* or Down* syndrome	Experience* or View* or Perspective* or Support or Barrier or Relationship* or Care* or Meaning or Qualitative	Dement* or Alzheimer*

3 | METHOD

The systematic review and thematic synthesis followed Joanna Briggs' Institute guidelines (The Joanne Briggs Institute, 2014). PsychInfo and the International prospective register of systematic reviews (Prospero) were searched to establish if similar reviews already existed. None were found and subsequently a review protocol was developed and registered with Prospero (registration number CRD42021298737).

4 | SEARCH

A systematic search was conducted in three databases: CINAHL, PsychInfo and Social Services Abstracts. An adapted version of the PICO framework for qualitative systematic reviews as recommended by the Joanna Briggs Institute was used to develop search terms (The Joanne Briggs Institute, 2014). Search terms were developed in relation to people with intellectual disability as the population of interest (P), experiences as the phenomena of interest (I) and dementia as the context of interest (Co). An overview of the search terms can be found in Table 1. Search terms were applied to the three databases and combined across columns using AND in an abstract and title search. This was complemented by a subject heading search unique to each database. Truncations were used to take account of word inflection. The search was run in May 2021 and later updated at the end of October 2021 to include publications that had been added to the three databases between May and October 2021. Additionally, reference lists of included articles were hand searched. Details of the full strategy can be obtained on request.

4.1 | Inclusion criteria

The inclusion criteria that guided the screening process ensured that papers included in the review were peer reviewed, contained primary data, included people with intellectual disability and dementia as research participants and were available in English. We also sought papers from studies that specifically discussed the experiences of people with intellectual disability affected by dementia.

The screening process consisted of two steps. First, all titles and abstracts of the results were screened based on the inclusion criteria by one reviewer. Second, all full-text records were assessed independently by two reviewers. Conflicts were resolved by a third reviewer, and particularly difficult decisions were taken after discussion with the whole review team.

4.2 | Critical appraisal of included studies

All studies were critically appraised by two members of the research team using the guidelines for appraisal of qualitative research developed by the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2019). Conflicts were brought to a team meeting and resolved through more detailed discussion. Critical appraisal of qualitative studies relies on the information that is provided in the included articles. Missing information does not necessarily indicate that processes were not followed or considered but may reflect that authors did not include all their decisions or steps within the write-up of the study. Therefore, similar to Long et al. (2020) we adapted the scoring of the CASP checklist to note if there was strong reporting of a criteria, partial reporting, no mentioning of a criteria or if decisions made appeared to be of poor quality based on the information provided. Additionally, instead of providing an overall score, we summarised the strengths and weaknesses of each study in line with a qualitative paradigm to highlight the specific context in which each was conducted.

4.3 | Data extraction and analysis

First, we collected information about the characteristics of included articles to provide an overview of each study. Second, we followed the approach to thematic synthesis outlined by Thomas and Harden (2008) to integrate findings across included studies. All articles were uploaded to NVivo 12 qualitative data analysis software. During the coding process, themes identified by the authors of the original papers were set aside to aid the development of new themes based on our research questions. Findings, discussion and conclusion section within the articles were coded line by line, to include not only original data but also meanings that were derived from the data and highlighted throughout the articles. This was an iterative process and as new codes emerged, previous articles were re-read to look for the presence of similar codes. As a second step, codes were arranged and re-arranged to identify connections and establish descriptive themes and sub-themes. The last step involved the development of analytic themes. We looked back at our descriptive themes and considered them in light of our research question (Thomas & Harden, 2008), aiming to better understand how people with intellectual disability experience dementia. This helped us to synthesise content across studies and to generate new overarching themes (Thomas & Harden, 2008). The first author coded all articles. Each step of the analysis was shared and discussed with the whole research team and at the end a second researcher compared the final draft with the findings sections of each article to ensure that no themes or nuances had been missed or misrepresented.

5 | RESULTS

6341 results were identified across the three databases and imported into Covidence systematic review management software (Veritas Health Innovation, n.d.). 495 duplicates were removed by Covidence leaving 5846 records to be screened. Of those, 5722 were identified

as irrelevant. A majority of results were excluded at the title and abstract stage for several reasons. First, it became apparent that our search terms yielded many results that discussed the support needs of people with intellectual disability and dementia without being based on original research. This included expert opinions or practice accounts published as book chapters, articles or conference papers. Second, many were bio-medical research studies, including genetic and animal studies investigating the causes and treatment of dementia. They appeared to be included in our search as many discussed *relationships* between genes or wrote about *views* and *perspectives* on treatment outcomes in their conclusion sections. We did consider tightening our search words, but as we were aware of the paucity of research in this area, we decided to keep the search broad to avoid missing potentially relevant studies.

In the second screening stage, 124 records were retrieved and assessed for full-text eligibility and 116 records were excluded at full-text. Most common reasons for exclusion were articles that were not based on primary data (literature reviews and opinion pieces), had a focus that was outside our interest such as service evaluations or a focus on end-of-life care, or were not peer reviewed articles. Eight articles met our inclusion criteria and were included in the review. An overview of the screening process and reasons for exclusion can be found in Figure 1.

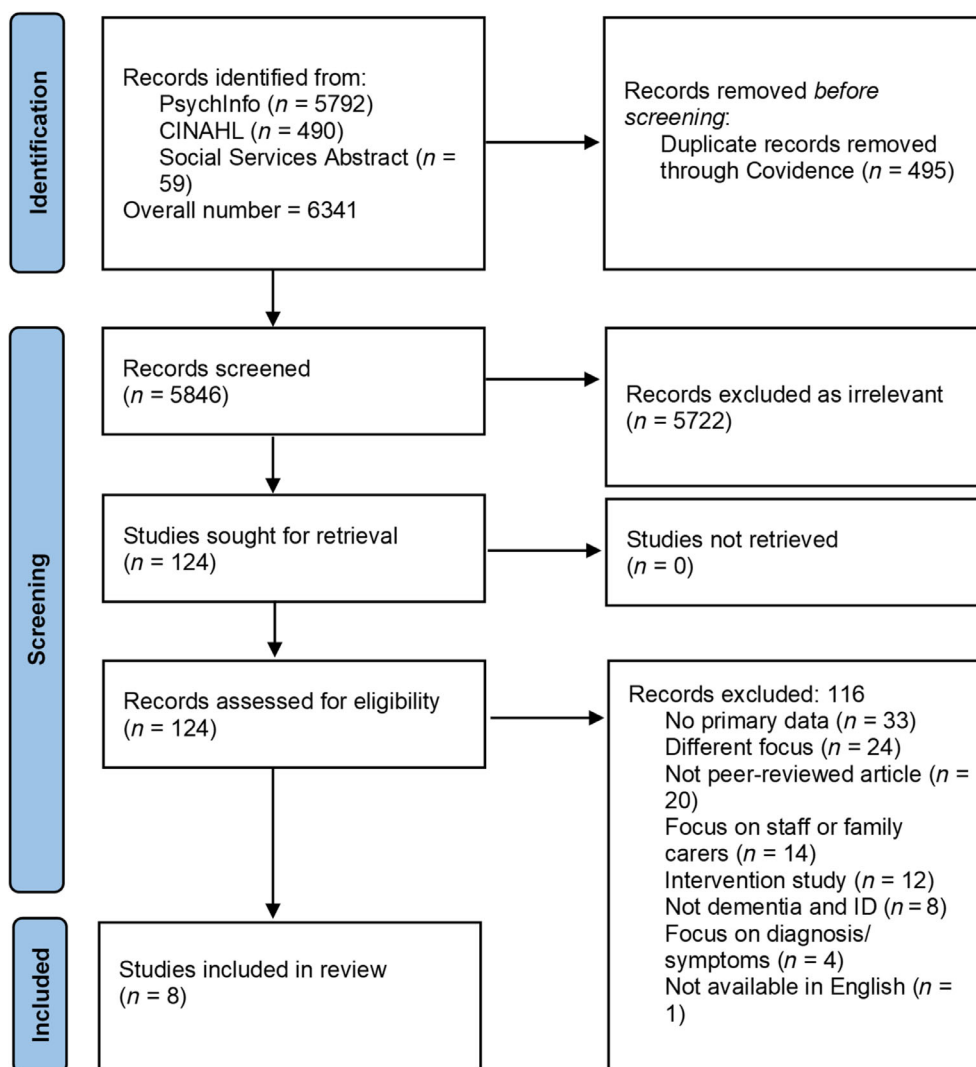
All included articles provided information about participants with intellectual disability and dementia (ages, gender, living circumstances) but there were differences across the eight articles in how people had been included. Acknowledging that verbal participation might not be feasible or appropriate for all participants with intellectual disability and dementia, some studies used methods other than direct interviews to understand the lives of people with intellectual disability and dementia. This included descriptive case studies and studies that used participant observations.

5.1 | Study characteristics

Two studies were conducted in Australia, three in the United Kingdom, one in Canada and two in the United States. Four studies focused on the experiences of people with Down syndrome and dementia (Carling-Jenkins et al., 2012; Iacono et al., 2014; Lloyd et al., 2007; Watchman, 2016). Sample sizes of participants with intellectual disability and dementia ranged from three to nine, with a mean of five. However, although one study had recruited eight participants with intellectual disability and dementia, data was only included for two of the participants due to lack of substantive data for six of the participants (Forbat & Wilkinson, 2008). Taking this into consideration brings the mean number of participants to four. The data included across studies reflects the experiences of 13 men and 18 women.

A range of data collection methods were included across the studies to include people with intellectual disability and dementia with participant observation being the most common (Manji & Dunn, 2010; Sheth et al., 2021; Watchman, 2016). Other methods were semi-structured interviews, nominal group technique and focus groups. Case study was the most frequent methodological approach

FIGURE 1 PRISMA flowchart



taken (Carling-Jenkins et al., 2012; Iacono et al., 2014; Manji & Dunn, 2010; Watchman, 2016) with Interpretative Phenomenological Analysis used by Lloyd et al., 2007.

5.2 | Quality assessment and methodological findings

None of the criteria were assessed as being of poor quality and no studies were excluded. An overview of the eight studies can be found in Table 2. The quality assessment is summarised in Table 3.

The main emphasis of four of the articles lay partly outside our focus on experiences of people with intellectual disability and dementia (Carling-Jenkins et al., 2012; Forbat & Wilkinson, 2008; Iacono et al., 2014; Watchman, 2016). Watchman's (2016) article focuses on ethical and methodological reflections of including people with intellectual disability and dementia in research, two articles had a strong emphasis on the experiences of staff and family members (Carling-Jenkins et al., 2012; Iacono et al., 2014), while Forbat and Wilkinson's study (2008) had an emphasis on how peers with intellectual disability

understood dementia in housemates. However, all were included as they contained data and findings in relation to the direct experiences of people with intellectual disability and dementia.

One study involved people with intellectual disability and dementia through interviews only (Lloyd et al., 2007), three combined observations with one to one conversations (Forbat & Wilkinson, 2008; Sheth et al., 2021; Watchman, 2016), one study used group conversations with people with intellectual disability and dementia, staff and family members (Sheth, 2019) and one used observations alongside interviews with staff (Manji & Dunn, 2010). Two drew on the knowledge of family members and professionals only to map people's journeys (Carling-Jenkins et al., 2012; Iacono et al., 2014). They were included as they provided detailed case studies of the journeys of people but with the caveat that included data were largely descriptive. One study involved peers alongside people with intellectual disability and dementia, including their perspectives and experiences of witnessing changes in their friends and housemates (Forbat & Wilkinson, 2008). All those research studies that involved people through interviews reported challenges in talking to participants about dementia as people were unaware of their diagnosis or appeared to

TABLE 2 Overview of included studies

Author and country	Aim	Participants and setting	Methodology	Key-findings
Carling-Jenkins et al. (2012) Australia	To understand the experiences of families and other carers in supporting people with Down syndrome and Alzheimer who lived most or all their lives with family.	Focus on the journeys of three people with Down syndrome and Alzheimer. Ages: 47, 52, 62. Two men and one woman. All had lived most of their life with family. At the time of the study two lived in a residential aged care facility and one at home. Interviews with each person's support network. Overall including 8 professionals, one pair of parents and two sisters.	Case study design. Semi-structured interviews with family members and health and social care professionals, including initial and follow-up interviews. Case study analysis used to analyse the data (timelines, case narratives, themes across cases)	Families were not aware of the increased risk of dementia in people with Down syndrome. The development of Alzheimer can happen at the same time of parents ageing and having increased support needs and some parents might not be alive anymore to support the process. Siblings often start to become more involved and take over responsibilities. Services and families often attribute behavioural changes to people's intellectual disability rather than considering the impact of dementia, even after a diagnosis has been made. This can lead to the provision of poor or inappropriate support and people being viewed as misbehaving. Changes in the person's personality can be difficult and distressing for family members. Families experienced financial and emotional difficulties within their caregiving roles.
Forbat & Wilkinson (2008) UK	To explore how people with intellectual disability understand and experience dementia.	Two groups of participants. One advisory group of eight people with intellectual disability (peers) Second group consisted of eight people with intellectual disability and dementia (but the data of only two is reported due to lack of substantive data for six of the participants). All participants were supported by an organisation in England providing residential and day services to people with intellectual disabilities.	Combination of focus groups with the advisory group, ethnographic fieldwork and interviews with people with intellectual disability and dementia. Thematic analysis used to analyse the data.	People with dementia had little awareness of what dementia is. This might be a defence-mechanism, related to cognitive decline or reflect fears of staff to talk to people about it. People with dementia are aware how they affect others, including partners, and how others can get annoyed with them. Dementia impacts on the person and those around them. Peers can feel resentful if they do not understand why people are treated differently. People can experience dementia in combination with other age-related changes such as becoming frailer. Some people are concerned about needing to leave their homes. There can be concerns about what alternatives are available and if they are suitable and appropriate.
Iacono et al. (2014)* Australia *Findings are based on the same larger study as Carling-Jenkins et al. (2012) but relate to different groups of participants.	To understand the experiences of social care staff supporting people with dementia and Down syndrome living in supported accommodation.	Focus on the journeys of nine people with Down syndrome and Alzheimer. Ages: 42–57. Five women, four men. All lived in small group homes. Interviews with 26 social care professionals supporting the nine people.	Case study design. Semi-structured interviews with social care staff involved in supporting the nine people, including initial and follow-up interviews. Case study analysis used to analyse the data (timelines, case narratives, themes across cases).	Changes people experience can relate to memory, functional skills, communication abilities, self-care, personality and behaviour. People lose some of their independence and become more dependent on others. Abilities and needs can fluctuate from day to day, requiring staff to be flexible in the strategies they use to support people. Staff can attribute behaviour to the person, viewing them as misbehaving. Staff seem to draw more on their knowledge about intellectual disability and training on challenging behaviour, rather than dementia knowledge to inform their support strategies, at times rejecting the advice and input from dementia and allied healthcare professionals.

(Continues)

TABLE 2 (Continued)

Author and country	Aim	Participants and setting	Methodology	Key-findings
Lloyd et al. (2007) UK	To understand the experiences of people with Down syndrome living with dementia.	Six people with Down syndrome and dementia. Ages: 49–59. Four men and two women. All lived in group residential home settings.	Semi-structured interviews with the six participants. Interpretative Phenomenological Analysis (IPA) used.	<p>Staff can feel conflicted between encouraging self-help skills and accepting people's need for increased support.</p> <p>Services can struggle to support people when they start wandering. Lack of resources and an unwillingness to accommodate an increase in support needs is a barrier to people ageing-in-place.</p> <p>People view their jobs and domestic tasks as a key part of their identity. They also help people to ascertain their independence and 'usefulness'.</p> <p>The onset of dementia can disrupt people's self-image and lead to a loss of roles and identity.</p> <p>Some people relate changes in their abilities to the process of ageing and growing old more generally, while some people resist viewing themselves as old. Identified coping mechanisms include emphasising abilities over difficulties, maintaining routine, withdrawal, and minimization of difficulties.</p> <p>People were all unaware of their diagnosis of dementia but had an awareness of their cognitive decline.</p> <p>Dementia related decline led to relationship difficulties when emerging difficulties resulted in negative responses and feedback from others.</p> <p>People relied on relationships to staff and family members to facilitate engagement in everyday activities and to feel safe.</p>
Manji and Dunn (2010) Canada	To understand the experiences of people with intellectual disability and dementia	<p>Focus on four people with intellectual disability and dementia. Ages: 49–59.</p> <p>Three women and one man.</p> <p>All lived in the same purpose-built group home for people with intellectual disability and dementia.</p> <p>Interviews with each person's support network. Including four family members and eight social care professionals.</p>	<p>Case study design.</p> <p>Observations of people within the group home, interviews with staff and family members alongside reviews of daily log notes completed by staff.</p> <p>Triangulation of data sources used to develop themes.</p>	<p>People experience losses in three main areas: 1. ability, 2. home and 3. community.</p> <p>People experience a decline in skills and become more dependent on others. The process of change is different for each person and can vary from day to day and within days. As a result of cognitive decline people might not want to attend social activities they have enjoyed previously. This can lead to a loss of community.</p> <p>People can experience empowerment within the environment of their service, but this takes place within a larger context of people depending on funding and services and living within segregated settings.</p> <p>Lack of resources to support people in their homes often necessitates the move to other services.</p>
Sheth (2019) USA	To understand how environmental factors influence day-to-day participation for people with intellectual disability and dementia.	<p>Four women with intellectual disability and dementia. Ages: 45–61.</p> <p>All lived in community group homes.</p>	Two nominal group technique sessions with the four women with intellectual disability and dementia and five traditional focus groups for family members and staff.	<p>People value their roles and responsibilities in daily life and view their jobs, domestic tasks and relationships to others (daughter, aunt, friend, romantic partner) as a key part of their identity.</p> <p>Participants were not aware of their dementia diagnosis.</p>

TABLE 2 (Continued)

Author and country	Aim	Participants and setting	Methodology	Key findings
Sheth et al. (2021)* USA *Sheth (2019) and Sheth et al. (2021) are part of the same PhD project. The included data relates to the same group of participants (three of the participants in Sheth et al. (2021) are the same as in Sheth (2019)) but has been collected at different points in time through different methods (focus groups in Sheth (2019), followed by interviews and observations in Sheth et al. (2021)).	To explore experiences of transition for people with intellectual disability and dementia	Three women with intellectual disability and dementia. Aged: 46–61. Two lived in a community group home and one in a residential care facility.	Participant observations of different environments and everyday activities. Subsequent interviews to reflect on observations across different activities drawing on photograph and object elicitation. Thematic analysis used.	People experience transitions in relation to moving from home into and between care settings, moving from supported employment to day services and leisure programs, as well as experiencing the loss of loved ones. People have little involvement in decisions that are made about moves to new living and care settings. Peer networks help people during and after transitions, offering emotional support. People miss seeing friends from previous settings and depend on staff to facilitate relationships. People feel that they need to comply with rules and regulations to avoid transitions and restrictions in their access to activities and settings. None of the participants were aware of their dementia diagnosis.
Watchman (2016) UK	To explore the lived experiences of dementia in three adults with Down syndrome* *This was the aim of the study. The article focuses largely on ethical and methodological issues but includes data and findings in relation to people's experiences living with dementia.	Three people with Down syndrome and dementia. Ages: 47, 56, 60. Two men and one woman. Each lived in different homes, including a group home, single tenancy and a generic care home for older people.	Case study design. Participants were visited monthly over a three-year period. Data collection involved participant observations, detailed field notes and one-to-one informal conversations. Using Stake's (2006) multi-case method of analysis including detailed case descriptions, followed by cross-case analysis.	Lack of verbal communication does not mean a lack of identity and people continue to express their preferences, feelings and wishes, albeit in different ways. Non-verbal communication can be overlooked by staff. None of the participants knew about their dementia diagnosis and changes were not explained to people. People experienced exclusion and isolation, losing previous relationships and access to activities.

TABLE 3 CASP quality assessment summary

	Aims stated and justified	Link design and research question	Participant selection	Data collection	Role of researcher	Ethics	Data analysis	Findings	Value of research	Strengths and weaknesses
Carling-Jenkins et al. (2012)	++	+	+	++	0	+	++	++	++	Detailed case studies provided with overview of each person's care journey over time. Summarising facilitators and barriers and how those influenced outcomes for each person with intellectual disability and dementia. Overall focus is on experience of family caregivers. Unclear why people with intellectual disability and dementia were not directly involved as part of the case studies.
Forbat & Wilkinson (2008)	++	++	++	+	+	++	+	++	++	Transparent about difficulties of involving people with intellectual disability and dementia. Use of advisory group. Unclear how observational data and ethnographic fieldnotes were used. Findings only include interview data.
Iacono et al. (2014)	++	+	+	++	0	+	++	++	++	Context of policy and service provision in Australia discussed and compared to other countries. Nuanced findings with extensive quotes from interviews. Focus is on experiences of staff. Unclear why people with intellectual disability and dementia were not directly involved as part of the case studies.
Lloyd et al. (2007)	++	++	+	++	0	++	++	++	++	Strong direct involvement of people with intellectual disability and dementia through interviews. Largest participant number (6). Theoretical discussion of findings. Limited discussion around participants being unaware of their diagnosis and what that meant for the consent and interview process and included data. No mention of using aids to facilitate interviews although difficulties to talk to participants about dementia acknowledged.

TABLE 3 (Continued)

	Aims stated and justified	Link design and research question	Participant selection	Data collection	Role of researcher	Ethics	Data analysis	Findings	Value of research	Strengths and weaknesses
Manji and Dunn (2010)	+	++	+	++	+	+	++	+	+	Case study of one service provider. Detailed information about setting. Observational data included alongside interview data. Findings reflect experiences of staff at the service more generally and few links are made to the specific everyday experiences of the four participants with intellectual disability and dementia.
Sheth (2019)	++	++	++	++	0	++	++	++	++	Use of accessible information for participants discussed. Bronfenbrenner's ecological model underlines research. Some discussion around participants not knowing about their diagnosis but no reflection what this meant for the included data and interview process.
Sheth et al. (2021)	++	++	++	++	+	++	++	++	++	Detailed information about setting provided. Strong discussion of organisational barriers and environmental influences on people's lives. Observational data provided alongside interview data. Detailed examples of everyday experiences of participants included. Participants not knowing about their dementia diagnosis stated but not explored further what this means for the included data and the data collection process.
Watchman (2016)	++	++	++	++	++	++	+	+	++	Focus of article is on methodological and ethical considerations. Thus, role of the researcher, ethics and lack of dementia disclosure are discussed in depth. Findings are a relatively small part of the article. Few original data presented to support findings.

Note: ++, strong discussion; +, partly discussed; 0, not mentioned; =, poor quality.

have limited knowledge about dementia (Forbat & Wilkinson, 2008; Lloyd et al., 2007; Sheth, 2019; Sheth et al., 2021; Watchman, 2016). Thus, researchers themselves were unable to directly ask about dementia and instead spoke to people about their experiences of ageing. This means that the included data reflected people's experiences of life more generally, rather than exploring dementia specific experiences. The implications of non-disclosure and difficulties in speaking to people about dementia were not discussed, or only partially discussed in relation to ethics and the role of the researcher within the data collection across papers. A notable exception was Watchman (2016) who provides a detailed account of concerns about researcher collusion with carers over withholding information, while also discussing boundaries of ones role as a researcher and the inappropriateness to disclose sensitive information without being able to support people to understand this.

It was evident that some methods had advantages in facilitating the involvement of people with intellectual disability and dementia in research. The use of visual prompts or objects appeared helpful to facilitate conversation in interviews (Sheth et al., 2021; Watchman, 2016). Ethnographic methods and participant observations enabled researchers to become familiar with people's lives and explore changes over a longer period of time, while also facilitating the involvement of people towards later stages of dementia when verbal interviews might be unsuitable (Manji & Dunn, 2010; Sheth et al., 2021; Watchman, 2016). Such approaches are consistent with suggestions in dementia research generally that trustworthiness and rigour may not be associated with typical methods of member checking (Beuscher & Grando, 2009). Increasing time with participants and triangulating data such as in case studies may be preferable, particularly as dementia advances. As dementia progressed, three studies

detailed how people were finding new ways to relate to others and how it was important to be aware of changes in communication in order to continue to listen to people's preferences and wishes (Lloyd et al., 2007; Manji & Dunn, 2010; Watchman, 2016).

5.3 | Thematic synthesis: Experiences of dementia in people with intellectual disability

During the analysis, we recognised that the included studies presented data relating to different spheres of experience. Spheres included descriptive experiences, describing what people were experiencing and subjective experiences, how people felt about and viewed those experiences. It was also apparent that descriptive and subjective experiences were influenced by, and needed to be understood within the wider context of people's lives. The different spheres started to frame the development of themes. An overview of the spheres and themes is provided in Figure 2.

5.4 | Descriptive experiences

Descriptions of people's lives detailed a decline in abilities and functioning, as well as a narrowing of people's lives.

5.4.1 | Abilities and functioning

Descriptions of changes in people's abilities included decline in physical functioning (e.g., the need to use a wheelchair), memory and verbal

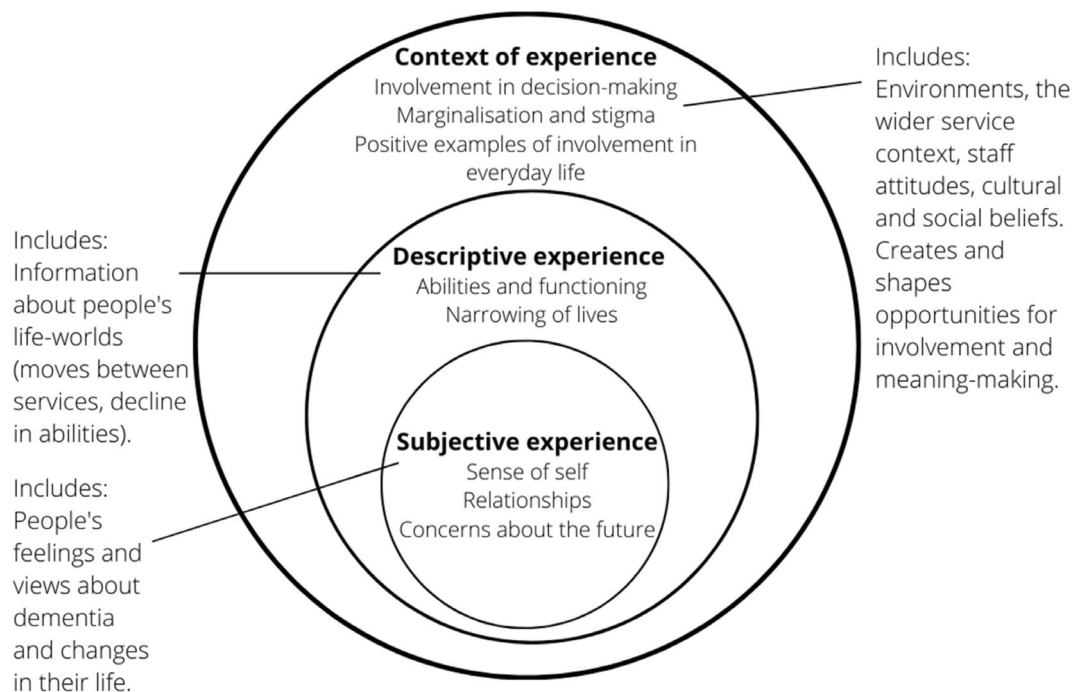


FIGURE 2 Spheres of experiences and developed themes

communication and the subsequent loss of areas of independence. While an overall gradual decline in abilities was observed, this was not always linear and was individual to each person. Abilities could change from day to day, at times fluctuate within days and sometimes a marked decline could be sudden.

She knew she wanted to stand up. She kept trying to stand up. She would yell at you to help her stand up. And then she would get scared halfway through and sit back down, and push herself to the back of the chair.... I knew she was walking yesterday, and I knew she was walking earlier this morning. But for some reason she couldn't get up. (Manji & Dunn, 2010)

Studies also reported an increase in associated health conditions such as the emergence of seizures, incontinence and experiences of pain, which at times improved once health professionals became involved and people started to receive treatment and medication (Carling-Jenkins et al., 2012; Iacono et al., 2014; Manji & Dunn, 2010).

5.4.2 | Narrowing of lives

Studies linked a change in functioning with a narrowing of people's lives, as people lost access to former everyday life networks. This included people discontinuing work and daytime commitments such as working in cafes or day centres and people withdrawing from leisure activities such as swimming clubs or singing groups. This was particularly prominent in cases where people moved to a new service or stopped their involvement with a previous setting as their dementia progressed (Manji & Dunn, 2010; Sheth et al., 2021; Watchman, 2016). In five studies, participants had left their families or previous supported living homes to move to dementia-specific or old-age specific settings (Carling-Jenkins et al., 2012; Manji & Dunn, 2010; Sheth, 2019; Sheth et al., 2021; Watchman, 2016), and two further studies discussed the likelihood of a future move to specialised services for participants should their support needs increase (Forbat & Wilkinson, 2008; Iacono et al., 2014). Studies also described a more general and gradual narrowing of people's everyday lives with less positive, less frequent and less reciprocal interactions with peers, housemates, family or staff (Carling-Jenkins et al., 2012; Iacono et al., 2014; Lloyd et al., 2007; Manji & Dunn, 2010; Sheth et al., 2021; Watchman, 2016). Carling-Jenkins et al. (2012) further highlighted that contact and involvement of family members could change and at times reduce as people's parents were getting older, becoming unwell themselves or dying.

5.5 | Subjective experiences

Four of the five studies that directly spoke to people with intellectual disability and dementia discussed that participants were not aware of their dementia diagnosis (Lloyd et al., 2007; Sheth, 2019; Sheth

et al., 2021; Watchman, 2016). Despite an absence of open and in-depth conversation with people about dementia, it was evident across studies that people had an awareness that their lives were changing and were responding and expressing their feelings about those changes. Verbal acknowledgments of change were the most detailed in Lloyd et al. (2007) and Sheth et al. (2021), while other studies highlighted the importance of being attuned to non-verbal ways in which people with intellectual disability and dementia were expressing their feelings and preferences in their everyday life interactions with others.

Rose spoke a few words at the start of the research period although this quickly changed to loud noises rather than words, the tone of which reflected her mood. (Watchman, 2016)

Descriptions of people's behavioural and affective states included experiences of confusion, frustration, distress and anxiety. However, while it was evident that people were able to express their feelings and preferences, it also became apparent that people often felt they had little control over decisions that were made about their lives and care.

Jennifer also frequently talked about her plans to move out of her CILA home and return to living with her parents. When probed, she disclosed that while she would like to live with her parents, "That's just not an option". (Sheth et al., 2021)

The wider context in which people's lives took place will be explored further in the last sphere. The following themes will discuss how people expressed their sense of identity, emphasised their independence, sought connections to others and reported fears about the future.

5.5.1 | Affirming and expressing sense of self

Amidst changes in their lives, people continued to relate to former identities. Studies that included staff and family members showed the importance of knowledge about people's life stories, their favourite activities or music to help maintain identities and celebrate lives.

Cynthia's staff member talked about finding various ways to comfort her when she made a 'grizzling' sound, including following her brother's suggestions to play 'ABBA'. (Iacono et al., 2014)

While affirming past selves was important, studies also showed that people were aware of a change in their identity, marked by the loss of former jobs, roles and responsibilities. People acknowledged a decrease in abilities and how this impacted on their engagement with previous networks and activities. Some had started to feel

overwhelmed by busy environments and chose to withdraw from previous social activities or work commitments.

I'm alright, just want peace and quiet. Just want to go in my room. (Lloyd et al., 2007)

Yet, while five studies included verbal acknowledgments of changing selves (Forbat & Wilkinson, 2008; Lloyd et al., 2007; Sheth, 2019; Sheth et al., 2021; Watchman, 2016), some people within the studies simultaneously resisted portraying themselves as ageing and more dependent (Forbat & Wilkinson, 2008; Lloyd et al., 2007; Sheth, 2019; Sheth et al., 2021; Watchman, 2016). For example, in interviews people with intellectual disability and dementia appeared to particularly focus on their jobs and domestic roles when speaking about their lives. It appeared that a focus on responsibilities and jobs was connected to participants seeking to emphasise their ability and independence; this was most prominent in the studies by Lloyd et al. (2007) and Sheth et al. (2021).

I don't need any other help. Louise (staff caregiver) has to do my bed for me sometimes. But I help as well. (Lloyd et al., 2007)

Both studies explained people's resistance to descriptions of themselves as ageing by making links to people's past experiences of stigma, a wish to challenge cultural views of people with intellectual disability as dependent and vulnerable and people resisting a lack of involvement in decision-making about their lives.

Four studies discussed that preserving routines helped people to maintain independence, stay engaged and involved, as well as giving people reassurance amidst a time of change and uncertainty (Iacono et al., 2014; Lloyd et al., 2007; Sheth, 2019; Sheth et al., 2021).

Participants with Down syndrome spoke at length about the theme of accessing activities, including their regular schedules and routines, highlighting the importance of consistency in supporting participation. (Sheth, 2019)

5.5.2 | Relationships to others

All studies discussed that consistent and familiar relationships were important for people with intellectual disability and dementia and facilitated engagement in everyday activities and involvement in everyday decision-making. People with dementia continued to seek connections to others, albeit at times in new and different ways.

Andrew [sought connection] when he moved an enormous teddy bear that he had bought for companionship for the researcher to sit on a chair. Rose's "conversation" using noises, body language and expressions and Amy's insistence on showing staff and

other residents that she had a visitor, were all evidence of [their relating to others]. (Watchman, 2016)

Relationships to peers were central in Sheth et al. (2021) and friendships were described as offering people support when dealing with grief or distress. All studies highlighted how interactions with others impacted people's sense of self and it appeared that relationships could act as an empowering support but could also add to experiences of marginalisation and isolation. In two studies, people showed an awareness of how changes in their behaviour and abilities impacted on peers, and how this could lead to negative interactions and views of people as difficult or annoying (Forbat & Wilkinson, 2008; Lloyd et al., 2007).

She said that she 'goes on a bit' when she repeats herself, and that this annoys people: particularly her boyfriend. (Forbat & Wilkinson, 2008)

Forbat and Wilkinson (2008) stress the importance of supporting peers and partners in their understanding of dementia to facilitate positive interactions. Similar observations were made in relation to the importance of supporting staff and family members to respond to people in empathetic ways and understand behavioural changes as part of dementia to prevent disempowering interactions (Carling-Jenkins et al., 2012; Iacono et al., 2014; Manji & Dunn, 2010; Watchman, 2016).

5.5.3 | Concerns about the future: Sense of uncertainty

In three studies people directly expressed concerns about their future (Lloyd et al., 2007; Sheth et al., 2021; Watchman, 2016). People made reference to having witnessed peers moving away to specialised services or experiences of family members becoming ill or dying and reported fears about other people's wellbeing, worries that they themselves might need to move away from their current homes, as well as expressing fears about their own death.

Alice: I don't want to pass away, I don't want to die. I can't, I can't lose. Interviewer: Do you worry about that a lot? What can't you lose? Alice: Yeah (pause), I don't want to pass away. I don't want to get old. I don't want to go to heaven. I can't, I can't lose it. The way things are. (Lloyd et al., 2007)

There were indications that as people were not supported to make sense of their experiences, some had an increased sense of uncertainty, being aware that their abilities were changing, but now knowing why.

Andrew's mother had Alzheimer's disease, and he regularly tapped his head and asked "Am I the same as my

mum?," a question that ethically could not be answered by the researcher. (...) Andrew had awareness and understanding of dementia and by not getting answers his fears were growing. (Watchman, 2016)

5.6 | Context of experiences

The last sphere aims to provide an understanding of the wider context of people's lives and how it shaped people's experiences. Themes explore people's involvement in current decision-making, past experiences of marginalisation and stigma, and lastly, we discuss some positive examples where people were listened to and supported to be engaged and involved in everyday life.

5.6.1 | Involvement in decision-making

All studies detailed a lack of involvement of people in decision-making about their lives. This was most notably in relation to people not being told about their dementia diagnosis, but was also reflected in wider service delivery changes, such as people moving houses within their service or moving from one service to another without being consulted. Available funding and resources informed decision-making and shaped people's lives. Funding determined the amount of support people were receiving and availability of staff determined people's quality of care and access to activities (Carling-Jenkins et al., 2012; Forbat & Wilkinson, 2008; Iacono et al., 2014; Manji & Dunn, 2010; Sheth, 2019; Sheth et al., 2021; Watchman, 2016).

"[If] we are short-staffed at the house...somebody loses out there." (Manji & Dunn, 2010)

Additionally, available routines and activities were determined by services and the programmes rather than by individual choice. People were not always listened to and had to adhere to the schedule and programme of the service even when they clearly communicated their preferences not to attend some activities (Sheth et al., 2021; Watchman, 2016).

Karen initially did not engage in this structured programming, notably walking off from the main activity. When told several times that she needed to come join the group, she walked over and sat with the other participants, but did not engage. (Sheth et al., 2021)

There was an additional complexity of what 'home' meant for people who were dependent on funding and support to be able to live and stay in their current home. People had at times experienced frequent moves between services throughout their lives, often shared their homes with others, while their home was also the workplace of staff and services.

Cynthia discussed multiple group home moves when seeing pictures of previous housemates on her bedroom dresser. (Sheth et al., 2021)

5.6.2 | Stigma and marginalisation

All studies described how a focus on people's intellectual disability and associated cultural views influenced how staff and family members responded to changes in people. People's behaviours were often interpreted by staff as challenging, without seeing behaviour as an expression of distress and communication (Carling-Jenkins et al., 2012; Iacono et al., 2014; Sheth, 2019; Sheth et al., 2021).

we went out and bought like 2 dozen big glasses, new glasses for them. And watched, I watched him [break the glasses], and I don't think it's got to do with Alzheimer's, I think it's got to do with him being a shit. (Iacono et al., 2014)

Authors reflected that this was not a new experience for people and that it was likely that distress or resistance had previously been framed as challenging or bad behaviour by carers (Lloyd et al., 2007; Sheth et al., 2021). Furthermore, Sheth et al. (2021) and Watchman (2016) both described a lack of encouragement and interest of staff in people's emotional states and feelings.

Rose was not observed to interact with staff or other residents causing staff at one point to ask why Rose was always so pleased to see the researcher (...) and with the question asked if Rose "could talk when she was a young girl." Rose could talk when she moved into the care home but was not engaged in conversation by staff. (Watchman, 2016)

There was a recognition that while people's lives with dementia were narrowing, many had always had few relationships and support networks outside of family and professional networks.

Interviewer: Who are your friends? Charlie: Louise and Jane (residential home carers), they're my friends.
Interviewer: Who else? Charlie: Erm (pause) There's no one else. What do you mean? (Lloyd et al., 2007)

Two studies made references to people growing up at a time when many people with intellectual disability lived in institutions and were largely excluded from society (Carling-Jenkins et al., 2012; Watchman, 2016).

Amy had originally grown up and spent her childhood and early adult years in a long-stay institution. (Watchman, 2016)

5.6.3 | Positive examples of involvement in everyday life

While acknowledging wider experiences of marginalisation and organisational barriers, three studies included examples where staff and people had formed close relationships that enabled staff to listen to the person, being attuned to their way of expressing themselves and involving them in everyday decision-making (Iacono et al., 2014; Manji & Dunn, 2010; Sheth, 2019). This included offering flexibility in routines, responding to non-verbal ways of communication, and offering closeness and reassurance. Staff and family members showed commitment, love and affection for people, and were advocating on people's behalf.

Even when hospitalization was necessary, the staff maintained their physical and emotional support for the individual in hospital according to a direct-care staff: "We will continue to...help the nurse...and sometimes it's just to be there to support them." (Manji & Dunn, 2010)

6 | DISCUSSION

Findings show similarities and differences to what is known from research about the experiences of people with dementia without an intellectual disability. Descriptions of a decline in memory, physical abilities and everyday functioning, as well as a narrowing of people's social lives are similar to changes reported by people with dementia in the population without intellectual disability (Górska et al., 2018). Additionally, the included studies describe how people seek to affirm their identities, while being simultaneously aware of a change in themselves and their lives. Those are familiar tensions highlighted by people with dementia without an intellectual disability (Mazaheri et al., 2013; Steeman et al., 2013), with other studies stressing the importance of subtle support from family members and carers to help people adapt to changes and maintain purpose and involvement in everyday life (Górska et al., 2018; Wadham et al., 2016).

Family members, specifically partners or adult children, often take on caring and advocacy roles for the person with dementia without an intellectual disability and facilitate their participation and engagement in life (Lloyd et al., 2016; Pozzebbon et al., 2016). The role of family members was less prominent across included studies in our review and instead relationships to support staff appeared key in facilitating people's involvement in life. Many people with intellectual disability will have used support services throughout their adult lives (Bigby, 2008). Additionally, fewer people with intellectual disability are married, live together with partners or have children and often have limited informal support networks as their parents age or die (Power & Bartlett, 2019; Ryan et al., 2014). Most participants across the studies lived in group homes or residential settings which are environments that have been shown to limit people's choices as people's lives are governed and structured by daily routines and social norms

(Clement & Bigby, 2010; Svanellöv, 2020). Relationships to staff are accompanied by greater power inequality and there is often a lack of consistency in relationships (Jacobs et al., 2021; Svanellöv, 2020). Our data reflect similar issues showing how communication of distress or expressions of preferences or resistance can be disregarded and interpreted by staff as bad or naughty behaviour. Yet, findings also included examples of supportive and empowering care, showing how carers can take on advocacy roles and facilitate the participation of people in everyday life (Iacono et al., 2014; Manji & Dunn, 2010; Sheth, 2019).

While our data included examples of people being involved in making some everyday life decisions such as stopping their involvement in local activities or continuing to work, the loss of relationships to peers, family or previous carers due to service moves seemed to occur with none to very limited involvement of people within decision-making processes. Findings highlighted people's fears about moves and losing existing networks. This was connected to past experiences of moves where people had not been involved in decision-making. Other studies have shown how people with intellectual disability experience the loss of important relationships due to service moves and are dependent on staff to support ongoing relationships (Jacobs et al., 2021; Small et al., 2013). The risk of further service moves or transitions can be heightened with the onset of dementia (Bigby et al., 2011; McCarron et al., 2010; Patti et al., 2010). Intellectual disability services were described as struggling to support people towards more advanced stages of dementia, while also fearing that services for older people did not have intellectual disability knowledge to adequately care for people (Carling-Jenkins et al., 2012; Forbat & Wilkinson, 2008; Iacono et al., 2014; Manji & Dunn, 2010; Watchman, 2016). Yet, studies about the end of life of people with intellectual disability in the United Kingdom and the Netherlands provide evidence that intellectual disability services can support people with dementia to stay and die at home (Bekkema et al., 2015; Bernal et al., 2021). Nursing expertise and adequate equipment appear to be key factors that enable people to remain in their home towards advanced stages of dementia (Bekkema et al., 2015), emphasising the importance of collaborative practice between intellectual disability services and those with specific knowledge about dementia, primary healthcare and palliative care (Cleary & Doody, 2017a; Holst et al., 2018).

Most participants in the included studies were not aware of their dementia diagnosis. The complexities of dementia disclosure have been discussed in the literature on dementia for people without intellectual disability. Developments in the field show a move towards thinking about how to speak to people about dementia, rather than if a diagnosis should be disclosed or not. This highlights the nuances and complexities involved in taking a person-centred approach to having conversations about dementia, taking into account people's current stage of the disease, their existing understanding of dementia, people's support networks, as well as their right not to know (Merl et al., 2022; Milby et al., 2017). Studies on the perspectives of people with dementia about disclosure reflect differences in people's wishes and preferences. While some people prefer detailed information,

others prefer to know less (Merl et al., 2022; Robinson et al., 2011). Yet, there is agreement for clear language, the provision of practical guidance on how to live with dementia and positive messages and hope alongside the diagnosis (Lecouturier et al., 2008; Merl et al., 2022; Poyser & Tickle, 2019). Benefits of speaking with people about dementia include the possibility for stronger involvement in future care planning and helping people to make sense of changes they are experiencing (Merl et al., 2022; Robinson et al., 2011). There is less comparable research in relation to disclosing information about life limiting conditions to people with intellectual disability who often continue to be shielded from such bad news (Tuffrey-Wijne et al., 2013, 2020; Witham & Haigh, 2018). However, work on speaking to people with intellectual disability who have cancer similarly proposes that professionals and carers continuously assess what information should be provided when and how, taking into account people's current stage of the illness, their ability to understand abstract concepts (including time), their life experiences, support network and preferences around disclosure (Tuffrey-Wijne, 2013; Tuffrey-Wijne et al., 2017).

Participants not knowing about their dementia diagnosis also affected how researchers in the included studies were able to explore people's subjective experiences. Researchers who directly spoke to participants faced the complexity of asking people to reflect on something they were unable to name, nor did it seem that participants with intellectual disability and dementia had previous experiences in reflecting upon or talking about dementia. We believe this resulted in interview data that often felt as if deeper meaning stayed partially hidden, with brief answers to questions which required greater interpretation by researchers (Forbat & Wilkinson, 2008; Lloyd et al., 2007; Watchman, 2016). Across the studies, it was evident that people's somewhat limited expression of their subjective experiences was connected to a lack of experiences of being listened to and a lack of choice and involvement in decisions about their life. It is not possible to know how far people had felt listened to throughout their lives, and how such experiences impact on ability to share experiences with others. This was also striking in relation to thinking about opportunities for people to express and explore their emotions (Sheth et al., 2021; Watchman, 2016).

7 | LIMITATIONS

Sample sizes of included studies were all relatively small and two studies were published in 2007. This highlights the scarcity of available evidence with the associated lack of potential for generalisation; participants included in the studies were not a representative sample of all settings and contexts. It also emphasises the need for new studies to advance understanding of the experiences of people with intellectual disability and dementia and to allow reflection on how practices and experiences might have changed. All studies were conducted in North America, Australia or the United Kingdom. Experiences of people in countries with different policies, service provision and cultural contexts will likely be very different. Additionally, with the exception of one participant who remained living with family (Carling-Jenkins

et al., 2012), all participants with intellectual disability and dementia had moved out of their family home and were supported by services at the time of data collection. While this included some people in supported living, the studies mainly featured people in residential or group homes. Many people with intellectual disability live with family members into old age supported by siblings or ageing parents (Bibby, 2013; Finkelstein et al., 2020; Knox & Bigby, 2007), while an increasing number live in their own accommodation (Larson et al., 2017; Scottish Consortium for Learning Disabilities, 2022). Thus, the majority of included studies do not reflect the experiences of people with intellectual disability and dementia living alone or those supported by family members.

8 | CONCLUSION

This is the first review to synthesise findings from a small but growing number of studies which attempt to include people with intellectual disability and dementia in research to explore their experiences. Our findings highlight the experiences of people with intellectual disability and dementia across three spheres. Descriptive and subjective experiences were influenced by, and needed to be understood within the wider context of people's lives. Others have argued for the value of exploring different layers to understand experiences of dementia (Górska et al., 2018; Shakespeare et al., 2019). Similar to our review, in a meta-synthesis of the experiences of people with dementia without an intellectual disability, authors frame their findings by utilising an ecological perspective, describing condition-related changes, how people respond to those changes and how contextual factors impact people's lives, aiming to understand the dynamic interplay between individual and environmental factors (Górska et al., 2018). An ecological focus is consistent with conceptualisations of disability within the World Health Organisation's (WHO) International Classification of Functioning, Disability, and Health (ICF) (World Health Organisation, 2001) and the Conventions of the Rights of People with Disabilities (CRPD) (United Nations, 2006). Both the ICF and CRPD use an ecological perspective to conceptualise disability as a dynamic interaction between the individual and their environment and an awareness of different layers will be important in future studies to explore the experiences of people with intellectual disability and dementia.

People's subjective experiences and views on how dementia affected their lives were more ambiguous compared to contextual data and the descriptive portrayal of how people's lives had changed. Thus, this review highlights the importance of researchers needing to consider how to facilitate conversations with people about their experiences and the ethics involved in conducting qualitative research with people with intellectual disability and dementia, particularly how to respond to participants not knowing about their dementia diagnosis. Spending time with participants over a longer period, getting to know how people communicate and the use of visual aids or everyday items were examples of approaches that supported research involvement.

Overall, despite an established tradition of inclusion and inclusive research methods with people who have an intellectual disability, this

does not extend to individuals who also have dementia. The lack of available studies highlights limitations to understanding the experiences of people with intellectual disability and dementia. This is often dependent on factors beyond the control of the person with intellectual disability, for example lack of a shared diagnosis or communication not adapted in response to individual need. Recognising such challenges and the importance of ethical considerations, the papers included have demonstrated ways in which people with intellectual disability and dementia have been included in research and how some of these challenges may be addressed. This is an important step in understanding experiences and enabling a more individualised and person-centred approach to care and support.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

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