

REVIEW ARTICLE

# Couples with intellectual disability where one partner has dementia – a scoping review exploring relationships in the context of dementia and intellectual disability

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## Abstract

Relationships and marriages between couples with intellectual disability are to be celebrated, as is the longer life expectancy now enjoyed by many with intellectual disability. However, dementia disproportionately affects people with intellectual disability, especially people with Down's syndrome. Research into experiences of couples without intellectual disability who are affected by dementia suggests that a relational perspective provides health and social care professionals with information to support the wellbeing of both partners. This dyadic perspective is missing for couples with an intellectual disability where one partner has dementia. There is currently no evidence base informing how each partner may best be supported. This scoping review, with three separate searches, aims to address this gap. The first search sought to establish if any studies had explored the experiences of couples with intellectual disability where one partner has dementia. After determining that no studies have been published to date, the review explores what is known about relationships in the context of dementia (N = 8) and in the context of intellectual disability (N = 10), in second and third searches. Different ways to approach care and support in relationships among partners, staff and other family members were identified and it was evident that support could act as a facilitator as well as a barrier to people and their relationships. While the lives of couples affected by dementia appeared to remain largely private, couples with intellectual disability had a high involvement of staff and family members in their life. Potential implications for future research with couples with intellectual disability affected by dementia are discussed, highlighting the importance of exploring how couples navigate emotional complexities and changes in their relationship, while understanding that the context in which the lives of people with intellectual disability take place and relationships happen is different.

**Keywords:** dementia; relationships; Down's syndrome; couples; intellectual disability; learning disability; care

## Introduction

Dementia not only affects the person with the diagnosis but also other people in their life. While individualistic deficit-views have dominated the field of dementia research for many decades, there has been a shift towards challenging those models by emphasising the importance of a relational understanding of dementia, one that sees people in the context of their relationships to others (Kitwood, 1997; Sheard, 2004). As McGovern (2011) argues, viewing dementia through the lens of affected relationships encourages and supports togetherness rather than separation, and allows space to see people as active and positive contributors to relationships. This shift in understanding is reflected in a growing body of studies that explore the experiences of couples where one partner has dementia (Evans and Lee, 2014; Wadham *et al.*, 2016; Bielsten and Hellström, 2019). Studies which focus on experiences of couples suggest that a better understanding of the dyadic perspective offers health and social care services and key stakeholders essential information to support positive relationships and the wellbeing of both partners (Miller *et al.*, 2016; Stockwell-Smith *et al.*, 2019). Such a dyadic perspective is missing in research for people with intellectual disability where one partner has dementia. There is currently no evidence base informing how each partner with intellectual disability may best be supported, and how relationships may be sustained.

People with intellectual disability are at increased risk of dementia. The incidence of dementia in people with intellectual disability other than Down's syndrome has been found to be up to five times higher than in the general population (Cooper, 1997; Strydom *et al.*, 2013). The risk is higher for people with Down's syndrome and increases with age, with estimates that more than half of people 60 or over will have dementia (McCarron *et al.*, 2017; Bayen *et al.*, 2018). Older adults have been identified as a rapidly growing group among people with intellectual disability in many western countries (Bittles *et al.*, 2002; Emerson and Hatton, 2008; Coppus, 2013; Ng *et al.*, 2015). Consequently, the prevalence of dementia among people with intellectual disability is also increasing and support for people to age well has been of increasing interest to researchers, practitioners and policy makers (Scottish Government, 2013; Chapman *et al.*, 2018). Older people with intellectual disability may experience additional challenges due to effects of lifelong disability and more general effects of ageing, which has led to some consensus that people with intellectual disability may be 'old' from the age of 50 onwards (Grant, 2001; Cooper *et al.*, 2015). In people with Down's syndrome 'old' age may be reached even earlier in life. A baseline assessment of typical functioning from which to measure any health change, including dementia, is recommended at age 30 in the United Kingdom (UK) (Down's Syndrome Association, 2018). Indeed, almost all individuals with Down's syndrome experience frontal lobe changes by age 40, even if not all will go on to develop the symptoms of dementia (Saini *et al.*, 2022). Furthermore, people with intellectual disability face inequalities in relation to health-care access, with poorer experiences of assessment and treatment processes (Heslop *et al.*, 2014; Truesdale and Brown, 2017; O'Leary *et al.*, 2018).

Such inequities are of concern in older age and difficulties have been highlighted for people in receiving a dementia diagnosis and appropriate post-diagnostic

support (Chapman *et al.*, 2018). Research about dementia in people with intellectual disability focuses largely on issues around recognition of dementia, support and training needs of staff, or highlights experiences of family members (Furniss *et al.*, 2012; Perera and Standen, 2014; Cleary and Doody, 2017). Few studies have explored the experiences of people with intellectual disability who have dementia (Lloyd *et al.*, 2007; Sheth, 2019). Additionally, there have been a limited number of studies exploring peer relationships in the context of intellectual disability and dementia (Forbat and Wilkinson, 2008; Watchman *et al.*, 2020). Available studies highlight how dementia affects the person and impacts on relationships with others, including friends and those with whom they live (Lloyd *et al.*, 2007; Forbat and Wilkinson, 2008; Sheth, 2019). While there has been recognition of the need to support peers alongside the person to help maintain positive relationships and interactions, there have been no studies to our knowledge that consider the experiences of couples with intellectual disability where one partner has dementia. Relationships are important for people's wellbeing and there has been a shift over past decades in policy and practice to recognise the right of people with intellectual disability to have intimate relationships (United Nations, 2007). Relationships and marriage can provide a sense of belonging, security and acceptance, and enhance the quality of life for people with intellectual disability (Lafferty *et al.*, 2013). However, there is also an awareness that people with intellectual disability continue to face barriers to forming and maintaining relationships (Bates *et al.*, 2020).

### Review aims

Scoping reviews are helpful to provide an overview of existing knowledge and look at intersections between concepts and themes, as well as identifying research gaps and informing future research (Arksey and O'Malley, 2005; Tricco *et al.*, 2016). This review initially sought to address the gap in evidence on couples with intellectual disability where one partner has dementia. After determining in an initial search (1) that research has not been published on this topic, we drew on intersecting topics in order to identify key themes and areas of interest that are relevant to future studies seeking to understand the experiences of couples with intellectual disability where one partner has dementia. Subsequent areas of review were: (2) experiences of couples where one partner has dementia (without intellectual disability) and (3) experiences of couples with intellectual disability (without dementia).

### Methods

The scoping review consisted of three independent searches. Search 1 involved a search for research on couples with intellectual disability where one partner has dementia, to establish if any research on this topic existed. Search 2 involved a search for research on couples where one partner has dementia and search 3 involved a search for research on couples with intellectual disability. The review followed Joanna Briggs's guidance (Peters *et al.*, 2015) to develop the review aims, inclusion criteria and search terms.

### **Inclusion and exclusion criteria**

Inclusion and exclusion criteria were established to guide the screening process to provide transparency and establish limitations to the review. Inclusion criteria required articles to be: peer-reviewed, qualitative research, published since 2000, and relevant to current service provision, policy and practice (for searches 2 and 3 only). Topic specific criteria were also included in each search. This was an iterative process that involved initial searches to develop familiarity with the existing evidence base. For example, an initial search of PsychINFO identified four systematic reviews that synthesised findings of qualitative studies on the experiences of couples where one partner has dementia. This indicated that for search 2 there were more than 30 studies that would meet our inclusion criteria. Thus, we took the decision to perform a review of reviews for search 2 to explore experiences of couples with dementia. Conducting a review of reviews allows for findings of separate reviews to be compared and contrasted (Smith *et al.*, 2011). Additionally, after an initial search for studies on the experiences of couples with intellectual disability, a decision was taken to exclude studies if the majority of participants were aged under 30 years. Our main research topic of interest lies with older couples with intellectual disability, and it became evident that their experiences differ from those of younger generations. Older adults are more likely to have experienced greater barriers to form and maintain relationships due to past societal attitudes and will also have experienced a different service provision context, with higher segregation and less community involvement in many past services (Craft and Craft, 1981; Welshman and Walmsley, 2006). Details of our inclusion and exclusion criteria for each search are given in Table 1.

A quality assessment is generally not performed as part of a scoping review where the objective is to focus on existing knowledge and areas of interest rather than assessing the quality of evidence as is typically seen in systematic reviews (Arksey and O'Malley, 2005; Pham *et al.*, 2014). The option of multiple structured searches in a scoping review rather than one in a systematic review was appealing given the focus in an area where there has not yet been published research. Limitations are also acknowledged with a lack of identifying robustness or rigour of the included studies. To mitigate this, we used the inclusion of peer-reviewed publications as a measure of quality (Pham *et al.*, 2014) and considered, as part of the data extraction process, how each study enabled and facilitated the involvement of people with dementia, and people with intellectual disability.

### **Search strategy**

Search terms were developed using PCC (Population–Concept–Context) (Peters *et al.*, 2015). We drew on existing studies to identify synonyms and related concepts for the main keywords (couples, intellectual disability, learning disability, dementia and qualitative research). The sensitivity of our search was tested using a set of indicator papers already identified as relevant for searches 2 and 3. For searches 1 and 3, we combined only Population and Context or Concept search words to ensure the searches were wide enough to identify existing studies. For search 1, we included the historic term ‘mental retardation’ as this was a term that was widely used in the past and we wanted to capture older studies on this topic. Search terms were

**Table 1.** Inclusion and exclusion criteria

Research topic and search	Inclusion and exclusion criteria
Search 1: couples with intellectual disability and dementia	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> <li>• Does the article contain information about couples with intellectual disability where one partner has dementia?</li> <li>• Is the information based on an original research study?</li> </ul> <p>No limitations relating to year of publication</p>
Search 2: couples with dementia (review of reviews)	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> <li>• Is it a peer-reviewed review? (including systematic, scoping and narrative reviews)</li> <li>• Is it a review of qualitative studies?</li> <li>• Is it a review of studies with primary data?</li> <li>• Does the review focus on couples where one partner has dementia?</li> </ul> <p>Exclusion criteria:</p> <ul style="list-style-type: none"> <li>• Not a peer-reviewed review</li> <li>• Includes a focus on the experiences of adult children or other family care-givers</li> <li>• Mixed-method or quantitative reviews</li> <li>• Published before 2000</li> <li>• Not available in English</li> <li>• Focus not exclusively on dementia</li> </ul>
Search 3: couples with intellectual disability	<p>Inclusion criteria:</p> <ul style="list-style-type: none"> <li>• Does it contain primary data?</li> <li>• Is it qualitative?</li> <li>• Does it include experiences of adults with intellectual disability over 30 years of age (or those who support them)?</li> <li>• Does it include findings about being in and maintaining relationships?</li> </ul> <p>Exclusion criteria:</p> <ul style="list-style-type: none"> <li>• Mixed-method or quantitative studies</li> <li>• Not peer-reviewed journal articles with primary data</li> <li>• Focus on adolescents or young adults</li> <li>• Focus on sexuality or love in abstract terms</li> <li>• Published before 2000</li> <li>• Not available in English</li> </ul>

combined and used in three databases (PsychINFO, CINAHL, Social Services Abstract; abstract and title) alongside a subject heading search. Additionally, experts within the field were contacted to ask if they were aware of research that had been undertaken, or was ongoing, about couples with intellectual disability affected by dementia, a search of ProQuest Theses was conducted and an advanced Google domain search was undertaken as part of search 1. For searches 2 and 3, reference lists of included articles were screened to identify studies that might have been missed and we used Google Scholar to identify sources that cited included articles since their publication. An overview of search terms with truncations is shown in Table 2. The process was supported by a subject expert librarian and the first search was conducted in May 2021. The search was later updated to include

**Table 2.** Search terms

Research topic and search	Population	Concept	Context
Search 1: couples with intellectual disability and dementia	Couple* or wife or wives or husband* or girlfriend* or boyfriend* or spous* or personal relationship* or intimate relationship* or romantic relationship* or lov* or married or marriage or significant other AND Learning disabilit* or intellectual disabilit* or developmental disabilit* or mental retardation* or Down* syndrome		Dement* or Alzheimer*
Search 2: couples with dementia	Couple* or wife or wives or husband* or girlfriend* or boyfriend* or spous* or partner* or personal relationship* or intimate relationship* or romantic relationship* or lov* or married or marriage or significant other	Experience* or View* or Meaning* or Qualitative or Perspective* or Support or Barrier* or Relationship* or Care*	Dement* or Alzheimer* AND Review* or Synthesis
Search 3: couples with intellectual disability	Couple* or wife or wives or husband* or girlfriend* or boyfriend* or spous* or personal relationship* or intimate relationship* or romantic relationship* or lov* or married or marriage or marital AND Learning disabilit* or intellectual disabilit* or developmental disabilit* or Down* syndrome	Experience* or View* or Perspective* or Support or Barrier* or Relationship* or Care* or Meaning or Qualitative	

publications that had been added to the three databases between May and October 2021. Details of the full strategy can be obtained on request.

### Search process

The three searches were conducted independently of each other and results were extracted into Covidence systematic review management software (Veritas Health Innovation, [nd](#)). The screening of titles and abstracts was conducted by one reviewer and all full-text records were assessed independently by two reviewers. Conflicts were resolved by a third reviewer, and difficult decisions were taken after discussions with the whole review team.

In search 1, combining couples with intellectual disability and dementia yielded few results across the three databases, as expected. Titles and abstracts of 57 records were screened against the inclusion criteria, and 51 were identified as not relevant as they related largely to genetic research and animal studies. Six full texts were retrieved but none met our inclusion criteria; two included information on couples with intellectual disability but without the presence of dementia, one was a duplicate, and three were not original research studies – including a practice case study from a nursing perspective and a personal account of a man with intellectual disability about living with his wife who had Alzheimer's disease.

Search 2 yielded 556 records. After screening title and abstract, 56 articles were retrieved and assessed for full-text eligibility with eight reviews meeting the inclusion criteria. The most common reason for exclusion at full text were reviews that included discussions of the experiences of other family members such as experiences of adult children or siblings. Quantitative and mixed-method reviews were excluded, but after discussions within the team it was decided to include the review by Holdsworth and McCabe (2018a), which includes two quantitative studies. It was unclear how the quantitative data were used by the authors in this review, with the findings section providing only a synthesis of the qualitative findings. Additionally, reviews which compared experiences of dementia with other health conditions such as depression were excluded.

In search 3, titles and abstracts were screened from 1,604 records, with 1,521 not meeting the inclusion criteria. Eighty-three records were retrieved and assessed for full-text eligibility with ten studies meeting the inclusion criteria. The most common reasons for exclusion at full text related to studies that focused on sexuality and on barriers for people to form relationships, without including data on people being in or maintaining relationships. Fifteen studies were excluded because they focused on the experiences of young adults with intellectual disability. We also excluded one study that focused on parents with intellectual disability.

No additional studies were identified through the screening of reference lists. An overview of all screening processes can be seen in Figure 1.

### **Data extraction and analysis**

Firstly, we collected information about the characteristics of included studies (year of publication, author names, country), followed by looking at how research was conducted, and whose perspectives were included (methodological findings). This first step of the data extraction process helped us to provide an overview of the included articles.

Secondly, we combined inductive and deductive approaches during the analysis and coding of articles, addressing predefined areas of interest while remaining receptive to unforeseen concepts and themes of relevance. The intention was to identify key themes related to each search rather than to synthesise across both (Pollock *et al.*, 2021). We started by coding articles line by line in relation to everyday experiences, support needs, and barriers and facilitators to support and maintain relationships and summarised those for each article (Tables 3 and 4). We developed new codes for content that did not fit our existing coding framework. New codes were re-read and connections were established leading to the

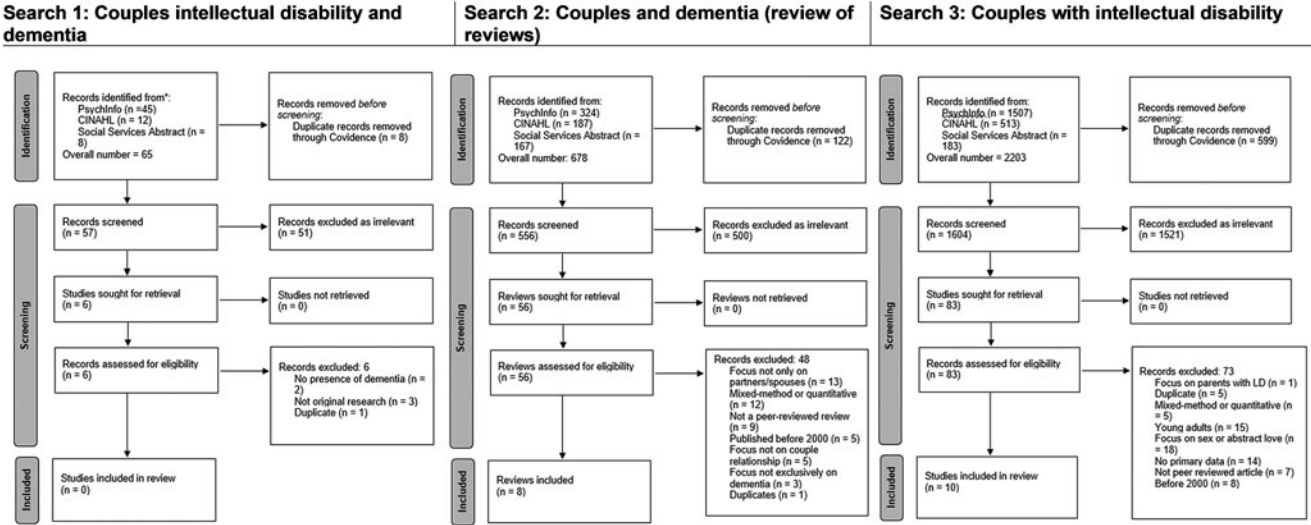


Figure 1. PRISMA flowcharts for searches 1–3.



**Table 3.** Overview of included reviews search 2

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Evans and Lee (2014) Australia	To understand the impact of dementia on marriage. Includes the experiences of both partners (married couples).	Systematic review. 19 studies included, of those 15 focus on the perspectives of the 'care-giver' and 4 include the perspectives of both partners. Thematic analysis used to synthesise data. Exclusion criteria: couples who are not married.	Changes in the relationship and daily routines are gradual. They are small at first but impact all aspects of life later on ('it creeps in'). It is not a linear process, changes can be sudden, 'jumps and starts'. The relationship becomes more unequal (care-givers and receivers, parent and child). Partners take on new tasks, which their spouse used to do. Spouses often support them slowly taking over. The changes in the relationship mean that both partners relate to each other differently. Some wonder if their relationship still constitutes a marriage, some still feel married and others do not. There is often less cognitive and physical intimacy but more emotional intimacy (cuddling, holding hands, just being together).	Getting the diagnosis can help partners to understand changes in their spouse and it can make it easier for them to be supportive. Partners can struggle with the fear of being alone in the future.	Life for couples often becomes narrower and partners often feel like they cannot do the same things together anymore, particularly in public life. Couples feel that friends and members of the public often do not understand 'odd' behaviour.

*(Continued)*

Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Egilstrød <i>et al.</i> (2019) Denmark	To understand the experience of spouses, their needs and how they manage changes in everyday life. Focus on the experience of care-givers.	Systematic review. 15 studies included, of those 3 include the perspectives of both partners. Thematic analysis used to synthesise findings. The review panel included spouses with a partner with dementia as lay-experts. Exclusion criteria: partners that do not live together or presence of advanced dementia.	Couples are in a state of transition, where they need to find a new normality. Partners can downplay and ignore changes in their spouse in the beginning. Often couples support each other to come to terms with the condition, but sometimes partners can be unsure if their spouse understands or feel that their spouse does not like to talk about dementia. Partners take on new tasks (household chores) as well as new caring tasks to support their spouse. Practicalities of performing tasks become the new focus of the relationship and everyday life. Some partners can find it empowering to have greater responsibility, while others struggle. The caring role can bring personal growth. The relationship becomes more unequal. Loss of meaningful communication and mutual activities is often linked to a decrease in intimacy.	Getting the diagnosis can be a relief and help partners to understand, but it can also come as a shock and cause worries about the future. Decisions around institutionalisation of their spouse is often very difficult for partners to make. Partners need support to be able to spend time without their spouse to have a break from their caring role. Partners can feel ambivalence towards their spouse. They can feel resentment and deep empathy at the same time.	Asking for support can be difficult due to associated taboos and stigmas. Some partners seek isolation, while others join groups to share mutual experiences. Spouses feeling exhausted and stressed by their caring role, negatively affecting their partner and the relationship.

(Continued)

Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Wadham <i>et al.</i> (2016) UK	To understand the impact dementia has on relationships, as well as the impact relationships have on dementia. Focus on the experiences of both partners (shared experiences).	Systematic review. 10 studies included, all include the perspectives of both partners. Meta-ethnography used to synthesise findings.	Dementia affects both partners, and as a shared experience creates a shared identity ('we are together in this'). Some partners see the support they provide as returning the favour for having been supported in the past. As roles become more unequal couples try to protect and prepare each other (e.g. teaching tasks like cooking), while for others role changes happen implicitly. Role changes impact people's sense of identity, particularly gendered identities. The fear of losing each other can bring couples closer. Others describe growing apart and losing the person they once knew. Couples reminisce about the past, live in the present and try to avoid thinking about the future.	Both partners can feel powerless in the face of dementia. Avoiding emotions of loss can lead to exhaustion of partners. Spouses fear becoming a burden and often conceal difficulties. Some partners feel it is their choice to stand by their spouse. Others feel it is their duty. Feelings of duty can lead to feelings of resentment and being trapped. Partners can experience both at different times.	Couples often see dementia as something external and they can become allies against dementia. Some partners try to promote their spouse's independence as long as possible ('supporting in subtle ways') and emphasise abilities over failures. This can help to uphold identity and foster meaning. Humour can help and knowing that other couples experience the same.

(Continued)

Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Nel and Board (2019) UK	To understand older husband's experiences of caring for their wives who have dementia. Focus on the experiences of men as care-givers.	Systematic review. 6 articles included, all focus on the perspectives of men as care-givers. No information about data synthesis provided.	Caring for their spouse is an expression of their commitment and loyalty for men. Some view care-giving as a reciprocal process, as 'paying back' for the times their spouse looked after them. As the relationship changes, men feel the loss of previous companionship and interactions.	Men need respite and time without their spouse to have a break from their caring role. Men can struggle to find spaces to share their experiences with others.	Men can feel invisible in their care-giving role. It can be difficult to rely on the support of friends or other family members. This was different in the included study of Malay husbands in Singapore, where the extended family is the main support system within a communal family culture. Access to safe support groups (all-male) can help men to share their experiences. However, most support groups are seen to focus on female carers and men can feel uncomfortable attending those. Men report a lack of temporary respite options.

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Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Pozzebon <i>et al.</i> (2016) Australia	To understand how spouses respond to, manage and negotiate changes in the relationship, particularly cognitive-behavioural changes of their partner. Focus on the experiences of care-givers.	Systematic review. 16 studies included, 4 include the perspectives of both partners. Thematic analysis used to synthesise findings. Exclusion criteria: couples who do not live together.	Partners describe a feeling of having lost their spouse as the relationship changes. As the relationship becomes more unequal (parent-child, partner-care provider) some partners feel less connected and this can lead to less physical intimacy. Dementia can be seen as a crisis in the couple identity as couples need to re-negotiate roles and routines. Some partners feel like they are not single but also no longer in a 'normal' marriage. The past history of couples influences responses to changes. Partners with a history of past conflict can struggle to be empathetic. A positive history and emotional closeness can make it easier for partners to accept and move on.	Changes in their spouse's personality and behaviour in everyday life can be difficult to understand for partners. Frustrations with changes in language abilities can lead to partners communicating less. The loss of their partner as a companion and someone to talk to can increase experiences of loneliness and burden. The diagnosis can help partners to understand the changes they see in their spouse and to respond with more compassion. Partners worry about the future (worsening of the condition as well as death of spouse).	Partners can struggle to ask friends or family members for help ('only concerns the two of us'). They can evade disclosure to avoid stigma and shame. This can lead to increased social isolation. Sharing memories of the past can help couples to stay and feel connected. Doing tasks together and supporting ongoing involvement of spouses can facilitate reciprocity and closeness.

(Continued)

Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Holdsworth and McCabe (2018a) Australia	To understand the impact of dementia on relationships, intimacy and sexuality in later life couples. Includes the perspective of both partners.	Systematic review. 11 qualitative studies included (2 quantitative), 10 include the perspectives of both partners. Themes were developed with the support of NVivo10. Exclusion criteria: participants under 60, homosexual couples, partners with dementia living in residential care.	Dementia brings changes in everyday lives for couples. Partners take on additional responsibilities, including the personal care of spouses, which can lead to feeling overwhelmed. Crossing gender boundaries to fulfil new tasks can cause partners anxiety. Relationships become more unequal (parent–child), which negatively impacts intimacy and sexuality. Some feel a new sense of intimacy based on kindness and care, with more frequent expression of love for each other. There can be a shift towards hand holding and cuddling as sex declines, others continue to have sexual intimacy. The history of the relationship influences how couples navigate changes.	Spouses can experience anger and depression as their memory declines and their dependency increases. This can lead to spouses struggling with their sense of identity. Partners often experience the loss of their spouse as a communication partner. Partners can feel annoyed with spouses, feeling guilt afterwards. Some partners wish to enter new relationships. Spouses can be concerned about the stress experienced by their partners and acknowledge the support they receive from partners.	Maintaining independence is important to spouses. Many partners support active involvement of their spouses in daily life ('subtle assistance'), focusing on successes and abilities over mistakes and difficulties. As dementia progresses this can become more difficult to do. Towards later stages couples try to avoid triggers and conflict. Couples focus on what remains the same amidst changes, taking 'one day at a time'. Some take joy in everyday routines such as sharing a meal or massage. Their love and commitment help couples to cope with changes.

(Continued)

Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
Holdsworth and McCabe (2018b) Australia	To understand the impact of young onset dementia on couple relationships, intimacy and sexuality. Includes the perspectives of both partners.	Systematic review. 11 studies included, 2 include the perspective of the partner with dementia and 1 focuses on the perspective of the couple. No information about data synthesis. Exclusion criteria: dementia onset in people over 65 years of age, homosexual couples.	There is often a decline in relationship quality. Partners can feel resentment and impatience towards their partner's changes in behaviour and daily functioning. There are changes in roles and increasing responsibilities for partners. Additional responsibilities can lead to exhaustion. Some find it difficult to provide care, others find satisfaction in their new role; often people can experience both at the same time. Spouses can feel being treated like children and want to maintain some independence. This can lead to conflict. Dementia and abilities fluctuate which can make it difficult to negotiate autonomy and care roles. As the relationship becomes more unequal there is often a change in intimacy and it can be difficult to negotiate sexual relationships. Partners experience the loss of their spouse as someone to talk to about their struggles.	The diagnosis can help partners to understand changes in their spouse and to facilitate the beginning of a process of grief for their past life. Verbal communication often decreases. Spouses can feel guilt about the impact of dementia on the family. They often experience the loss of their former identity and a future with their partners, children and grandchildren. Similarly, their partners can experience a change in identity from professionals to informal care-givers.	With increasing behaviour changes often comes increasing social isolation and narrowing of social lives for both partners. Partners can feel 'trapped' in their care-giver role and some want to protect their partner from social embarrassment. Spouses often lose their work and friend networks, and experience a lack of meaningful activities. Couples can experience financial pressures as spouses stop working, and partners need to decrease or stop work to provide care to their spouse, as well as paying for formal support. Some couples find a new closeness in 'just being together' and some feel united in 'us against dementia'.

(Continued)

Table 3. (Continued.)

Author, year and country	Aim and focus	Method	Findings in relation to everyday experiences	Findings in relation to support needs	Findings in relation to facilitators and barriers
MacDonald <i>et al.</i> (2020) Canada	To understand the experiences and perceptions of partners providing care for community-dwelling adults with dementia. Focus is on the experience of care-givers.	Systematic review. 19 studies included, all focus on the perspective of spouses as care-givers. Meta-aggregation used to synthesise findings. Exclusion criteria: partners with dementia living in supported or residential care.	Partners become multi-taskers, as they take on new tasks and roles. Men can take on traditional women's work (housekeeping) and women traditional men's work (finances). As needs and behaviours change, partners experience unpredictability in how to best support their spouse. Couples experience the loss of their past life, they remember their past relationship, need to learn to accept their new life and try to move forward. This is an individual process and different for every couple. Partners can experience a continuum of emotions from grief, love, to a sense of empowerment. Dementia can take over the life of the couple, as partners feel less able to have visitors in their home or to go out.	Access to information and external resources is important for partners to understand the diagnosis and changes in their spouse. Partners need to learn strategies to respond to challenging behaviour towards themselves, as well as keeping their spouse safe. Partners can experience gradual social isolation as disruptive behaviour of their partner increases. Partners can keep difficult experiences to themselves to protect their children and other family members and avoid embarrassment. Partners struggle with the uncertainty of each day and the future.	There can be a lack of information at the early stages of dementia. Partners can feel invisible and unsupported by the health system and general public. Available support is not affordable for all and partners often experience financial pressures. Some partners can find it difficult to accept external support. Support groups can be helpful. Partners often draw on 'inner' resources such as their love for their spouse, extended family and community support, their faith and humour.

Note: UK: United Kingdom.



Table 4. Overview of included studies search 3

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Abbott and Burns (2007) UK	To understand what helps and hinders LGB people with intellectual disability to express their sexuality and form relationships. Includes the perspectives of people with intellectual disability and staff.	Semi-structured interviews with 20 people with intellectual disability who identify as lesbian, gay or bisexual. Ages: 22–59, most in their thirties and forties. Semi-structured interviews with 71 staff across 20 services. Using a constant-comparative approach to analyse data.	Relationships are important to people, they provide love, support, care, romance, intimacy, companionship and commitment. People value the reciprocity of romantic relationships and sharing their life with someone else. People's hopes and aspirations for relationships are not different to those of people without a learning disability. It is the context in which relationships happen that is different, due to high involvement of professionals and family members.	It can be difficult for people to maintain relationships when one person moves. It is important that staff support people to maintain relationships. Many people feel isolated and feel like they have few people in their lives they can talk to. People would like support to go to LGB places and become part of the LGB community. Many people are dependent on staff to access social networks and spaces.	People need to negotiate their identity and rights with their dependence on services, staff and family. Some people have been told that they are not allowed to have relationships. Some keep their relationships a secret from staff or family members. Living independently can help people to express their sexuality and form relationships. People can be scared to come out to others. Many people have had negative experiences, including from family members and staff. Some feel their family or staff might make them leave their home, services, support groups or jobs if they talk openly about their sexuality. Staff can feel reluctant to get involved in issues that relate to people's relationships and sexuality. Staff can feel a lack of confidence to support LGB people and some are worried about adverse reactions from family members or other members of staff. Wishes of families can be respected over the wishes of the person.

(Continued)

**Table 4.** (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Bane <i>et al.</i> (2012) Ireland	To understand the views of people with intellectual disability about relationships and the support they need to have and keep them. Focus on the perspective of people with intellectual disability.	16 focus groups with 97 people with intellectual disability. Ages: 42 participants over 30, 17 under 30, other ages unknown. Focus groups facilitated by researchers with intellectual disability and academic supporters. Thematic analysis, easy-read summaries, pictures and role play used to analyse the data.	A partner is someone who cares, offers support and with whom to do activities. People enjoy being with someone who cares about them and to share physical closeness. Some people are not sure what the difference is between friends and romantic relationships.	Some people can feel embarrassed to talk about love and relationships.	Parents can be strict and are not always supportive of relationships. Some people feel that they are being treated like children instead of adults. Staff and family members can offer support to people to talk about relationship problems. People are aware that support from staff depends on funding. Access to transport is important for couples who do not live together. Having their own accommodation helps people to develop and maintain relationships.
Bates <i>et al.</i> (2017) UK	To understand the importance of love to people with intellectual disability in relationships. Focus on the perspective of people with intellectual disability.	Semi-structured interviews with 11 people with intellectual disability (including couples). Ages: 5 participants over 35 and 6 under 35. All participants were heterosexual and had experiences of relationships lasting over 6 months. Van Manen's hermeneutic phenomenological approach used to analyse the data.	Love is important to people. Partners can provide people with companionship and more 'than just a presence'. Partners can support each other, reducing the reliance on staff. Being in a relationship gives people a sense of pride, social status and normality. People enjoy physical intimacy and affection. Experiences of love in a romantic relationship can help people to reconcile past experiences of marginalisation and abuse.	Some people require the support of staff to develop and maintain relationships. This includes open advice around physical intimacy. People can feel lonely even if they have daily contact with staff or other housemates.	Open and supportive attitudes of staff and services are important facilitators.

(Continued)

Table 4. (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Bates <i>et al.</i> (2020) UK	To understand the experiences of UK support staff helping people to develop loving and lasting relationships. Focus on the perspective of support staff.	Focus groups with 26 social care support staff (23 women, 3 men). Thematic analysis used to analyse the data.	Relationships are important to people's lives, providing love and companionship. This is also true if there are difficulties in relationships, such as one partner developing dementia.	People might express their need for belonging and love in different ways and might find it difficult to verbalise it. People can place themselves at risk. This includes people entering abusive relationships, as well as behaving sexually inappropriately towards others. Staff struggle to balance supporting relationships with keeping people safe and feel they need more training on how to support relationships.	Most staff understand people's desire to have intimate relationships. Staff view people who live independently with small support packages as the most vulnerable, with little opportunity to support people to develop and maintain loving relationships. Old-fashioned staff attitudes are a barrier for people to develop relationships. Staff can be judgemental towards people showing physical affection. Services are often reactive rather than proactively supporting relationships. Staff often lack training on how to support relationships and are unsure about their organisation's stance and policies.

(Continued)

Table 4. (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Lafferty <i>et al.</i> (2013) Northern Ireland	To understand the experiences of couples with intellectual disability. Focus on the perspective of people with intellectual disability.	Semi-structured interviews with 8 heterosexual couples (16 participants). One joint and one single interview. Ages: 15 participants were over 30, 8 were over 50. Grounded theory used to analyse the data.	Couples in relationships value their love for each other and comradeship. Relationships are characterised by reciprocity and mutuality. People take care of each other, support each other with different tasks and look after each other when one is unwell. Being in a couple can help people to be more social and active. This can increase people's independence and self-esteem. People are committed to each other through ups and downs.	Some people have had negative experiences in past relationships including domestic abuse and having money taken from them. Before being in a relationship some people felt lonely and isolated.	People wish to live together or close to each other. Living far away from each other can make it difficult for people to see each other due to a lack of access to transport.

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Table 4. (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
McCarthy <i>et al.</i> (2022) UK	To explore relationship issues with adults with intellectual disability. Focus on the perspective of people with intellectual disability.	Semi-structured interviews with 40 adults with intellectual disability. Ages: 22–71. Half of the sample were in a relationship at the time of interview. Advisory group of people with intellectual disabilities informed the research design and dissemination. Thematic analysis used to analyse the data.	Love and loving relationships are important for people. Mutual support helps people to be engaged and increases confidence. People enjoy being cared for, as well as caring for and about someone else. People emphasise feelings and emotions of love over practical aspects of the relationship. People describe their relationships as having ups and downs and changing over time. It is important to work through difficulties to sustain a relationship.	People can feel lonely when they are not in a relationship. Some people had negative experiences in past relationships. Many people are dependent on staff to access social spaces or visit their partner.	A lack of public transport and money can make it difficult for people to visit partners or afford social activities like going to the cinema. Shift patterns of staff can prevent people from visiting events that happen late in the evening or at night. Overnight stays are often subject to safeguarding checks. People often experience a lack of privacy. Staff support are often not proactive. People can experience staff and parents as overpowering. Supportive and open-minded staff are able to provide practical support and help people to maintain relationships. Strong family support can help to sustain long-term relationships. Special support services that offer educational workshops or support groups can be helpful to people.

(Continued)

Table 4. (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Neuman (2020a) Israel	To understand the attitudes of support staff towards couple relationships of people with intellectual disability in comparison to couples without intellectual disability. Focus on the perspective of support staff.	Semi-structured interviews with 40 direct support staff (including social workers, therapists and support workers). Thematic content analysis used to analyse the data.	Relationships give people a sense of belonging and not feeling alone. People share their lives and activities. Couple relationships are more equal and mutual than other relationships in the lives of people.	Staff describe that couples need support to communicate with each other and solve conflicts within the relationship. Staff are concerned about abusive relationships and consent to sexual intimacy. Staff see their role as providing support, guidance and counselling.	Many staff view couple relationships of people with a learning disability as different to couples without a learning disability. Differently to couples without a learning disability, staff emphasise that relationships are a status symbol, an opportunity for people with a learning disability to develop skills or an expression of normalisation. Many staff locate difficulties between partners within people's impairment, viewing people as lacking ability to take care of themselves and others. Some staff believe couples with a learning disability have fewer difficulties as they receive support and have fewer responsibilities. Staff view families as having a significant influence on couples. It is important for families to be supportive. Some staff state that over-involvement of staff and families can prevent couples from making their own decisions.

(Continued)

**Table 4.** (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Neuman (2020b) Israel	To understand what couple relationships mean to people with intellectual disability, and what support helps people to develop and maintain relationships. Focus on the perspectives of people with intellectual disability.	Semi-structured interviews of 20 heterosexual couples (partners interviewed separately), who had been in the relationship for at least a year. Ages: 22–76, mean = 43.6. 15 couples lived together. Thematic content analysis used to analyse the data.	Couples can offer each other support after experiences of distress. Partners are committed to each other and wish for their relationship to be lifelong.	Partners can worry about the future and the possibility of losing each other. Some fear being separated by others, and this being outwith their control. Couples can experience difficulties when there is asymmetry in wishes for physical and sexual contact. Conflict between partners can result in violent incidents. Some couples wish to be married.	Positive attitudes of staff and family members help people to enter relationships and sustain them. Some people find support and interferences of professionals intrusive. Helping each other, having a reciprocal relationship and giving each other space when needed help people to maintain their relationships.

(Continued)

**Table 4.** (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Neuman (2020c) Israel	To understand the perceptions of parents on the relationships of their adult children with intellectual disability. Focus on the perspective of parents.	Semi-structured interviews with 30 parents. Ages of adults with intellectual disability: 22–53, mean = 30. All lived outwith their parents’ home. Thematic content analysis used to analyse the data.	Parents see relationships as characterised by mutual support. They see a wish for physical intimacy and emotional warmth as a main reason for people to want relationships. Since their adult children moved out of the parental home, parents view their role as listening and being there for their children, but would like support staff to have a more direct role to offer guidance, educate and directly assist with issues around physical intimacy and conflicts arising from couple relationships.	Some parents believe that people with a learning disability have more difficulties maintaining relationships due to difficulties with understanding social situations and limited communication abilities.	Parents believe that relationships can enable some people to be more accepted by their wider communities. Parents believe that people have the right to have intimate relationships, but many felt that their children were not ready for sexual relationships. Additionally, many opposed relationships leading to marriage or parenthood.

(Continued)



**Table 4.** (Continued.)

Author, year and country	Main focus and aim	Method	Findings in relation to day-to-day experiences	Findings in relation to support needs (particularly to maintain relationships)	Findings in relation to facilitators and barriers
Puyaltó <i>et al.</i> (2019) Spain	To understand barriers and supports people with intellectual disability encounter having a loving partner. Focus on the perspectives of people with intellectual disability.	Inclusive research study conducted by an advisory group of nine adults with intellectual disability in conjunction with an academic research group (advisers chose the research topic and were involved in the design and structure of the study). Eight focus groups were held in which advisers explored the topic and shared their experiences and views. Ages: 26–45, 5 over 30. Thematic content analysis used to analyse the data (conducted by two academic researchers).		It is helpful for people to feel able to ask for support and access information. This includes financial and economic information, information about managing everyday life and doing household chores, about managing relationships and information about sex.	People often rely on the consent and support of family members and professionals. Families can oppose relationships and support staff can experience tensions in upholding the rights of people or submitting to pressures from families. Services can have rules and practices that restrict people having relationships. People feel that others often have low expectations of them and their abilities to manage relationships. Families sometimes plan the future adult life of people without considering people's wishes to be in a couple or live together.

Note: UK: United Kingdom.

nification of additional key-processes that were of relevance to our research question. Thus, during the coding process we began to extend our predefined areas of interest to think more closely about different approaches to care and support in relationships that were evident in searches 2 and 3 and sought to capture how the context in which relationships happen is different for couples with intellectual disability compared to couples affected by dementia in the general population. As a last step, we summarised differences in the context of people's lives, barriers and facilitators, and key-processes for each search. The first author led the analysis with each step discussed with the research team to ensure that no information or nuances had been missed or misrepresented.

## Overview of included articles

### ***Search 1: couples with intellectual disability where one partner has dementia***

Search 1 of our scoping review established that there has, to date, been no research on the experiences of couples with intellectual disability where one partner has dementia. In the following section we will provide an overview of findings from searches 2 and 3, before discussing differences in the context of people's lives and drawing out approaches to care and support and facilitators and barriers that were identified in each search.

### ***Search 2: couples (non-intellectual disability) where one partner has dementia***

Of the eight included reviews, four were conducted in Australia, two in the UK, one in Denmark and one in Canada. Seventy-three primary qualitative studies were included across the eight reviews (including six dissertations and theses), and correspondingly to where the review teams were located, 34 studies were conducted in North America, 33 in Europe, 11 in Scandinavia and 17 in the UK. Thus, findings related predominantly to experiences of western populations with two reviews highlighting that experiences in other cultures will be different (Nel and Board, 2019; MacDonald *et al.*, 2020). Nel and Board (2019) also highlighted the role of extended family support in their study of Malay husbands in Singapore. Three reviews highlighted that most of their included studies related to people in the early stages of dementia (Pozzebon *et al.*, 2016; Wadham *et al.*, 2016; Egilstrod *et al.*, 2019) and four had excluded studies in which partners were no longer living together (Pozzebon *et al.*, 2016; Holdsworth and McCabe, 2018a; Egilstrod *et al.*, 2019; MacDonald *et al.*, 2020). Additionally, four reviews excluded the experiences of LGBT couples from their review (Holdsworth and McCabe, 2018a, 2018b; Egilstrod *et al.*, 2019; Nel and Board, 2019), and one reflected that, although they would have included LGBT couples, all included primary studies had been based on interviews with heterosexual couples (MacDonald *et al.*, 2020). Fifty-three studies focused on the perspective of partners without dementia, 18 included the perspectives of both partners and one focused only on the experience of the person with dementia (Harris, 2004). Additionally, one study included separate sections on the experiences of partners without dementia and, from different couples, the experiences of people with dementia (Harris and Keady, 2009). There

was little information or reflections in primary studies and reviews about difficulties or successes in involving people with dementia in interviews or if additional methods had been used to facilitate their inclusion. Notable exceptions included the use of observations alongside interviews (Boyle, 2013), photo and video elicitation to capture everyday life experiences (Phinney *et al.*, 2013) and ethical considerations of consent issues (Hellström *et al.*, 2007).

All reviews offered insight into the everyday experiences of couples and how they navigated changes and complexities in their relationship. There was less information about facilitators and barriers to support and it was evident across all reviews that the experiences of couples were largely presented without making references to wider support systems, policies and the service provision context. The limited mention of formal support in the lives of couples in search 2 may be indicative of studies being conducted with couples at early or mid-stages of dementia when informal care may be the main source of support (Kerpershoek *et al.*, 2019). Thus, narratives of care and support needs remained firmly located within the private lives of the couple. There were few reflections on the quality of care and support that couples received from professionals or services. Reviews highlighted the need for emotional support after the dementia diagnosis to help couples process information about the progression of dementia (Evans and Lee, 2014; Pozzebon *et al.*, 2016; Holdsworth and McCabe, 2018b; Egilstrod *et al.*, 2019). The need to strengthen support towards more advanced stages of dementia was evident in three reviews, detailing that partners without dementia need help to plan their spouse's care and manage complex emotions about a possible move into a care setting and the anticipated death of the person with dementia (Pozzebon *et al.*, 2016; Egilstrod *et al.*, 2019; MacDonald *et al.*, 2020). Additionally, a lack of formal support was indirectly implied by emphasis on stress and care burden of partners without dementia, and how this negatively impacted on the relationship (Pozzebon *et al.*, 2016; Wadham *et al.*, 2016; Holdsworth and McCabe, 2018a; Egilstrod *et al.*, 2019). Partners without dementia were described as becoming informal carers, next to being partners, and regular respite from their caring role was identified as a facilitator to maintain positive relationships by two reviews (Egilstrod *et al.*, 2019; Nel and Board, 2019). Furthermore, MacDonald *et al.* (2020) described how couples often experience financial pressures and the authors made links between inequalities in access to support and financial resources available to couples.

There were differences identified depending on whose perspectives were included. Studies that excluded the perspective of the partner with dementia emphasised experiences of care burden and stress of the partner without dementia (Pozzebon *et al.*, 2016; Egilstrod *et al.*, 2019; MacDonald *et al.*, 2020). Reviews that included studies on the experiences of partners with dementia described occurrences of reciprocity and included more positive descriptions of love and affection between partners, with a greater recognition of the needs and experiences of both partners (Evans and Lee, 2014; Wadham *et al.*, 2016; Holdsworth and McCabe, 2018a).

An overview of the eight reviews and findings in relation to everyday experiences, support needs, and facilitators and barriers can be found in Table 3. To avoid referring to one partner as 'the partner with dementia' throughout, the

term spouse is used when referring to the individual with dementia, and the term partner to refer to the person without dementia.

### **Search 3: couples with intellectual disability**

Of the ten included studies, five were conducted in the UK, three in Israel, one in Ireland and one in Spain. All three articles from Israel were conducted by the same researcher and explored couple relationships from the perspectives of people with intellectual disability, family members or professionals (Neuman, 2020a, 2020c, 2020b). Likewise, three of the UK publications included the same researchers, with two focusing on the perspectives of people with intellectual disability (Bates *et al.*, 2017; McCarthy *et al.*, 2022) and one on the views of support staff (Bates *et al.*, 2020). Overall, six articles explored the topic from the perspective of people with intellectual disability (Bane *et al.*, 2012; Lafferty *et al.*, 2013; Bates *et al.*, 2017; Puyaltó *et al.*, 2019; Neuman, 2020b; McCarthy *et al.*, 2022), one article included the perspectives of both people with intellectual disability and staff (Abbott and Burns, 2007), two utilised the perspective of professionals only (Bates *et al.*, 2020; Neuman, 2020a) and one article focused on the experiences of parents (Neuman, 2020c). Eight studies included data on experiences of heterosexual relationships, with only Abbott and Burns (2007) including experiences of LGB people with intellectual disability, and the study by McCarthy *et al.* (2022) including two participants attracted to the same sex. Three studies had inclusive research teams with people with intellectual disability acting as co-researchers and advisers (Bane *et al.*, 2012; Puyaltó *et al.*, 2019; McCarthy *et al.*, 2022). All three were the only studies in this search that referred to using alternative data collection methods alongside interviews to explore the topic with participants with intellectual disability. This included using easy-read material, visual methods, case-stories and role-play.

The included studies provided evidence of barriers to people forming relationships, ranging from lack of staff training, attitudes of staff, cultural views of people with intellectual disability as vulnerable and different, to environmental barriers such as lack of access to private living spaces and own accommodation (Bane *et al.*, 2012; Lafferty *et al.*, 2013; Bates *et al.*, 2020; Neuman, 2020a; McCarthy *et al.*, 2022). Additionally, our findings suggest that moves to new services and couples not living together can be particular barriers for couples with intellectual disability to maintain relationships due to a lack of access to transport and dependence on staff to support visits (Bane *et al.*, 2012; Lafferty *et al.*, 2013; McCarthy *et al.*, 2022). However, information about everyday experiences of couples remained somewhat superficial. Findings highlighted the value of love, companionship and mutual support for people, but there was little exploration of emotional complexities and how couples navigate changes in their relationship (Lafferty *et al.*, 2013; Neuman, 2020c; McCarthy *et al.*, 2022). This may be explained by a stronger focus on experiences of and attitudes towards people forming intimate relationships, rather than exploring experiences of actually being in a relationship. Three of the ten included studies contained minimal information on people's experiences of being part of and maintaining relationships (Abbott and Burns, 2007; Bane *et al.*, 2012; Puyaltó *et al.*, 2019).

An overview of the ten studies is given in Table 4.

## Findings

### **Context: private and public lives**

Both searches 2 and 3 highlighted that being a partner, husband or wife is an important part of people's identity and that love and support from the relationship helps couples to manage challenges and overcome adversities (Abbott and Burns, 2007; Wadham *et al.*, 2016; Bates *et al.*, 2017, 2020; Nel and Board, 2019). It was the context in which people's lives took place and relationships happened that was different across the two searches. While search 2 focused primarily on the care-dyad involving both partners, studies in search 3 described the lives of couples with intellectual disability happening within a web of relationships with professionals and family members. This demonstrated a care-triad that was impacted upon by service provision, as well as cultural attitudes, resources and policies.

Findings from search 3 showed that most couples with intellectual disability have support structures in place before the diagnosis of dementia. Yet, all studies in search 3 described how support could at times act as a barrier to people's relationships. For example, both searches 2 and 3 discussed issues of consent in relation to sexuality and physical intimacy. This is a new area of complexity for couples without intellectual disability where one partner has dementia, and one that seemed to remain largely private (Evans and Lee, 2014; Pozzebon *et al.*, 2016; Holdsworth and McCabe, 2018b). For people with intellectual disability, their wishes to have physically intimate relationships was often public, with staff or family members functioning as gatekeepers (Abbott and Burns, 2007; Bates *et al.*, 2020; Neuman, 2020a, 2020c; McCarthy *et al.*, 2022). There was evidence in both searches that people, including professionals, can feel uncomfortable talking about sexuality and that it is still a neglected area of support for people with dementia (without intellectual disability) and people with intellectual disability (Abbott and Burns, 2007; Holdsworth and McCabe, 2018a, 2018b; Bates *et al.*, 2020; Neuman, 2020c). Thus, although the intimate lives of people with intellectual disability were often managed and governed by others, they were simultaneously also disregarded and hidden.

Overall, the private lives of couples in search 2 stand in contrast to a focus on societal barriers in search 3. All studies in search 3 on the experiences of couples with intellectual disability had a strong focus on context and made close links to the influence of societal attitudes, service provision and available resources. However, a detailed understanding of how couples with intellectual disability navigate complexities and how relationships can change over time was lacking from search 3.

### **Search 2: exploring emotional complexities over time**

In search 2, included reviews explored emotional complexities and identified gradually changing relationships. An altered sense of identity and routines were explored as happening over time, with partners referring to the unpredictability of dementia. Dementia was described as involving a steady decline, individual to each person, but not always linear. Abilities of people could change from day to day, at times fluctuating quickly and sometimes with a marked decline (Evans

and Lee, 2014; MacDonald *et al.*, 2020). Couples reported difficulties in planning for and thinking about the future which was linked to a sense of *taking one day at a time* and *living in the present* (Wadham *et al.*, 2016; Holdsworth and McCabe, 2018a). Additionally, reviews highlighted the importance of understanding the history of couples to make sense of their experiences (Pozzebon *et al.*, 2016; Wadham *et al.*, 2016; MacDonald *et al.*, 2020). It was evident that dementia is a shared experience and affects both partners, provoking complex emotions of love, empathy, loss, resentment, anger, ambivalence and guilt. Several reviews highlighted that differences in emotional responses could be partly explained by past dynamics and ways of relating (Pozzebon *et al.*, 2016; Holdsworth and McCabe, 2018a; MacDonald *et al.*, 2020). However, a lack of situating these experiences into the wider context of available formal support was problematic as difficulties and problems were at times seemingly linked to the behaviour and support needs of the person with dementia, instead of emphasising a wider lack of support for couples.

### **Search 3: different approaches to support and care**

Ways of supporting and caring were framed differently and could shift within presented narratives across the articles in search 3. This included thinking about support as unidirectional and being provided by one person to enable the independence and autonomy of another. This concept of support was most prominent in the narratives of staff in search 3. Here barriers to relationships were linked to people with intellectual disability lacking skills and knowledge to have safe relationships (Bates *et al.*, 2020), relationships were seen as a learning process enabling people with intellectual disability to improve their social skills (Neuman, 2020a) and, on another level, staff themselves felt they lacked skills and needed training to provide people with relationship support (Abbott and Burns, 2007). Thus, support was seen as teaching people skills and educating them to develop ability and capacity to be in relationships with arguments of incapacity, risk and vulnerability used to explain why relationships might be discouraged. However, staff narratives across the three studies interestingly also included ways to think about support in more relational ways. Here risks and vulnerability were linked to social isolation (Abbott and Burns, 2007; Bates *et al.*, 2020). Staff stressed the importance of being there for people as *an attentive and supportive presence* (Neuman, 2020a: 720) with barriers to form and maintain relationships explained by an absence of continuity in close support networks for people with intellectual disability. Similarly, staff also talked about their own support needs in relational ways, talking about feeling left alone and often unsupported, and staff in two of the studies critiqued an organisational culture that responds to incidents or brings in external professionals to provide isolated interventions rather than building internal capacities and networks of support for people (Abbott and Burns, 2007; Bates *et al.*, 2020).

### **Searches 2 and 3: relational care, belonging and reciprocity**

Relational ways of thinking about support were characteristic of the narratives provided by couples with intellectual disability and couples with dementia. People with

intellectual disability stated that they needed the support of others to maintain relationships (Bane *et al.*, 2012; Bates *et al.*, 2017; Puyaltó *et al.*, 2019; Neuman, 2020b). Thus, people challenged an individualistic view of choice and ability by highlighting the need for interdependence, stressing the need for the support of others to realise their choices and wishes. When the support they received focused on an assumed lack of abilities or was based on views that people with intellectual disability are different and that intimate relationships are inappropriate, then support of others became oppressive and disempowering (Abbott and Burns, 2007; Bane *et al.*, 2012; Bates *et al.*, 2017; Neuman, 2020b). Thus, the experiences of people with intellectual disability highlighted that relational support did not mean having many people in one's life. Bates *et al.* described that experiences of isolation and loneliness

did not appear to be influenced by the number of people participants came into contact with as their living situations typically included numerous staff and housemates. This suggested the significance of their relationship with their partner who provided more than just a 'presence'. (Bates *et al.*, 2017: 70)

Similarly, couples in search 2 described feelings of isolation and loneliness. Couples described feeling that others did not understand their experiences and that there was little acceptance or inclusive spaces for people with dementia in public (Evans and Lee, 2014; Nel and Board, 2019; MacDonald *et al.*, 2020). Many couples experienced a narrowing of their lives, and the relationship could be one of the only places where partners with dementia continued to experience belonging (Pozzebon *et al.*, 2016; Holdsworth and McCabe, 2018a, 2018b).

It was evident across searches 2 and 3 that couples and people with intellectual disability linked inclusion and involvement with a sense of belonging, rather than learning or retaining skills. Belonging was defined by people as feeling valued and accepted, and seemed to be the main objective of providing relational support. Partners without dementia supported their spouse in subtle ways (Wadham *et al.*, 2016; Holdsworth and McCabe, 2018a), stressing the importance of doing things together and keeping each other company (Pozzebon *et al.*, 2016) over agency or *the efficient completion of a task* (Wadham *et al.*, 2016: 7). In this context, when talking about care and support, many couples talked about reciprocity. In search 2, reciprocity, seeing the value and contribution of both partners to the relationship, seemed to help partners without dementia to re-frame their care-role in a positive light as giving back (Nel and Board, 2019). Furthermore, partners with dementia saw themselves as giving and supporting within the relationship and this helped them to uphold identity and foster meaning. At the same time, all reviews included narratives that described the increasing unequal relationship between partners and four drew comparisons to parent-child relationships (Evans and Lee, 2014; Pozzebon *et al.*, 2016; Holdsworth and McCabe, 2018a, 2018b). Advanced stages of dementia were linked with the inability of partners with dementia to contribute to the relationship. The possibility of reciprocity was questioned in relationships where one partner needed to care physically for the other, dressing or bathing them, or where the person with dementia was seen as no longer able to engage verbally or cognitively (Pozzebon *et al.*, 2016;



Egilstrød *et al.*, 2019). Other studies continued to see people with dementia as active participants within their relationships by emphasising people's care and love for their partner without dementia, expressed through concerns about their wellbeing, holding hands, cuddling and just being together (Baxter *et al.*, 2002; Hellström *et al.*, 2007; Evans and Lee, 2014; Wadham *et al.*, 2016).

Reciprocity was also used to describe experiences of couples with intellectual disability (Abbott and Burns, 2007; Lafferty *et al.*, 2013; Bates *et al.*, 2017). The relationship to a partner was important to people because it provided them with a sense of belonging, facilitating independence and social participation through interdependence. Studies described levels of reciprocal care and mutuality between partners, where partners helped each other with everyday tasks and health-care needs, increasing possibilities for participation and independence. This experience was contrasted to experiences of being treated as a child in other relationships in their lives (Bane *et al.*, 2012; Puyaltó *et al.*, 2019; Neuman, 2020b). Thus, in contrast to search 2, experiences of inequality for people with intellectual disability related to their relationships to staff and family. People with intellectual disability felt that they were often viewed as care recipients, with staff and family members in the role of care-givers.

## Discussion

We identified processes that were associated with facilitating positive interactions in relationships, helping couples to maintain relationships and increasing social inclusion. This included relational care, belonging and reciprocity; concepts that are discussed below drawing on wider literature about people with intellectual disability and dementia. Additionally, it was evident that care and support are complex processes that take place across different spheres, which may help to understand how care and support can be both empowering and oppressive.

### *Belonging and reciprocity*

Belonging and reciprocity have been highlighted as key components of social inclusion, both in relation to people with intellectual disability (Fulton *et al.*, 2021) and people with dementia (Gove *et al.*, 2017). Furthermore, Sheth's (2019) study on barriers and facilitators to participation in daily life for people with intellectual disability and dementia highlights that reciprocity and helping others is important for people with intellectual disability and dementia, and creates meaning and purpose. Yet, search 2 also highlighted the complexity of what reciprocity means in an increasingly unequal relationship. Articles in our review included narratives that depicted partners with dementia as unable to reciprocate as their verbal and cognitive abilities were declining. This view has been challenged by researchers who stress that reciprocity in relationships can be richer and more complex than thinking about it as giving and taking in equal measures, and that it is important not to overlook subtle ways of reciprocity by people with dementia, such as a smile or reaching out (Ericsson *et al.*, 2013; Gove *et al.*, 2017; Driessen, 2018). In her ethnographic study of Dutch residential services for people with dementia, Driessen (2018) explores how moments of pleasure are experienced relationally and require



the engagement of the person with dementia and those supporting him or her. She argues that moments of pleasure and joy, such as dancing together, having a meal or listening to music, is shared and experienced by both people in the care relationship, blurring lines between care-givers and receivers. Similarly, Fulton *et al.* (2021), in their recent systematic review on belonging and reciprocity among people with intellectual disability, stress that reciprocity is not contingent upon equal exchange. Thus, as people's abilities change, they might need others to take the initiative in creating possibilities for inclusion and participation, but the experience of those moments and interactions is a shared one to which both partners contribute (Ericsson *et al.*, 2013).

### **Relational care and support**

Within the field of disability studies, care and support are often seen as somewhat opposite concepts. The term care has been critiqued as reinforcing views of people with intellectual disability as passive recipients of care and associated with a past of institutionalisation and experiences of oppression and powerlessness (Schormans, 2015). It is a term that is at times avoided when writing about the lives of people with intellectual disability. Instead, the term support is commonly used to emphasise agency, choice and independence, which is reflected in policies that promote self-directed services (Glendinning, 2008; Jingree, 2015; Lakhani *et al.*, 2018). As our findings showed, an individualistic view of support can also be problematic because it can negate needs associated with vulnerability (Barnes, 2015) and can suggest that skills and abilities are intrinsic properties that can be learned or retained. Subsequently, people's abilities to make choices and participate in decision-making processes can be denied (Jacobs *et al.*, 2021). Similarly, Jingree (2015), in her discourse analysis of staff arguments about facilitating choice for people with intellectual disability, demonstrates how emphasising incapacity as an intrinsic property is frequently used by staff to deny people involvement and choice. Our review shows that a relational perspective may offer greater possibilities for social inclusion. A relational perspective asserts that being a person is not defined by being rational and autonomous, but by having the capacity to be in relationships with others and add value to their lives (Kittay, 2001). Correspondingly, people with intellectual disability and partners with dementia stressed the importance of a sense of belonging and reciprocity over independence and being able to do things alone. They emphasised how belonging was connected to feeling valued and accepted, and how reciprocity enabled a view of both people within a relationship as giving and receiving. Vulnerabilities could be acknowledged alongside people's rights to participation, as inclusion and involvement were not dependent on internal properties and skills but seen as taking place in and through relationships in everyday life (Ursin and Lotherington, 2018).

### **Different spheres of care and caring**

As Morris (1991) previously argued, there appears to be value in expanding our definitions of support and care from a narrow focus on physical tasks and experiences of care-givers and care-receivers separately, towards shared experiences of

caring. Alongside physical and practical ways of providing support, our findings highlight the importance of emotional support. Considering identified support needs across the two searches, there appears to be value in paying closer attention to the emotional realm of caring. In search 3 people with intellectual disability stressed the need to have people in their lives they could talk to about difficulties in their relationships, while studies also highlighted that staff and parents can feel uncomfortable or lack confidence to support couples to manage conflicts (Abbott and Burns, 2007; Neuman, 2020a, 2020c). In search 2, two reviews described how after the dementia diagnosis couples can feel left alone with the fears it evokes, with little ongoing emotional support (Nel and Board, 2019; Macdonald *et al.*, 2020). The need for emotional support after a dementia diagnosis has also been highlighted by social care staff and family members of people with intellectual disability and dementia (Carling-Jenkins *et al.*, 2012; Iacono *et al.*, 2014). Furthermore, it was evident from search 2 that couples needed support to make sense of changes in their relationship over time and manage emotional complexities that occur. For example, while couples felt commitment and empathy, they could also experience moments where they blamed their partner and resented them. This was linked to people feeling exhausted and struggling to respond to distressed behaviour in empathetic ways. This is important to keep in mind when considering the experiences of couples with intellectual disability where one partner has dementia as evidence does not tell us how couples with intellectual disability navigate this complex process. We know from search 2 that dementia affects both partners and provokes complex emotions of love, empathy, guilt, ambivalence and loss. This may be similar for partners with intellectual disability, and it is important to explore how people navigate this emotional complexity and identify support needs.

Emotional responses and dynamics between partners do not take place in isolation but are influenced by the wider support systems that are available to couples. Rogers (2016) outlines three spheres of caring: the *emotional caring sphere*, the *practical caring sphere* and the *socio-political caring sphere*. She stresses the importance of exploring interactions between people's emotional responses to care and caring, practices of care within people's microsystems, and the wider socioeconomic context in which care and caring take place.

Drawing on Nodding's (2002) work on ethics of care, Rogers (2016) differentiates between care in relation to practical activities, the realm of caring for and the emotional realm of caring about someone, feeling responsibility, commitment, love and empathy. She explains that a better understanding of different spheres can help us to understand how care and support can be both empowering and oppressive. People can provide practical care and support for someone while feeling resentment towards them or viewing them as lacking abilities. An acknowledgement of different spheres can also help to understand how individuals can care about each other and provide important experiences of love and belonging but might be unable to provide practical support and care in equal measures. Additionally, Rogers (2016) stresses the importance of understanding that care takes place and is dependent on wider systems of support. She argues for the importance of lifting care out of the private realm, to examine critically how it is valued and how far those within care relationships are supported by society. Thus, care becomes both a private matter and a public concern (Schormans, 2015).

### **Implications for future research with couples with intellectual disability where one partner has dementia**

Findings highlight the need to investigate further the emotional realm of care and support, as well as the importance of situating people's experiences within the wider socio-political context, noting the influence of available resources, networks of formal support and societal attitudes. Given the lack of existing evidence, it will be important to explore if people with intellectual disability are given the option to care for their partner in the context of dementia, if caring roles are overlooked, and how both partners are and can be supported, including how couples manage emotional complexities. It is apparent from research on adults with intellectual disability living with older parents that people's contributions to care relationships are often not noticed, and are seldomly reflected on (Walmsley, 1993; Knox and Bigby, 2007; Truesdale *et al.*, 2021). In relation to couples with intellectual disability where one partner has dementia, this might translate into a risk that the partner without dementia is not recognised and supported in their caring role. In her research on people with intellectual disability in caring roles, Walmsley (1993) describes how providing care for someone else can be an opportunity for people to experience social value and acceptance but can also result in experiences of exploitation if people's caring role is not formally recognised.

Fears about the future in relation to dementia advancing, the possibility that people with dementia might need to leave their home and the death of the person with dementia were prominent for couples in search 2 (Evans and Lee, 2014; Pozzebon *et al.*, 2016; Egilstrod *et al.*, 2019; MacDonald *et al.*, 2020). Fears about the future might be further exacerbated for people with intellectual disability who often experience that decisions about their life are made beyond their control. Staff may avoid talking to people with intellectual disability about life-limiting conditions and death as they are concerned that it will upset the person (Tuffrey-Wijne *et al.*, 2013; Tuffrey-Wijne and Rose, 2017). People with intellectual disability are not always told about their dementia diagnoses (Watchman, 2016; Sheth, 2019) and are not routinely involved in Advanced Care Planning (Heslop *et al.*, 2014; Wiese *et al.*, 2014; Noorlandt *et al.*, 2020). It will be important for future studies to explore how far the person with intellectual disability and dementia and their partner are involved in planning future care and support. This should also involve an exploration of dementia disclosure and if, how and when information about the progression of dementia is communicated to both partners. Qualitative research on the experiences of people with intellectual disability who have life-limiting conditions, predominantly cancer, have shown the importance of taking a person-centred approach, sensitively disclosing information and having conversations as people's needs and circumstances are changing. This includes continuously assessing people's understanding of their illness and of abstract concepts such as time, in addition to exploring their preferences for disclosure to facilitate involvement in care planning (Tuffrey-Wijne, 2013; McKenzie *et al.*, 2017).

Finally, it was notable across both searches 2 and 3 that there is often little consideration or reflection on the process of including people with intellectual disability or dementia as research participants in accessible ways. Using inclusive approaches will be important in future studies, as previous researchers have

highlighted challenges of meaningfully including people with intellectual disability and dementia using traditional interview methods (Lloyd *et al.*, 2007; Forbat and Wilkinson, 2008; Sheth, 2019). Using alternative approaches might help researchers to explore the journey of the couple over time to capture changes in their relationship and facilitate an understanding of the complex concepts of past, present and future. Additionally, alongside recognition that care and support take place within extended support networks, it can be valuable to explore the topic from different perspectives, including staff and family members, as well as both partners.

## Conclusion

Exploring relationships in the context of older couples with intellectual disability and couples affected by dementia allowed us to identify areas of interest and key processes that will be relevant for future research with couples with intellectual disability where one partner has dementia. Search 2 highlighted how couples affected by dementia can be supported to maintain positive interactions. This included the need for emotional support for both partners, emphasising interdependence over independence, and recognising that partners with dementia continue to show love and affection while the relationship becomes more unequal in other areas. Search 3 emphasised that the starting point for most couples with intellectual disability will be different to that of couples in the population generally. While formal support is likely to be in place for couples with intellectual disability, it can act as a facilitator as well as barrier to the relationship. People with intellectual disability are often referred to in terms of vulnerability and difference, not involved in key decisions that affect their lives, and are dependent on staff, organisational processes and available resources.

As studies were not available about the experiences of couples with intellectual disability living with dementia, implications for future research can only be tentative until more robust evidence is generated. Future studies about this topic have the potential to emphasise the importance of intimate relationships in the lives of people with intellectual disability throughout the lifespan and may challenge the invisibility of people with intellectual disability in caring roles.

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