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Ageing with an Intellectual Disability

Sharena Thind

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Institute of Health and Wellbeing

College of Medical, Veterinary and Life Sciences

University of Glasgow

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Chapter 1: Systematic Review

Quality of life of adults with intellectual disabilities within residential care settings for older adults: A Systematic Review and Narrative Synthesis

Prepared in accordance with the author requirements for the Journal of Applied Research in Intellectual Disabilities (JARID)

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Abstract

Background

There are a proportion of adults with intellectual disabilities residing within generic residential care settings for older adults. These settings are not necessarily set up to provide care and support for adults with intellectual disabilities. Therefore, developing a deeper understanding of the quality of life for people with intellectual disabilities within this setting is imperative.

Methods

A systematic search of relevant electronic databases was completed in April 2023. The databases searched were OVID interface (MEDLINE and EMBASE), EBSCO (CINAHL, PsycINFO and SocINDEX) and Web of Science Core Collection. Six studies met the inclusion criteria for this review. Each study was assessed and rated using the Joanna Briggs Institute quality appraisal checklist. Results were summarised using a narrative synthesis.

Results

Synthesis of the results highlighted poor scores on dimension specific measures of quality of life for people with intellectual disabilities residing in residential care settings for older adults.

Discussion

There is a need for more inclusive policy development and future planning to occur alongside adults with intellectual disabilities themselves. Future studies should aim to use validated measures of quality of life and address methodological weaknesses within studies.

Keywords: intellectual disabilities, residential care settings, older adults, quality of life.

Introduction

An estimated 950,000 adults with intellectual disabilities live in the United Kingdom, approximately 2% of the population (Office for National Statistics, 2020). Life expectancy for people with intellectual disabilities has increased significantly, although it remains lower than the general population (Heslop et al., 2014). This increase in life expectancy can be attributed to improvements in medical, health and social supports (Beadle-Brown et al., 2010; Dean et al., 2021). For example, medical and health research have led to regular health check-ups (Robertson et al., 2014) and increased physical fitness (Oppewal & Hilgenkamp, 2019). In addition, there have been considerable changes in the models of support and care provision for people with intellectual disabilities.

In particular, the 1990s saw the move towards deinstitutionalisation and community living (Mansell & Beadle-Brown, 2010). Hence, the proportion of people with intellectual disabilities who reside in their own homes and with their families has increased substantially (Woodman et al., 2014). In the United Kingdom approximately two-thirds of adults with intellectual disabilities reside with their families (NICE, 2018). Of these, two-fifths of individuals live with a family carer over the age of 60 and one third with a family carer over the age of 70 (NICE, 2018). This can create uncertainty as family carers may struggle to continue to provide care as they reach old age (Innes et al., 2012; Brennan et al., 2018). Without planning for a move from the family home, the death of a parent can lead not only to loss of a loved one but also the loss of the family home (Karavella, 2013).

Residential Transitions

Some ageing adults with intellectual disabilities remain unknown to services until they require further assistance (NICE, 2018). This means that people with intellectual disabilities can be forced to leave the family home in a crisis situation, following the illness or death of a parent (Innes et al., 2012; Taggart et al., 2012; Tilley et al., 2023). As a consequence, some adults with intellectual disabilities are forced to move into long-term residential care settings (Bigby et al., 2011; Dieckmann et al., 2019). Residential settings that people with intellectual disabilities move to include residential aged care settings for older adults within the general population (i.e., nursing homes); community residences such as group homes for people with intellectual disabilities and other residential care settings specifically for people with intellectual disabilities.

Research has highlighted many reasons adults with intellectual disabilities may move into residential care settings for older adults. This has included death of primary caregivers, shortages in accommodation for people with intellectual disabilities and experiences of health and functional decline (Bigby et al., 2011; Taggart et al., 2012; Dieckman et al., 2019; Egan et al., 2022; Tilley et al., 2023) . Residential care settings for older adults within the general population can include services which provide support by registered nurses and care assistants (i.e. nursing homes) and residential care homes where there is no access to registered nurses. In the United Kingdom, between 2017 to 2018, approximately 1,075 adults with intellectual disabilities aged between 18 and 64 years resided within nursing homes, and an additional 620 people over the age of 65 years (NICE, 2018). Specific figures for adults with intellectual disabilities in the United Kingdom residing within residential care settings for older adults outside of nursing homes were unavailable. Given that younger people with intellectual disabilities are being moved into elderly care settings, this raises questions about the appropriateness of these settings and the quality of life they provide.

Quality of Life

The term 'quality of life' has become a crucial concept within research, for many populations, including adults with intellectual disabilities (Buntinx & Schalock, 2010). Measuring and understanding quality of life can help professionals, family members, policy makers and wider services to meet individuals' needs. In addition, examining quality of life can highlight wider societal health inequalities and promote change (Schalock, 2004). Schalock et al. (2008) proposed that quality of life is multi-dimensional and presented the concept as containing eight domains which can be indicative of quality of life (see Table 1).

Table 1. *Quality of life domains and indicators (Schalock et al., 2008).*

Quality of life domain	**Examples of quality of life indicators**
Personal development	Education status, personal competence and performance.
Self-determination	Choices/decisions, autonomy, personal goals.
Interpersonal relations	Social networks, social activities, interactions.

Social inclusion	Community integration/involvement, community supports and roles.
Rights	Human, legal.
Emotion well-being	Safety, self-concept, satisfaction, contentment.
Physical well-being	Nutrition and health status, leisure activities.
Material well-being	Financial, housing and employment status.

There have been many attempts to provide a unified definition of quality of life. While there are contrasting views, Shalock et al's definition appears to convey the general consensus that quality of life is multidimensional and includes objective, subjective, cultural, personal, and environmental factors (Van Hecke et al., 2018). Schalock et al. (2002) highlighted that quality of life outcomes could be a key driver to improve conditions for individuals who experience social exclusion, such as adults with intellectual disabilities. Research suggests people with intellectual disabilities score lower on measures of quality of life than the general population (Keith & Bonham, 2005; Verdonschot et al., 2009), albeit that these findings are not universal across the literature (McVilly et al., 2000).

Quality of life measures for individuals with intellectual disabilities

There have been several published reviews into the use of quality of life measures for people with intellectual disabilities (Verdugo et al., 2014; Nieuwenhuijse et al., 2019). A challenge for summarising findings from reviews is the lack of consistency and consensus on agreed measures (Schalock et al., 2002; Townsend-White et al., 2012). As a consequence, it is not uncommon for unvalidated or dimension specific measures to be used to infer overall quality of life. Research that has investigated quality of life for adults with intellectual disabilities within residential settings for older adults has focused on dimensions such as community integration, family involvement and choice making (Thompson et al., 2004; Higgins & Mansell, 2009).

Quality of life measures rely on self and/or primary caregiver report. Within residential aged care settings quality of life can often be collected via staff report. Research has highlighted potential limitations with this reporting method such as the biases that may exist from staffs' own interpretation of terminology within concepts such as self-determination (Nota et al., 2007). In contrast, Stancliffe et al. (1999) found that staff and self-report on quality of life dimensions did not significantly differ. However, they highlighted the importance of considering the differences that may occur such as the nature of their interpretations and the level of clarity with the responses.

Quality of life within residential care settings for older adults

Empirical evidence within the United Kingdom suggests there are more than 1,600 people with intellectual disabilities living within residential care settings for older adults (NICE, 2018). There has been no systematic review about the quality of life experienced by people with intellectual disabilities in residential care settings for older adults. The insights obtained from a review could support improvements in the quality of care provided to people with intellectual disabilities in these residential services. Therefore, this systematic review aims to synthesise the available research to address the following question:

What is the quality of life of adults with intellectual disabilities residing in residential care homes for older adults?

Methods

Search Strategy

In line with PRISMA guidance (Page et al., 2021), this systematic review protocol was registered with the international Prospective Register of Systematic Reviews (PROSPERO) (CRD42023400649).

Studies were identified by searching six database search engines on 6th April 2023. The databases searched were OVID interface (MEDLINE and EMBASE), EBSCO (CINAHL, PsycINFO and SocINDEX) and Web of Science Core Collection. An overarching search strategy was developed alongside a specialist librarian, and this can be found in Appendix 1.1. The searches had no date restrictions imposed as this is an original systematic review. Searches were amended for each database, as appropriate, and included using four groups of search terms: Group 1 “intellect* disab*” OR “intellect* impair*” OR “intellect* OR handicap*” OR “learning disab*” OR “learning difficult*” OR “learning disorder*”; AND Group 2 “homes for the aged” OR “aged residential home*” OR “nursing homes” OR “nursing facilit*” OR “care home*” OR “elderly care home*”; AND Group 3 “older adults” OR “elderly” OR “seniors” OR “geriatric*” OR “ageing” OR “old age” OR “late* life”; AND Group 4 “quality of life” OR “life quality”. Validated filters for quality of life were used and articles were restricted to an adult population and in English.

Eligibility Criteria

Studies were included if they: (a) reported participants as adults (18 years or older) with intellectual disabilities; (b) reported on participants residing within a residential care setting specifically for older adults within the general population; (c) quantitively measured and reported scores of self, family or staff/carer report of quality of life or indicators of quality of life.

Studies were excluded if: (a) global terms were used to describe participants with no explicit statement of intellectual disabilities (i.e., “cognitive impairment”); (b) studies were not published in full in English within a peer reviewed journal; (c) residential care setting was specifically for people with intellectual disabilities.

Data Extraction and Synthesis

A narrative synthesis was used to analyse and present the data. Narrative synthesis allows for similarities and differences between studies to be explored, and for patterns within the data to be identified. This was deemed the most appropriate analysis due to the heterogenous nature of the included studies. Guidance by Popay et al. (2006) was adhered to and included:

- Developing a preliminary synthesis
- Exploring relationships within and between studies
- Quality appraisal
- Assessing the robustness of the synthesis

Preliminary synthesis

Data were extracted manually with an extraction format designed by the researcher, and this can be seen in Table 2. Studies that had prospective or longitudinal designs with multiple time-points were included within the review. Each time-point was reported separately and distinctly. An independent reviewer, who had relevant training in research methods, cross checked three (50%) of the included studies to ensure data had been extracted accurately.

Exploring relationships between studies

Study characteristics and findings were then used to explore relationships between studies with regard to quality of life for adults with intellectual disabilities, residing in residential care homes for older adults.

Quality Appraisal

Quality appraisal was used to assess risk of bias, validity of the study findings, and to consider the strengths and limitations of the studies included. The Joanna Briggs Institute (JBI) checklist for analytical cross sectional studies was used.

The JBI checklist was chosen as it was suitable for the parameters of analytical cross sectional studies, it allows for depth of critical appraisal, and was developed with materials to aid novice researchers (Munn et al., 2020). It entails 8 questions which focus on sampling strategy, confounding factors, measurements used and analysis. Each quality appraisal question is assessed via a ‘yes’, ‘no’, ‘unclear’, and ‘not applicable’. This quality appraisal was also deemed applicable, by the researcher and research supervisors, for the studies with longitudinal designs as each datapoint was assessed separately and distinctly from other time-points.

Assessing the robustness of the synthesis

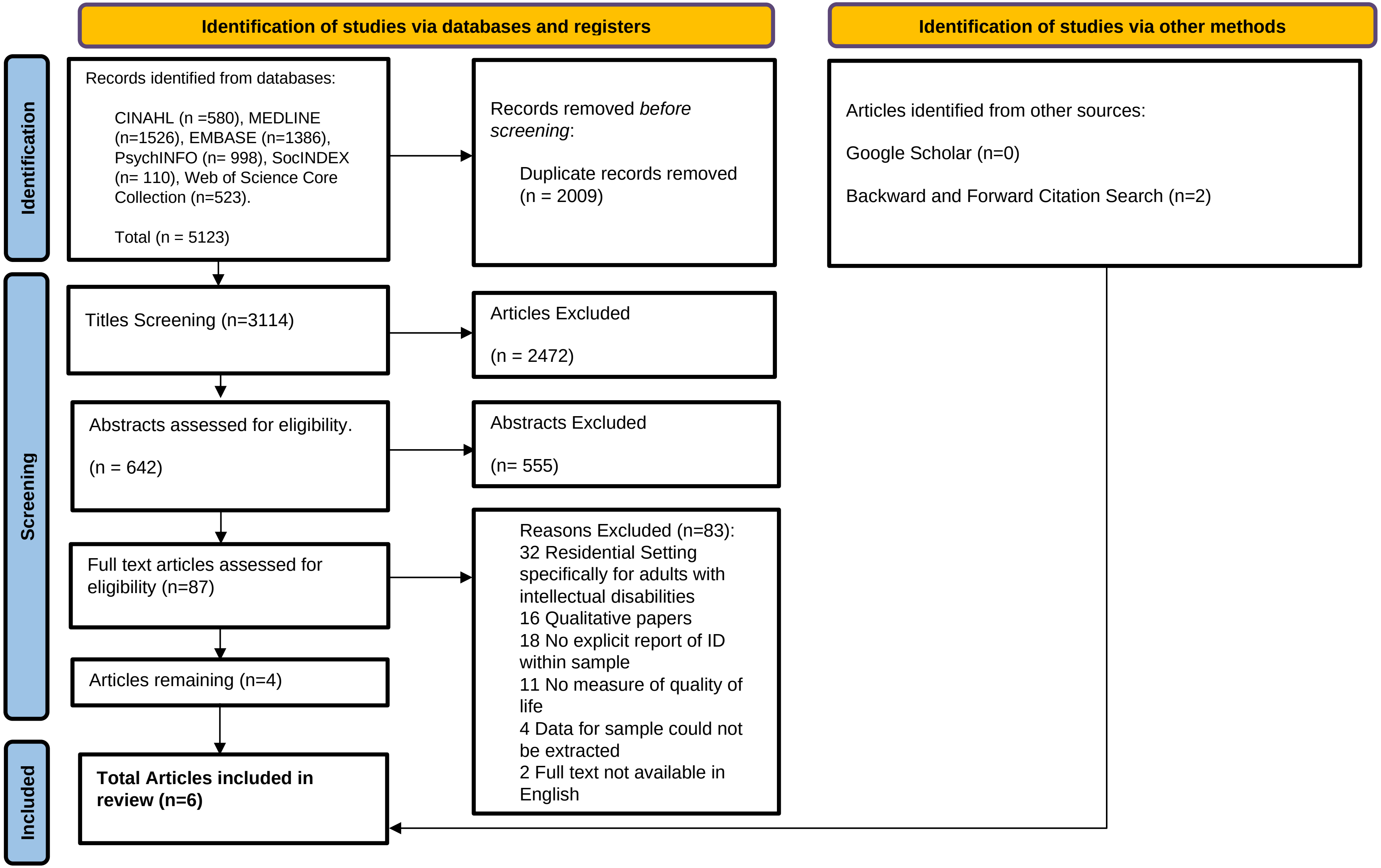
No studies were excluded based on their methodological quality. However, methodological quality was considered when discussing the findings and their robustness. The same independent reviewer, who supported with data extraction and has relevant training in research methodology, appraised half of the included studies. Initial inter-rater appraisal ratings revealed 94% agreement; disagreements were discussed until consensus was reached.

Results

Data Screening and Selection

The flowchart in Figure 1 shows the process of selecting the papers for review. Following the search of six literature databases a total of 5123 articles were identified, 2009 duplicates were removed. The remaining 3114 articles were then screened. Following review of the title, 2472 articles were removed and a further 555 articles were removed after reviewing the abstracts. A second reviewer screened a subset to ensure accuracy and no disparities were found between reviewers. The remaining 87 articles were reviewed in full and 83 were excluded as they did not meet the inclusion criteria. A backward and forward citation search was completed for the remaining four articles and an additional two articles were included. A search of grey literature databases was conducted; however, no additional articles were identified. Lastly, a scoping search of Google Scholar literature found no additional articles that met the eligibility criteria. In total, six articles were included in the narrative synthesis.

Figure 1. *PRISMA (2020) protocol – process of extraction, screening and inclusion.*



Study Characteristics

Six studies were included within the review, and these were published between 1998 and 2009 (see Table 2). Studies were undertaken in two countries: America (n = 4) (Heller et al., 1998[a]; Heller et al., 1998[b]; Heller et al., 2002; Hsieh et al., 2009); and the United Kingdom (n = 2) (Thompson et al., 2004; Higgins & Mansell, 2009). Overall, the studies included 1,956 participants; 662 (34%) of these participants were from longitudinal study designs where data responses were collected at multiple time-points from the same group of individuals. Age range of participants varied from 30 to 89 and sample sizes varied greatly, from 19 (Higgins & Mansell, 2009) to 331 participants (Heller et al., 1998[a]). Gender of participants was also variable within studies: one study provided no report (Thompson et al., 2004); two studies reported their sample as 52% male and 48% female (Heller et al., 1998[a]; Hsieh et al., 2009); one study reported 42% male and 58% female (Higgins & Mansell, 2009); one study reported 51% male and 49% female (Heller et al., 1998[b]) and one study reported 51% female and 49% male (Heller et al., 2002). Furthermore, studies varied in the detail they provided regarding the level of intellectual disability of their sample. Two of the studies reported using the Inventory for Client and Ageing Planning to define “level of mental retardation” (Heller et al., 1998[a]; Heller et al., 1998[b]), two studies reported no detail on the level of intellectual disability of the sample (Thompson et al., 2004; Higgins & Mansell, 2009) and two studies reported specific intellectual disability diagnoses as either mild, moderate, severe, profound or other (Heller et al., 2002; Hsieh et al., 2009). Five of the studies explicitly reported that residential settings were nursing homes (Heller et al., 1998[a]; Heller et al., 1998[b]; Heller et al., 2002; Hsieh et al., 2009; Thompson et al., 2004) and one study reported “older people’s homes that are not designed for people with intellectual disabilities” (Higgins & Mansell, 2009).

Studies all focused on adults with intellectual disabilities; however, studies had heterogeneous designs and were comprised of one prevalence study (Thompson et al., 2004), one prospective cohort study (Hsieh et al., 2009), three longitudinal group comparisons (Heller et al., 1998[a]; Heller et al., 1998[b]; Heller et al., 2002) and one cross-sectional group comparison (Higgins & Mansell, 2009).

Heller et al. (1998)[a] conducted a longitudinal study with two timepoints. However, their baseline measurement is the only time point included with the review. The second time point within the study did not report quality of life within nursing homes separately from other residential settings and therefore was excluded. All other longitudinal designs, which are presented in Table 2, allowed for multiple-time points to be reported and this included two studies with two timepoints (Heller et al., 1998[b]; Heller et al., 2002) and one study with three timepoints (Hsieh et al., 2009). It should be noted that Heller co-authored four of the studies included within this review (Heller et al., 1998[a]; Heller et al., 1998[b]; Heller et al., 2002; Hsieh et al., 2009). These studies report similar, but not identical, participant characteristics and are all within the same American city, Chicago. Further sample details could not be obtained from the authors and there is no stated overlap between participants included in the different studies. Therefore, all studies have been included and reported on separately. In addition, Heller co-authored two studies in 1998 therefore, [a] and [b] have been used to allow clarity in differentiating between studies (Heller et al., 1998a; Heller et al., 1998[b]).

Lastly, measurements of quality of life varied considerably and comprised the Community Integration Scale (Heller et al., 1998[a]; Heller et al., 1998[b]; Heller et al., 2002; Hsieh et al., 2009), The Index of Community Involvement (Higgins & Mansell, 2009), Lifestyle Satisfaction Scale (Heller et al., 1998[b]), the Choice Making Scale (Heller et al., 2002; Higgins & Mansell, 2009) and the Index of Participation in Domestic Life (Higgins & Mansell, 2009). Furthermore, there were two studies with self-made questionnaires which included a focus on community integration (Thompson et al., 2004) and family involvement, to infer quality of life (Thompson et al., 2004; Hsieh et al., 2009). Studies varied in terms of respondent and included self-report (Higgins & Mansell, 2009), staff report (Heller et al.,1998[a]; Heller et al., 2002; Thompson et al., 2004; Hsieh et al., 2009) and self and staff report (Heller et al., 1998[b]).

Table 2: *Study Characteristics, main findings and limitations.*

Citation, location and residence of sample.	**Study Design & Respondent (self/staff/family)**	**Article Aim**	**Sample Characteristics** **No. Participants, Age (mean & range), gender, ethnicity**	**Intellectual Disability Details** **Any other co-morbid disabilities**	**Quality of Life Assessment Tool**	**Outcome Mean Scores with Standard Deviations and assessment tool outcome range**	**Limitations**
Heller et al. (1998)[a] America. Nursing homes	Longitudinal group comparison design Longitudinal data could not be extracted for target sample at time point 2 therefore, only baseline timepoint included. Staff report	To examine environmental characteristics of nursing homes and community based settings on well-being of adults with intellectual disabilities.	N=331 M=49.60 (31-88) 52% male, 48% female Ethnicity: Not reported.	The inventory for Client and Ageing Planning was used to define the "level of mental retardation" for sample was reported; M= 3.9, SD= 1.20 (0 = no retardation to 5 = profound)	○ Community Integration Scale (CIS, Heller & Factor, 1991)	CIS: M=1.17, SD=0.29. Low levels of community integration	Community integration as the only measure indicator of quality of life. Reflections provided on staff potential biases as respondents however, no strategies to manage this.
Higgins & Mansell (2009) United Kingdom. "Older people's	Non-equivalent comparison group design Self-report	To compare quality of life in group homes and older persons' homes for people with intellectual disabilities.	N=19 M=66 (50-83) 42% Male 58% Female	All participants had intellectual disabilities, as reported from a staff member within nursing homes. 68% reported additional impairments/disabilities.	○ Index of Participation in Domestic Life (IPDL, Raynes et al., 1994) ○ Choice Making Scale (CMS, Conroy &	IPDL: M=1.0, SD= not reported. Poor range. CMS did not achieve acceptable levels of	No specific reports of intellectual disability level of sample No reports on nature of

homes not designed specifically for those with intellectual disabilities”			90% White British, 10% not reported.		Feinstein, 1986) ○ The Index of Community Involvement (ICI, Raynes et al., 1994)	reliability and therefore was not used in the analysis. ICI: M=15.9, SD= not reported, scored within poor range.	additional impairments.
Thompson et al. (2004) United Kingdom. Nursing homes	Prevalence study Staff report	To describe the circumstances of people with intellectual disabilities who reside in generic services for older people.	N=196 No sample characteristics provided as sample was extracted from much wider participant pool.	Participant inclusion criteria was that participants must have an “Intellectual Disability”. Staff within residential care homes for older adults identified eligible individuals within the nursing homes.	○ Author self-made closed questionnaire with 2 questions ○ Q1 asked staff to rate individuals’ opportunities to do things outside of the nursing home. ○ Q2 collected the frequency of contact with family and friends.	Q1 – 49.4% getting out more than 3 times a week, 26% at least once a week, 11.2% once a month and 19.89% less than once a month. Limited opportunities for individuals to get outside of the nursing home. Q2: 80.9% stated to have surviving family, 47.5% stated to have friends. 42.7% of respondents saw a family	Sample demographics very limited. Including no report of level of intellectual disability of participants. No validated measures of quality of life used. No reflections on the possible confounds of the study and management of this, including potential biases of staff report.

						or friend at least once a month. 53.7% did not have regular contact with anyone outside of services. Limited contacts with friends and family. “Low quality of life indicated from respondents”.	
Heller et al. (1998)[b] America. Nursing homes	Longitudinal group comparison design. Staff report for community inclusion. Self-report for lifestyle satisfaction (only collected from participants with mild to moderate intellectual disabilities).	To examine the impact of moving out of nursing homes into community based settings for adults’ developmental disabilities.	**Baseline:** N=232 M=49 (32-88) 51% Males, 49% Females. Ethnicity – not reported. **Time 2 (3 years later):** N= 165 M=50.97 (range not reported)	**Baseline** The inventory for Client and Ageing Planning was used to define the “level of mental retardation for the sample.” (0 = no retardation to 5 = profound). M= 3.71 – 3.9, SD=1.16-1.20. **Other disabilities:** Cerebral Palsy = 48% and/or Epilepsy = 45%. **Time 2:**	**Baseline and Time 2** ○ Community Integration Scale (CIS, Heller & Factor, 1991) ○ Lifestyle Satisfaction Scale (LSS, Heal & Chadsey-Rusch, 1985)	**Baseline** CIS: M=1.16 - 1.23, SD=.29 - .34. Low levels of community integration. LSS: (N=51) M=4.41 - 11.41, SD=15.80-25.92. Between dissatisfied and extremely dissatisfied ranges. **Time 2**	Demographics of sample are limited. Gender and other developmental disabilities only reported at baseline and ethnicity not reported throughout. Standard deviations on lifestyle satisfaction scales are high.

			Gender – not reported. Ethnicity – not reported.	“Mental Retardation” level, M= 3.90, SD= 1.16. **Other disabilities:** Not reported.		CIS: M= 1.17, SD= .28. Low levels of community integration. LSS: (N=37), M=9.75, SD=19.24. Dissatisfied range	Data at baseline has to be reported as between ranges as the data used is provided as two datasets.
Heller et al. (2002) America. Nursing homes	Longitudinal group comparison design. Staff report	To identify specific characteristics of residential services that contribute to the wellbeing of adults with intellectual disabilities over an eight year period.	**Baseline:** N=186 M=47.02 (31-81) 51% female, 49% male 81% European American and 19% African American **Time 2 (eight years later):** N=53 No study specific	**Baseline** 13% mild “mental retardation”, 9% moderate, 6% unknown, 72% Severe and profound 51% also had cerebral palsy, 43% had epilepsy. No reports on co-morbidity. **Time 2** Not reported	Baseline ○ Community Integration Scale (CIS, Heller & Factor, 1991) **Time 2** ○ Choice Making Scale (CMS, Heller et al., 1999) ○ Community Integration Scale (CIS)	**Baseline** CIS: M= 1.16 - 1.18, SD=.28 - .29. Low levels of community integration Time 2 CMS: M=1.54, SD=.70 Low range of choice making. CIS: M=1.35, SD=0.29 Low community integration	No study demographics reported at time 2, even though sample dropped significantly. Choice Making Scale scores only collected at Time 2. No strategies to manage confounding factors reported.

			characteristics reported				
Hsieh et al. (2009) America. Nursing homes.	A 10 year cohort design Staff report	To examine which residential characteristics are associated with mortality over, a 10 year period, among adults with intellectual disabilities who have lived in nursing homes.	**Baseline (1989-1990):** N=330 M=46.95 (30-89) 52% Male, 48% Women 79% White, 21% African American, 1% other. **Time 2 (1991-1992):** N=267 No specific characteristics reported. **Time 3 (1997-1999):** N=177 No specific characteristics reported.	Participants with Intellectual disabilities were recruited. **Baseline** Mild N=49 Moderate N=36 Severe N=91 Profound N=119 Unknown N=35 **Other disability** 45% cerebral palsy 44% epilepsy 26% had both cerebral palsy and epilepsy, 11% had Down Syndrome. **Time 2** Not reported **Time 3** Not reported	**Baseline, Time 2 and Time 3** ○ Community Integration Scale (CIS, Heller & Factor, 1991). ○ Self-made family involvement question. Rated from 1 (never) to 5 (monthly or more).	**Baseline** Community Integration: M=1.18, SD= 0.30. Low range of community integration. Family Involvement: M=2.18, SD=1.59. Low range of family involvement. **Time 2** Community Integration: M=1.15, SD= 0.26. Low range of community integration. Family Involvement: M=2.14, SD=1.61. Low range of family involvement. **Time 3**	One unvalidated measure used to indicate quality of life. No sample demographics reported for time 2 and 3 even though number of participants changed. Strategies to manage confounding factors not discussed.

		Community Integration: M=1.34, SD= 0.30. Low level of community integration. Family Involvement: M=2.09, SD=0.41. Low level of family involvement.

Quality Appraisal

There was variability in methodological quality of the studies shown in table 2. Overall, no studies fulfilled all the critical appraisal criteria (i.e., "yes" as a response to all questions), and scores ranged from 2/8 to 7/8. Although no papers were excluded based on quality ratings, these ratings are considered with regard to the strength of the conclusions that can be drawn from the findings.

Four papers scored relatively highly on quality rated as 7/8 (87.5%) (Heller et al.,1998[a]; Heller et al., 1998[b]; Heller et al., 2002; Higgins & Mansell, 2009). These were found to have considered the risk of bias across sampling strategy, design, conduct and analysis. However, only one paper reported on confounding factors and their use of strategies to mitigate the potential impact of these (Higgins and Mansell, 2004). Higgins and Mansell (2004) used validated measures and completed additional analyses on these, to increase the reliability of findings. Test-retest reliability checks were carried out, if good levels of reliability were not obtained then these measures were not included in their analyses, as the findings could not be confidently interpreted. The majority of papers considered confounding factors but did not discuss any methods used to mitigate these (Heller et al., 1998[a]; Heller et al., 1998[b]; Heller et al., 2002; Hsieh et al., 2009).

Hsieh et al. (2009) obtained moderate quality appraisal ratings of 6/8 (75%). The paper had strengths in terms of its description of study setting and description of participant details, such as level of intellectual disability and reporting of other disabilities such as epilepsy. However, these details were only reported at baseline. Participant numbers declined over the timepoints. Therefore, understanding the participant demographic details became challenging at timepoints 2 and 3. In addition, only one validated measure was used to indicate quality of life and strategies to manage confounding factors were not discussed.

Thompson et al. (2004) scored low on quality appraisal ratings and obtained a score of 2/8 (25%), this indicated that the paper was at higher risk of bias. The paper had relative strengths in its description of the study setting and statistical analyses. However, the authors opted to focus on two indicators of quality of life, which included community integration and family involvement, and explored these via two self-made questionnaires. A validated measure would have decreased the risk of bias. In addition, the authors simply stated that participants had an intellectual disability but provided no further sample characteristics such as age, gender or ethnicity. Lastly, the authors did not explore confounding factors or any strategies to deal with these.

Table 3. *Critical Appraisal Ratings*

	Heller et al. (1998)[a] Cross Sectional	Higgins and Mansell (2009) Cross Sectional	Thompson et al. (2004) Cross Sectional	Heller et al. (1998)[b] Longitudinal	Heller et al. (2002) Longitudinal	Hsieh et al. (2009) Longitudinal
Q1) Were the criteria for the inclusion in the sample clearly defined?	Y	Y	Y	Y	Y	Y
Q2) Were the study subjects and the setting described in detail?	Y	N	N	Y	Y	Y
Q3) Was the exposure measured in a valid and reliable way?	Y	Y	N	Y	Y	N
Q4) Were objective, standard criteria used for measurement of the condition?	Y	Y	N	Y	Y	Y
Q5) Were confounding factors identified?	Y	Y	N	Y	Y	Y
Q6) Were strategies to deal with confounding factors stated?	N	Y	N	N	N	Y
Q7) Were the outcomes measured in a valid and reliable way?	Y	Y	N	Y	Y	N

Q8) Was the appropriate statistical analysis used?	Y	Y	Y	Y	Y	Y
Total critical appraisal raw score and percentage	7/8 87.5%	7/8 87.5%	2/8 25%	7/8 87.5%	7/8 87.5%	6/8 75%

Narrative Synthesis

The results below outline the findings regarding the quality of life of adults with intellectual disabilities residing in residential care settings for older adults. The measures used vary between studies. Therefore, the results will outline the findings from these different measures in turn.

Community Integration and Involvement

All six studies included a measure of community involvement or integration. Responses on measures indicated low levels of community integration/involvement. Four studies used the Community Integration Scale (Heller & Factor, 1991) which provided a mean rating of the frequency of individuals participating in 12 activities, which included visiting family or friends outside of the nursing home, going to the cinema, shops, restaurants and church. The scale was rated from 1 (none) to 4 (two or more times per week). Heller et al. (1998)[a] reported low levels of community integration, with scores averaging just above 1 (M= 1.17, SD= 0.29). Heller et al. (1998)[b] reported very similar results in their study, with low levels of community integration at two timepoints (baseline; M=1.16-1.23, SD=.29, time 2; M=1.17, SD=.28). In their later study, Heller et al. (2002) also reported low levels of community integration at two timepoints (baseline; M=1.16-1.18, SD= 0.28-0.29, time 2; M=1.35, SD=0.29). Lastly, Hsieh et al. (2009) found low levels of community integration at three timepoints (baseline: M=1.18, SD=0.30; time 2: M=1.15, SD=0.26; time 3: M=1.34, SD=0.30). All four studies using the Community Integration Scale reported similarly low community integration scores. A note of caution when considering these findings is that all four studies were authored or co-authored by Heller. They reported similar, although not identical, study characteristics. Staff were respondents in all of the studies, and the respondents were all from nursing homes in the city of Chicago.

Higgins and Mansell (2009) used the Index of Community Involvement (Raynes et al., 1994), to ascertain whether participants had used specified facilities within the community in the last month. This included asking individuals if they engaged in the following: sporting activities; social activities or use of facilities such as public transport. This measure requires self-report and provides a final score from between 0 (no level of community involvement) to 100 (very high level of community involvement). The scores indicated very poor levels of community involvement (M=15.9, SD=not reported).

Lastly, Thompson et al. (2004) used a self-made questionnaire to infer community involvement. They asked staff to state how often individuals had the opportunity to do things outside of their residence. Residents' opportunity to do things outside of the home was measured via a response of at least three times a week, at least once a month and less than once a month. Of the individuals who responded 49% stated that they were able to get outside of the residence more than 3 times a week, 26% stated once a week, 11% stated once a month and 19% stated less than once a month. Thompson et al. (2004) concluded that there were limited opportunities for individuals to be involved in opportunities outside of their residence.

Whilst there were differences in measures of community integration/involvement, the six studies all consistently reported low levels of community integration and activity for adults with intellectual disabilities living in nursing homes.

Lifestyle Satisfaction

One paper examined lifestyle satisfaction within the context of quality of life. Heller et al. (1998)[b] used the Lifestyle Satisfaction Scale (Heal & Chadsey-Rusch, 1985). This measure required self-report from participants. Therefore, data were only collected from participants with mild to moderate intellectual disabilities, who had the cognitive and communicative ability to complete the scale, at two timepoints. At baseline (N=51) participants reported lifestyle satisfaction between the dissatisfied and extremely dissatisfied ranges (M=4.41-11.41, SD=15.80-25.92). At timepoint two (N=37), three years later, participants reported scores within the dissatisfied range (M=9.75, SD=19.24).

Choice Making

Two papers assessed choice making using the Choice Making Scale (Conroy & Feinstein, 1986). However, only one study was able to provide results. Hsieh et al (2009) did not report their choice making findings as poor levels of test-retest reliability were found and they concluded that the results could not be confidently interpreted. In addition, Heller et al. (2002) only collected choice making responses at timepoint 2, and there was no justification for the lack of utility of this measure at baseline. At timepoint two staff reported that people with intellectual disabilities residing in nursing homes had limited opportunities for choice making (N= 53, M=1.54, SD=0.70).

Family Involvement

Two studies explored family involvement in relation to quality of life for adults with intellectual disabilities living in residential care settings for older adults via self-made questionnaires. Results from both studies suggested low to little family involvement. Hsieh et al. (2009) collected staff report at three timepoints (baseline: 1989-1990;

time two: 1991-1992; time three 1997-1999). Staff were asked how the participant had visited a family member in the past year, this ranged from 1 (never) to 5 (monthly or more). Results indicated few contacts with family (baseline: N=330, M=2.18, SD=1.59; time two: N=267, M=2.14, SD=1.61; time three: N=177, M=2.09, SD=0.41). Similarly, Thompson et al. (2004) asked staff to report the frequency of contact with family and friends in the past year. This included visiting family and friends, telephone contacts, birthday and Christmas card contact. Results indicated low levels of family involvement with the more than half of respondents not having regular contact with anyone outside of their residential service (N=196, 42.7% saw a family or friend at least once a month, 53.7% did not have any regular contact with family or friends). However, the limitation of these findings for both studies are that the questionnaires were developed by the researchers and lack any data on their validity and reliability.

Participation in Domestic Life

Lastly, Higgins and Mansell (2009) examined participation in meaningful activity using the Index of Participation in Domestic Life Scale (Raynes et al., 1984). This scale measures participation in 13 household tasks during the last month. The items include cleaning own bedroom and preparing meals. They reported poor scores (N=19, M=1.0, SD= not reported). Poor scores indicated that there were limited activities of participation in domestic activities for adults with intellectual disabilities within nursing homes.

Discussion

This review identified, appraised and narratively synthesised six articles that quantitively reported on quality of life data for adults with intellectual disabilities within residential care settings for older adults. All studies identified the residential setting as a nursing home and used dimension specific measures to infer quality of life. This included community integration/involvement, lifestyle satisfaction, choice making, family involvement and participation in domestic life. Scores on all dimension specific measures indicated low levels of quality of life for adults with intellectual disabilities residing within nursing homes. Due to the limited studies within this field, and the small number of studies included within this review, it is difficult to generalise findings. However, this review may be able to provide initial insights into the quality of life for adults with intellectual disabilities residing in residential care settings for older adults.

The review findings are consistent with previous research which has suggested that nursing home environments are not suitable for adults with intellectual disabilities (Heller et al., 1998; Bigby et al., 2008; Shieu et al., 2021). Heller et al. (1998)[b] explored the environmental characteristics of nursing homes and community-based settings on the wellbeing of adults with intellectual disabilities. They revealed that nursing homes generally are not able to provide the type of service settings which have been evidenced to benefit people with intellectual disabilities. This is in keeping with research that suggests community living demonstrates improvements in most outcomes, compared to those living in more institutional residences for people with intellectual disabilities (Kozma et al., 2009). This has been further supported by qualitative research exploring individuals' perceptions of community living compared to more institutionalised settings (Esteban et al., 2023).

Furthermore, the review also found that the age range of adults with intellectual disabilities residing in residential care settings for older adults was 30 to

89 years. Previous research has suggested that nursing homes are not designed for younger residents and therefore, this can result in unmet psychosocial and recreational needs (Persson & Ostwald, 2009; Barber et al., 2021). Shieu et al. (2021) conducted a scoping review on the lived experiences and quality of life of younger nursing home residents. This review highlighted low reports of quality of life and five themes which suggested individuals' dissatisfaction with life within these settings. Often, papers have reported younger residents as having "cognitive impairment" and it was difficult to ascertain if this specifically referred to adults with intellectual disabilities. However, there is increasing and growing evidence to suggest nursing homes are not suitable residential settings for younger residents with cognitive impairments or intellectual disabilities (Heller et al., 2002; Persson & Ostwald, 2009; Bigby et al., 2011).

Evidence has suggested that adults with intellectual disabilities may be inappropriately placed within residential settings for older adults due to shortages within accommodation (Taggart et al., 2012; Dieckman et al., 2019). Many of these moves have been made within a crisis situation for example, following the death of a parent (Taggart et al., 2012; Tilley et al., 2023). Previous research has suggested that family members express worry and concern over the future residence of their adult child with intellectual disabilities (Bigby et al., 2011; Hole et al., 2013). Bigby et al. (2011) found that family members take seriously their responsibility as carers however, had little knowledge about their rights to safeguard their loved one in regard to future residence. Adults with intellectual disabilities can remain unknown to services until they require further supports, which can lead to a crisis placement (NICE, 2018). Further collaboration between the government, families and adults with intellectual disabilities themselves may facilitate the development of future residential planning that is able to provide better quality of life for people with intellectual disabilities.

Quality of life has been defined as a multi-dimensional concept however, the majority of studies investigated only one or two indicators. Townsend-White et al. (2012) conducted a systematic review of quality of life measures for adults with intellectual disabilities, they revealed that there was lack of consensus on agreed measures and no measure existed that accounted for all eight theoretically accepted domains of quality of life. Two studies included measures designed by their research team however, they failed to examine the test-retest reliability, content validity and internal consistency of these measures (Thompson et al., 2004; Hsieh et al., 2009). If novel measures continue to be used within research, it would be important that validation of these measures is considered. Connell et al. (2018) highlighted the importance of including the target population within the development of quality of life measures. They found that individuals favoured items if they felt they could respond accurately and honestly; this will impact on the validity and sensitivity of the measure.

Limitations

Findings from this review must be considered carefully within the context of its limitations. It was considered important to understand the evidence to date within this field whilst acknowledging the limited studies available. There were a small number of papers included within the review and four of these were co-authored by overlapping researchers, from similar recruitment settings, nursing homes, and from the same city, Chicago. These papers were all included within the review as there was no explicit statement of overlap by the researchers and further details could not be obtained from the authors. However, caution and care should be taken when interpreting the findings. Furthermore, due to the limited number of studies available it may have been beneficial for the researcher to use a comparison group to explore quality of life for typically developing peers residing within the same residential settings. Alternatively, the researcher may have benefitted from widening the search strategy to allow for mental health outcomes to be considered and allowing for qualitative studies to be included. The researcher decided alongside the research team and specialist librarian that as this was a novel systematic review it may be beneficial to have a very specific focus. In future, a broader scope may allow for a wider understanding due to the limited research within the field to date.

Furthermore, inclusion of only English language and peer-reviewed studies introduces publication bias. The researcher modelled key search terms based on English language (i.e., residential care settings for older adults included searches targeting nursing homes). A possible bias is that countries and cultures who use alternative terms were missed from the review. However, the author did scope an array of culturally diverse literatures in the creation of the search strategy and attempted to contact specialist researchers from different countries in the field to clarify terminology. Unfortunately, not one responded to this request.

Lastly, studies reported limited demographics which constrains interpretation of representatives for different groups. This included: two studies who did not report level of intellectual disability of their sample (Thompson et al., 2004; Higgins and Mansell, 2009); three studies who did not report ethnicity (Heller et al., 1998[a]; Heller et al., 1998[b]; Thompson et al., 2004); one study which did not report age or gender of sample (Thompson et al., 2004). Three longitudinal studies had changing numbers of participants through the years; however, they only reported demographics for the baseline participant pool (Heller et al., 1998; Heller et al., 2002; Hsieh et al., 2009).

It’s possible that different demographics such as cultural norms may influence individuals’ responses.

Clinical Implications and Future Research

This review has suggested that there are low indicators of quality of life in relation to community integration/involvement, lifestyle satisfaction, choice making, family involvement and participation in domestic life for adults with intellectual disabilities residing in residential care settings for older adults. These findings could be used to inform care practices, whereby staff recognise and promote the importance of these dimensional aspects of life quality. However, many of the studies included within this review are from the same state in America, Chicago. It is possible that different cultural norms and societal structures influence individuals’ responses on quality of life measures. Therefore, further studies within Scotland and England may enhance understanding of quality of life for adults with intellectual disabilities within residential care settings for older adults within the United Kingdom.

Furthermore, speaking with adults with intellectual disabilities themselves and their families to future plan could be a good first step in obtaining a residential environment they value. Creating policy and legislation which advocates and supports adults with intellectual disabilities and their families to future plan could provide a level of safeguarding, that families have expressed feeling they are without (Bigby et al., 2011). Previous research has highlighted that adults with intellectual disabilities can be left out of the development of policy and government provision (Foster & Boxall, 2015). To ensure the development of inclusive policy, it is imperative that this includes the voices of adults with intellectual disabilities themselves. Despite the launch of previous government frameworks from the United

Kingdom, such as Valuing People Now which aimed to provide more joined up support to adults with intellectual disabilities and their families, research continues to suggest that adults with intellectual disabilities and their families can remain alone until family members pass away (Bigby et al., 2019).

Lastly, future research could focus on creating and validating a holistic measure of quality of life which covers all eight domains of life quality. The critical appraisal of studies within this review demonstrated areas of methodological improvement required in future quality of life research for this population, to maximise validity of findings. It may be beneficial for future studies to measure dimensions of quality of life that have been unexplored to date for adults with intellectual disabilities within residential care settings for older adults. This could include measuring indicators that explore human and legal rights.

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Chapter 2: Major Research Project

When I get older: the views of people with mild to moderate intellectual disabilities about life and support in older age

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Plain Language Summary

Title

When I get older: the views of people with mild to moderate intellectual disabilities about life and support in older age.

Background

People with intellectual disabilities are living longer than previously. Ageing with an intellectual disability can be different to the general population. For example, adults with intellectual disabilities often have health difficulties presenting at a younger age and can remain more dependent on their families as adults. Despite these differences, qualitative research has largely focused on ageing within the general population. Research has included asking adults within the general population to share their views and preferences for their later life. However, there has been little research looking at the views and preferences of adults with intellectual disabilities for their later life.

Aims

This study aimed to ask people with intellectual disabilities about their hopes, worries and preferences for later life.

Methods

Nine adults with mild to moderate intellectual disabilities, aged between 42 and 54 years, took part in this study. Each person was interviewed by the researcher, who asked about their hopes, worries and preferences. The interviews were recorded and analysed using thematic analysis. This approach allowed the researcher to look in detail at what people said to try to understand what ageing meant to them.

Results

There were four main areas that people talked about. 1) Old age as “too far away”: A distant concept; 2) Opportunities for fulfilment prior to old age; 3) Old age as “scary”: Loss of life as it is; 4) Old age as an ending.

Conclusion

On the whole, it seemed participants had complicated views and feelings about old age. This included fears about ageing, death and dying. It is hoped the findings from this study will help people with intellectual disabilities to get the support they need and want as they grow older, and to be supported within their adulthood to have open discussions about death, old age and end of life.

Abstract

Background

People with intellectual disabilities are living longer than previous generations; yet there is a paucity of research exploring people with intellectual disabilities' perspectives on their later life.

Methods

A qualitative, cross-sectional design was employed using semi-structured interviews to capture adults with intellectual disabilities views of later life. Nine adults with mild to moderate intellectual disabilities, between the ages of 42 and 54 years (M = 47.3 years), were interviewed. These data were analysed using thematic analysis.

Results

The following themes were generated from the participants' interviews: Old age as "too far away": A distant concept; Opportunities for fulfilment prior to old age; Old age as "scary": loss of life as it is with two subthemes reflecting two aspects of loss described; Old age as the end of life.

Conclusion

Participants had complex and conflicted views about their later life, this included concerns about who to discuss topics with such as death, end of life and loss. This study highlighted the need to create more spaces for adults with intellectual disabilities to openly discuss fears surrounding death, grief and old age.

Keywords: intellectual disabilities adults, later life, qualitative, ageing.

Introduction

In recent decades there have been considerable demographic changes for people with intellectual disabilities, most notably with increases in life expectancy (Coppus, 2013; Guzman-Castillo et al., 2017). Although estimated life expectancy does not match the general population, the prospect of reaching old age is now a reality for most people with intellectual disabilities (O’Leary et al., 2018; Hughes-McCormack et al., 2022). Increases in life expectancy are a result of improved health and socioeconomic conditions (Beadle-Brown et al., 2010; Dean et al., 2021). Researchers have highlighted factors such as improved residential environments (Vlot-van Anrooji et al., 2020; Hatzikiriakidis et al., 2023) and tailored health provision for people with intellectual disabilities (Lennox et al., 2011).

Although there have been positive changes to the provision of care and support, people with intellectual disabilities continue to experience health inequalities throughout their life course, when compared with the general population (Emerson & Hatton, 2014; Krahn & Fox, 2014; De Winter et al., 2016). People with intellectual disabilities have a higher prevalence of health needs, and these are often unrecognised and can remain untreated (Emerson et al., 2011; Shady et al., 2022). Ageing with an intellectual disability can have a different trajectory to the general population with health difficulties often presenting at an earlier age of onset (Cooper et al., 2015; De Winter et al., 2016). Unmet health needs can lead to individuals developing further chronicity of illness and even earlier mortality (Heslop et al., 2014; Nicholson et al., 2022).

Furthermore, ageing comes with increased likelihood of individuals experiencing bereavements, particularly the loss of a close family member. For adults with intellectual disabilities, this may mean the loss not only of a loved one but also of a primary caregiver, as well as a family home (Karavella, 2013). In the United Kingdom, over two-thirds of adults with intellectual disabilities live with their families, typically parents (NICE, 2018). Many family carers have provided a lifelong caring relationship; this has often led to an intertwined lifestyle with a family carer on many levels, emotionally, practically and financially (Bigby et al., 2019). As people with intellectual disabilities age, uncertainty around the future can increase as parents are no longer able to provide support or have passed away. Many parents express concerns about their ageing adult child's future (Woodman et al., 2014), and some have reported feeling hopeless (Pryce at al., 2017). In some instances, adults with intellectual disabilities can be moved to a new residential setting as a result of a crisis, such as the death of a parent. This can be done without giving adequate consideration to the individuals' needs and preferences (Bigby et al., 2011; Brown et al., 2019).

Qualitative research is well positioned to enrich understandings of particular individuals' preferences and perspectives. There is a wealth of literature exploring views of ageing within the general population and the participants are often middle aged looking towards their later life. These studies have found that individuals raise various concerns about their old age, including worries about physical deterioration (Wurm et al., 2017), cognitive decline (Higgs & Gilleard, 2017), mortality (Tjernberg & Bokberg, 2020), and the aesthetics of ageing such as the development of wrinkles and grey hair (Chonody & Teater, 2016). In addition, individuals expressed hopes about living independently or with family members and having close emotionally meaningful relationships (Stephens et al., 2015). Ageing adults with intellectual disabilities have often experienced different lives from those in the general population. Therefore, it is important to understand the particular perspectives of people with intellectual disabilities.

A previous study has explored the perception of retirement amongst older adults with intellectual disabilities (Judge et al., 2010). Findings from that study included a desire to remain active, the value attached to the social aspects of day centres and general feelings of confusion on the meaning of ‘retirement’. Other studies have asked parents and carers about their hopes and concerns for the future of their loved one or the person they support (Woodman et al., 2014; Pryce et al., 2017). In a study by Hole et al. (2013) family members and adults with intellectual disabilities were interviewed separately about their hopes and concerns for the future. Concerns were raised by parents about the future quality of life of their loved one, particularly in relation to their safety and security. Adults with intellectual disabilities themselves reported wanting to pursue a range of activities and interests, whilst they also raised concerns about loneliness, and worries about a lack of agency with future decision making.

The previous research, outlined above, provides important insights. Research investigating the needs of ageing adults with intellectual disabilities is growing, however, there is still a need for a study focusing more broadly on the views people with intellectual disabilities have about their later life. Therefore, the aim of the current study is to explore the hopes, worries, and preferences of adults with intellectual disabilities for their later life.

Methods

This study was reported in accordance with the Consolidated Criteria for Reporting Qualitative Studies (COREQ; Tong et al., 2007; see Appendix 2.1). The original project proposal can be found in Appendix 2.2.

Design

A qualitative, cross-sectional design was employed using semi-structured interviews to explore participants with mild to moderate intellectual disabilities' hopes, worries, and preferences for old age.

Ethical approval

Ethical approval for this study was granted by the University of Glasgow's College of Medical, Veterinary and Life Sciences Ethics Committee (see Appendix 2.3).

Procedure

Convenience sampling was used whereby managers of Third Sector Organisations supporting adults with intellectual disabilities in Scotland were contacted and invited to support with recruitment to the study. Eligibility criteria were employed for participation in the study, the inclusion criteria entailed the following: (a) adults aged between 40 and 55 years, (b) having a diagnosis of a mild to moderate intellectual disability, (c) being able to converse about feelings, thoughts or experiences and (d) able to provide informed consent. The researcher shared eligibility criteria and managers agreed to disseminate study information booklets (see Appendix 2.5) to potential participants. If individuals wanted to participate, following review of the information booklet, they were asked to contact the researcher via a prepaid envelope enclosing a response sheet or by telephone to express their interest. In line with Scotland’s Capacity to Consent Framework (Adults with Incapacity Act, 2000), the researcher took time to discuss the study with participants and ensured they understood the content of the study, the possible impact of participating and that participation was voluntary. It was also made clear that they could withdraw from the study at any time, without providing any reason. If participants still wished to proceed with participation, a date and time for interview was organised. If there was a doubt on a participant’s competence to provide consent, further conversations would be had with the potential participant and the manager of the Third Sector Organisation.

All participants signed a written consent form prior to the interview beginning (see Appendix 2.6). Interviews took place within private rooms of Third Sector Organisations. Interviews lasted between 14 and 43 minutes (M= 23 minutes 19 seconds). These were recorded using an encrypted dictaphone and transcribed verbatim.

Socio-demographic information and interview

Socio-demographic information was gathered on age, gender, intellectual disability diagnosis and living accommodation. These details were provided via self-report from participants at the start of the interview.

A semi-structured interview was developed to facilitate discussion with participants (see Appendix 2.4). The interview was designed to be flexible in nature, to allow participants to explore novel issues and to elicit more nuanced responses, rather than being rigid or restrictive. An interview schedule was developed by the researcher, in collaboration with academic and clinical supervisors, to guide the exploration of participants’ views of old age. The interview began with general questions exploring the participants’ life, interests and supports they were currently receiving. The remainder of the topic guide focused on facilitating discussions on hopes, worries, and preferences for later life.

The initial section of the interview was created to allow participants to develop rapport with the researcher, before moving to discuss potentially emotive topics. Previous research has suggested that an initial “opener” question can support participants to “warm into” the interview (Smith & Osborn, 2015). Interviews ended with an opportunity for participants to discuss any additional questions or topics they wished to raise.

The interview schedule was trialled with the first two participants who consented to take part within the study. The researcher had not piloted the interview schedule therefore, the first two interviews were transcribed following participation and reviewed by the research team to ensure suitability of the interview schedule. Through discussion it was deemed that the interview schedule was appropriate and therefore was not amended further.

Participants

Nine adults with mild to moderate intellectual disabilities (six females and three males) were recruited and included in the final sample. A full list of participants’ demographic details, alongside pseudonyms, can be found in Table 1. All participants were aged between 42 and 54 years (M = 47.3 years) and had diagnoses of mild to moderate intellectual disabilities. To maintain individuals’ anonymity, it was agreed with University of Glasgow Ethics Committee that managers of Third Sector Organisations would not detail specific diagnoses but would identify individuals with either diagnoses of mild or moderate intellectual disabilities.

All participants stated they were living independently within the community. This was described as living alone (44.4%) or with family members (55.6%) and all participants stated they were receiving support from external support agencies. They could all converse about their feelings, thoughts or experiences and were able to provide informed consent.

Table 1. *Participant Characteristics*

Pseudonym	**Age**	**Gender**	**Living Accommodation (all receiving external supports)**
Melissa	53	Female	Residing alone
Lauren	42	Female	Residing with family
Erin	42	Female	Residing with family
Adam	54	Male	Residing alone
Sylvia	43	Female	Residing with family
Rebecca	51	Female	Residing with family
Martin	42	Male	Residing alone
Luke	48	Male	Residing alone
Elena	51	Female	Residing with family

Data Analysis

Thematic analysis was used to explore themes within participants' views of their future old age, this was conducted manually on Microsoft Word. This approach allows for patterns to be identified across transcripts, leading to the development of themes. The process was iterative and allowed the researcher to develop ideas and initial themes and review these as new knowledge and information was gained from the coding. A critical realist stance was adopted which allows for careful interpretations about the views, hopes and worries of adults with intellectual disabilities. This stance acknowledges that the researcher’s cultural context and individual characteristics may impact the construction of themes.

The six-phase model of thematic analysis (Braun & Clarke, 2019) was chosen as it was considered appropriate in allowing for the exploration and discovery of new perspectives, whilst also allowing for similarities and differences among participants to be identified. The researcher adhered to the following process: firstly, the researcher immersed themself in the data through transcription, reading, re-reading, and making some initial notes on observations or patterns. Phase two included the generation of initial codes which were then organized into meaningful groups. In phase three, initial themes were generated by searching and clustering patterns from the data. During phases four and five, the researcher named and reviewed the themes before the final phase of write up.

The researcher kept reflective notes when reviewing the literature, designing the research questions, during data collection, and the process of analysis to ensure a transparent process of decision making. The researcher is a Trainee Clinical Psychologist, who has provided support to individuals presenting with mental health difficulties. It was therefore important for the researcher to maintain an awareness of potential biases towards mental health related themes. In addition, as a woman from an ethnic minority background, the researcher was aware of their own experiences of marginalisation and potential attunement to marginalisation within themes. It was important for the researcher to capture the data as represented by individuals, rather than potentially searching for experiences of inequality. Research supervisors independently identified codes and themes within a sample of the data. These analyses were discussed, and agreement reached, providing a credibility check for the analyses.

Results

After analysing the interviews, four themes and two subthemes were identified. These are shown in Table 2. The themes are described and illustrated with verbatim quotes from participants.

(…) indicates that some text was omitted and [ ] brackets indicate a pause from the participant.

Table 2. *Overview of themes and subthemes*

Research Question	**Themes and Subthemes**
What are the hopes, worries, and preferences of adults with intellectual disabilities for their later life?	1. Old age as “too far away”: A distant concept
	2. Opportunity for fulfilment prior to old age
	3. Old age as “scary”: Loss of life as it is Subtheme 1: Living with loss Subtheme 2: Losing control
	4. Old age as an ending

Theme 1: Old age as “too far away”: A distant concept

Prior to talking with participants about their own futures, all individuals were asked about someone that they had either known or considered to be an “older adult”. Some participants spoke about their parents or caregivers and others discussed characters from television series. All participants stated they categorised these individuals as older adults based on their estimated chronological age (reported as being between 48 and 70). Reflections on the prospect of individuals' themselves as future older adults was mostly resisted by participants and met with responses that this felt "too far away". Many participants appeared to see old age as a distant concept despite, for some, being chronologically close in age to the older adults they had previously described. It could be that some participants had negative perceptions of old age, and therefore could not see the relevance of this concept for themselves.

At the most extreme end of the scale, Erin and Adam found the prospect of being older adults in the future laughable: "I'm too young *laughs* [ ] no too far" (Erin) , and "no, no *laughs* …it's too far away" (Adam). Erin and Adam both described older adults that were similar in age to themselves. This may suggest that they identified as being younger than their chronological age, hence old age felt far away. This may also imply an unconscious bias in how they categorised their own age versus how they categorised others' ages. Objective chronological age was the only marker used to categorise others as older adults. However, objective chronological age was implied as a reductionist measure for defining individuals' own age.

Despite some participants being initially dismissive, all went on to discuss their preferences for later life. For many, there appeared to be challenging emotions related to the idea of ageing. As Rebecca said:

Interviewer: Have you thought about yourself becoming an older adult one day?

*"no, no, no [ ] not yet [ ] *laughs* yeah not me [ ] too far away yet.[ ] I don't like talking about that…I don't know about me being older. Not for me."*

This may suggest some complicated feelings towards later life including fear and an element of avoidance. Interestingly, Rebecca's quote also appears to suggest that there may an element of choice to becoming an older adult. This could be used as a protective psychological defence to regulate difficult emotions evoked by the concept of some individuals envisaging themselves as older adults.

Theme 2: Opportunities for fulfilment prior to old age

When talking about their hopes for old age, it appeared that individuals spoke more generally about their hopes for the near future. Elena and Erin were excited when expressing wishes to take up employment for the first time. Martin also talked about potential new employment opportunities:

"I want to keep working here and maybe start working at the pub…I've wanted to do that [ ] yeah"

It could be that old age felt too far into the distance, that instead individuals responded with their hopes for their near future. Some participants, like Martin and Elena, related their hopes for old age as wanting to do more than previously. For example, one participant linked growing older with the potential for greater freedom:

"I would like it to be different to what it is [ ] I would be able to be free [ ] and I would be able to travel the world on my own and see places I've never been to, and you know maybe have a good life because you know [ ] yeah [ ] mhmm… I would like to find [ ] I would like in the near [ ] to find a person and live happily ever after but maybe it [ ] it doesn't happen that way." (Melissa)

It may be that individuals felt denied of many adult experiences, which can be a prelude to older adulthood. Expressing hope in their 40s and 50s about the possibilities of having a relationship or work, may suggest that these aspirations for adult experiences and opportunities for fulfilment remain at the forefront of some participants minds.

Theme 3: Old age as "scary": Loss of life as it is

When participants talked about their worries of their later life, many described the idea of old age as "scary" and appeared to link this to losses they anticipated experiencing. Implicit within participants' accounts were that old age is not a continuation of life as it is, and that old age is associated with unwanted change and loss. The following two sub-themes represent two aspects of loss that participants referred to.

Subtheme 1: Living with loss

Participants expressed concerns that their social networks would shrink in later life. There were differences in the concerns that participants raised, some accounts indicated anxieties surrounding the fragility of their social networks: "*I don't wanna be bored shitless and not see anyone. I want to go out lots, like now, to the shops, to see my family, for curries." (Sylvia) and "I think it might be different to now, sc-scary new people who don't know me…lots more sitting around, I think I might be lonely" (Erin).* These views, and others, appeared to relate old age with slowing down and loneliness, perhaps suggesting that they were worried they would be forgotten or left friendless and unsupported, if their existing social and support networks were to change. This also highlights the importance the participants attached to their established relationships.

Other participants described concerns that social networks will change as a result of individuals they know dying. This appeared to leave participants feeling their later life may be quite harrowing and outside of their control and they raised the topic of death and dying. For example: "*I might be lonely…we're all going to die; my family, my friends, me and you, I don't want that to happen." (Luke).* Some participants said that they had not talked about death with anyone before and were unsure who they could speak to about this topic. They appeared worried about causing other people distress by raising this topic. This may suggest that death is seen as a taboo topic. As a result, some individuals may remain alone with their worries. For example, as one participant said:

"As I get older, less people around…People I know will die, I'll start to know less and less people, I get scared and an upset stomach whenever I think about it. No one talks much about dying, maybe they get an upset stomach too." (Martin)

Subtheme 2: Losing control

Fears surrounding the loss of autonomy appeared particularly prominent. Some participants said they were scared about who would take control of their lives as they become older. Sylvia expressed worries that decisions would be made by her care team rather than herself. Whereas Melissa raised concerns that decisions would be made by the government and council:

"Interviewer: I wondered if you had any worries about being an older adult one day?

Melissa: I would be scared that you know when it comes to that kind of thing in life that they are going to lock me up in a place that I won't have contact with my family, friends or anything like that… that the council or government would take over me..

I've heard stories of when people get this…and I don't want that for me, I really don't want that"

Melissa, Sylvia and others, expressed some deep concerns about losing their autonomy and also indicated feeling limited power in influencing the course of their later lives. This may indicate that people anticipate later life as not being their own. Other participants described the sense of autonomy that having their own homes had given them, and they spoke in detail about the energy and time they had expended to create a life that they felt was their own. Rebecca described valuing the privacy that her home had given her. Lauren described her home as being related to her sense of identity and was concerned that she could lose that in her later life:

"I feel safe there [ ] it's like I would feel more comfortable [ ] I feel more myself in my home. I know where I am, where things are but I don't like when my support worker moves things around. If I were anywhere else, things be moved around lots and not feel like me…I'm scared as I am not sure if I will be able to stay here"

Theme 4: Old age as an ending

Many participants talked about seeing their old age as being synonymous with the end of their lives. Both death and end of life care were topics that were not included on the researchers' topic guide. Participants raised these themselves, unprompted, and appeared to have thought carefully about the care they would like to receive for the end of their lives. Lauren, detailed her plans and wishes:

"I hope to erm speak to my social worker and give my er what's the name [ ] wishes. You know if I ever became unwell and was to go in an ambulance and I do not want

to be resuscitated, I would not want to die in the hospital. I would want to die at home… I wanna be at my home, I love my home."

Lauren was very measured and calm but was also assertive in expressing her wishes for her end of life care. She wanted to be somewhere comfortable, safe and familiar. Other participants, spoke about the importance of having support and company at the end of their lives. As Melissa said:

"I just wanna be in [ ] like a council flat [ ] near a place that deals with when it comes to my time to be unwell I want to be where people can look after me…I mean if I get sick and it's my time to leave the world, I would need somebody there with me to get me through."

This sentiment was shared by many participants however, the majority of individuals expressed only a few words which indicated the importance of their family members being present. For example: *"I would want my Dad there when it's my time to die." (Adam).* Relationships with parents appeared vital, it could be that this relationship is magnified given the limited number of other close relationships individuals described.

Discussion

This study explored adults with intellectual disabilities hopes, worries and preferences for later life. Four themes and two subthemes were developed using thematic analysis:

1. Old age as "too far away": A distant concept
2. Opportunity for fulfilment prior to old age
3. Old age as "scary": Loss of life as it is
    - Subtheme 1: Living with loss

- Subtheme 2: Losing control

4. Old age as an ending

Notably, this study found that individuals held conflicted views about their own later life, something that is consistent with research on ageing within the general population (Minichiello et al., 2000; Weiss & Lang, 2012; Lamb, 2019). Many participants dismissed considering themselves as older adults in the near-to-medium term future however, simultaneously provided detailed preferences for how they wished their lives would look in the future. Participants were clear in defining others age via chronology. However, many did not view themselves as the chronological age they were, often participants implied feeling chronologically younger. This finding is similar to reports by Lamb (2019) who found adults within the general population aspired to “stave off oldness”. Minichiello et al. (2000) found adults within the general population would list reasons as to why they were younger than their chronologically aged peers. This list included individuals’ describing themselves as not aesthetically looking old, not acting old and remaining fit and active. Concerns regarding the aesthetics of ageing has been voiced repeatedly within the general population (Lamb, 2019; Minichiello et al., 2000) however, this was not raised as a concern within the present study or previous studies exploring ageing for adults with intellectual disabilities.

Research has suggested that negative age stereotypes may be driving individuals’ dissociation from their own current or future later life (Weiss & Lang, 2012; Burke et al., 2014). Many participants initially created distance between themselves and their future later life, perhaps as a result of negative views of old age. Other research has suggested that individuals can struggle to envisage themselves as future older adults (Renoult et al., 2016; Bauckham et al., 2019). One theory that has attempted to explain the underlying mechanisms of this phenomenon is “presentism bias”. This is a tendency to interpret ones past and future self in relation to present wishes and motives (Cameron et al., 2004; Renault et al., 2016). This could be in line with specific findings from this study, such as when participants appeared to discuss their hopes for their present future rather than hopes for their later life. Such as obtaining employment for the first time.

Alternatively, it could be that participants felt that older age would provide an opportunity to fulfil many adult experiences they had been unable to yet, such as having a relationship or holding employment: things that can be a prelude to older adulthood. Individuals may have discussed more present hopes as these aspirations remained at the forefront of their minds. This interpretation could be consistent with previous studies which have reported adults with intellectual disabilities feeling they had limited opportunities within their adulthood, so changes in circumstances may be viewed, by some, as having positive aspects (Merrells et al., 2017; Fulford & Cobigo, 2018). Research has suggested adults with intellectual disabilities hope for more intimate relationships as adults, such as a boyfriend or girlfriend (Knox & Hickson, 2001; Healy et al., 2009; Fulford & Cobigo, 2018). Furthermore, adults with intellectual disabilities are persistently under-employed and express a want for further employment opportunities (Lindsay et al., 2023).

Participants discussed the losses that they associated with their future old age. They implied that this life stage would not be a continuation of their life to date but a loss of life as it is known. Participants particularly discussed loss in relation to their social networks and autonomy. This finding is consistent with concerns raised by caregivers (Woodman et al., 2014; Pryce et al., 2017). In addition, this finding is consistent with some themes identified by Hole et al., (2013). Themes were identified within concerns raised by adults with intellectual disabilities in relation to loneliness and worry of lack of control in regard to future living arrangements.

Participants referenced fear of staff and services gaining agency over their decision making in later life rather than having autonomy over this themselves. This has been a common concern raised by ageing family members (Hole et al., 2013; Brennan et al., 2018). Moreover, these concerns can be in keeping with reality, as evidence shows that older adults with intellectual disabilities are sometimes moved to new settings in crisis, without adequately considering their needs or taking their views into account (Bigby et al., 2011; Brown et al., 2019). In addition, Kahlin et al., (2016) conducted an ethnographic study and found ageing people with intellectual disabilities are vulnerable in terms of choice making and reported that this can be restricted by staff members. More inclusive relationships that allow adults with intellectual disabilities greater agency in later life may help to allay individuals' fears about ageing.

Participants also expressed concerns that their social networks would change as a result of their loved ones passing away. Participants appeared to view death as a taboo topic and some participants felt they could not approach others for support with this concern. As adults with intellectual disabilities are living longer, they are also experiencing more bereavements than previously (Karavella, 2013; Bigby et al., 2019; Todd et al., 2020; Fernandez-Avalos et al., 2023). Adults with intellectual disabilities have described limited close relationships however, parents remain a large source of support on many levels (Karavella, 2013). Experiencing the loss of a parent when they have fulfilled a multifaceted role for an individual may lead to an acute response. Lord et al. (2017) conducted a meta synthesis and found there was "a cautious silence" around discussions on death and grief. There is a need to provide spaces for adults with intellectual disabilities to discuss their worries and fears about death openly.

Lastly, many participants within the study demonstrated an awareness of the inevitability of their own death. Participants implied fears around being alone when it comes to this time in their life and expressed hopes of wanting to be supported by a loved one. There is limited research within this field for adults with intellectual disabilities. However, existing evidence has highlighted that deaths of adults with intellectual disabilities can sometimes be unanticipated which may be facilitating the limited end of life care planning (Hunt et al., 2020; Todd et al., 2020). There is a need to increase and include adults with intellectual disabilities themselves to be active persons in planning for the end of their lives.

Study Limitations

Several limitations must be considered when interpreting the findings of this study. Firstly, interviews with participants were fairly short and lasted between 14 and 43 minutes (M= 23 minutes 19 seconds). During transcription of the interviews, the researcher became aware of areas of discussion that could have benefitted from further exploration, such as hopes for employment and end of life. Further exploration may have allowed for greater depth within interpretation and analysis.

Secondly, limited demographic data was collected for individuals that participated within the study. Collecting further information such as ethnicity might have enhanced understanding of the perspectives of individuals, it is possible that individuals who have been exposed to different cultural norms, may have different perceptions of ageing. There may have also be other background information that might have helped with the interpretation of the findings. However, it was not possible to collect this information due to the risk of participant anonymity being breached.

Lastly, the study was not longitudinal in design and therefore provided only a snapshot of individuals looking toward their later life. Whilst this supported in gaining an understanding of particular individuals views of ageing at a specific time within their lives, a longitudinal design may provide a more complete understanding of how individuals perspectives of ageing develop over time.

Implications and Future Research

These findings highlight the conflicted and complex views that appeared to exist for nine adults with mild to moderate intellectual disabilities in regard to their later life. Some unexpected findings were identified, with participants raising the topic of death, but feeling unsure whom they could speak to about this, and individuals also asserted clear preferences for their end of life care. These findings suggest the importance of further information and support for people with intellectual disabilities to understand, discuss and provide their preferences in relation to old age, death and end of life. Encouraging staff and individuals supporting adults with intellectual disabilities to discuss death, end of life and old age could be a first step in enabling individuals to discuss their fears and worries.

Furthermore, participants expressed wants for more intimate relationships within their lives. Maintaining curiosity and asking adults with intellectual disabilities what aspirations they have for their adulthood may support in these actualising. Supporting adults with intellectual disabilities to build further relationships and expand their social networks by creating and facilitating further social integration could aid development of further relationships. Alongside a want for further intimate relationships, many participants discussed hopes for employment within their futures. Despite the Scottish Government creating previous and existing frameworks, such as the Same as you? (2000-2012) and the Keys to Life (2019-2021) which committed to further employment and social opportunities for adults with intellectual disabilities, research suggests some individuals' needs can remain unfulfilled and unequal compared to the general population. It may be that alongside government led transformational change frameworks, there is a need for practical and tangible steps to increase employment for adults with intellectual disabilities. For example, research has indicated that organizational culture can be a factor that hinders the employment of adults with intellectual disabilities (Vornholt et al., 2013). Therefore, clear steps on tackling culture that could be impacting fair recruitment processes is needed, in the first instance.

Lastly, asking adults with intellectual disabilities themselves about their hopes, worries and preferences for their current and future livelihoods could support in individuals feeling they have agency over their lives. Ageing may be a positive thing for people, it may give individuals greater independence than they have had before however, this is dependent upon services and others involved in a person's life giving them the opportunity for this.

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Appendices

Appendix One: Systematic Review

Appendix 1.1 Search terms by database

MEDLINE (OVID)

Ovid MEDLINE(R) ALL <1946 to April 06, 2023>

1. Learning Disorders/
2. Intellectual Disability/
3. Mentally Disabled Persons/
4. Mental Disorders/
5. Developmental Disabilities/
6. Fragile X Syndrome/
7. Rett Syndrome/
8. Down Syndrome/
9. Autistic Disorder/
10. Angelman Syndrome/
11. Cerebral Palsy/
12. Tuberous Sclerosis/
13. (learning adj1 (disab$ or difficult$ or problem$ or disorder$ or handicap$)).tw.
14. (mental$ adj1 (retard$ or disab$ or deficien$ or handicap$ or incapacity or disorder$)).tw.
15. (intellect$ adj1 (disab$ or impair$ or handicap$)).tw.
16. cognitive impairment.tw.
17. (development$ adj1 disab$).tw.
18. (multipl$ adj1 handicap$).tw.
19. fragile x syndrome.tw.
20. Rett$ syndrome.tw.
21. Lennox Gastaut syndrome.tw.
22. Down$ syndrome.tw.
23. tuberous sclerosis.tw.
24. (autism or autistic).tw.
25. Angelman$ syndrome.tw.
26. West$ syndrome.tw.
27. cerebral palsy.tw.
28. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27
29. homes for the aged/
30. exp nursing homes/
31. (aged adj2 (care or nursing or healthcare or residential) adj2 (facility or facilities or home?)).ti,ab.
32. ((geriatric or elderly) adj2 (facility or facilities or care home?)).ti,ab.
33. ((care or convalescent) adj (home? or center? or centre? or facility or facilities)).ti,ab.
34. ((skilled or intermediate) adj (nursing facility or nursing facilities)).ti,ab.
35. (resident* adj2 (care or facility or facilities)).ti,ab.

36. ((nursing or group or residential) adj home?).ti,ab.
37. ((longterm or long term) adj3 (care or facility or facilities)).ti,ab.
38. (healthcare adj2 (facility or facilities)).ti,ab.
39. residential facilities/
40. assisted living facilities/
41. assisted living.ti,ab.
42. halfway houses/
43. 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42
44. 28 and 43
45. exp aged/
46. geriatrics/
47. (gerontol* or ageing or aging or elder* or geriatric* or seniors or old age or older or late* life).ti,ab.
48. (older adj (person* or people or adult* or patient* or inpatient* or outpatient*)).ti,ab.
49. 45 or 46 or 47 or 48
50. 44 and 49
51. Quality of life/
52. "quality of life".ti,ab.
53. "life quality".ti,ab.
54. personal satisfaction/
55. "personal satisfaction".ti,ab.
56. patient satisfaction/
57. "patient satisfaction".ti,ab.
58. activities of daily living/
59. "activities of daily living".ti,ab.
60. quality-adjusted life years/
61. "quality-adjusted life years".ti,ab.
62. personal autonomy/
63. "personal autonomy".ti,ab.
64. happiness/
65. "happiness".ti,ab.
66. patient preference/
67. "patient preference".ti,ab.
68. fear of death/
69. "fear of death".ti,ab.
70. self-concept/
71. "self-concept".ti,ab.
72. family relations/
73. "family relations".ti,ab.
74. religion/
75. "religion".ti,ab.
76. social support/
77. "social support".ti,ab.
78. financial support/
79. "financial support".ti,ab.
80. positive experience/
81. "positive experience".ti,ab.

82. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81
83. 50 and 82

Total papers: 1386

EMBASE (OVID)

Embase 1947-Present, updated daily

1 Learning Disorders/

2 Intellectual Disability/

3 Mentally Disabled Persons/

4 Mental Disorders/

5 Developmental Disabilities/

6 Fragile X Syndrome/

7 Rett Syndrome/

8 Down Syndrome/

9 Autistic Disorder/

10 Angelman Syndrome/

11 Cerebral Palsy/

12 Tuberous Sclerosis/

13 (learning adj1 (disab$ or difficult$ or problem$ or disorder$ or handicap$)).tw.

14 (mental$ adj1 (retard$ or disab$ or deficien$ or handicap$ or incapacity or disorder$)).tw.

15 (intellect$ adj1 (disab$ or impair$ or handicap$)).tw.

16 cognitive impairment.tw.

17 (development$ adj1 disab$).tw.

18 (multipl$ adj1 handicap$).tw.

19 fragile x syndrome.tw.

20 Rett$ syndrome.tw.

21 Lennox Gastaut syndrome.tw.

22 Down$ syndrome.tw.

23 tuberous sclerosis.tw.

24 (autism or autistic).tw.

25 Angelman$ syndrome.tw.

26 West$ syndrome.tw.

27 cerebral palsy.tw.

28 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27

29 homes for the aged/

30 exp nursing homes/

31 (aged adj2 (care or nursing or healthcare or residential) adj2 (facility or facilities or home?)).ti,ab.

32 ((geriatric or elderly) adj2 (facility or facilities or care home?)).ti,ab.

33 ((care or convalescent) adj (home? or center? or centre? or facility or facilities)).ti,ab.

34 ((skilled or intermediate) adj (nursing facility or nursing facilities)).ti,ab.

35 (resident* adj2 (care or facility or facilities)).ti,ab.

36 ((nursing or group or residential) adj home?).ti,ab.

37 ((longterm or long term) adj3 (care or facility or facilities)).ti,ab.

38 (healthcare adj2 (facility or facilities)).ti,ab.

39 residential facilities/

40 assisted living facilities/

41 assisted living.ti,ab.

42 halfway houses/

43 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42

44 28 and 43

45 exp aged/

46 geriatrics/

47 (gerontol* or ageing or aging or elder* or geriatric* or seniors or old age or older or late* life).ti,ab.

48 (older adj (person* or people or adult* or patient* or inpatient* or outpatient*)).ti,ab.

49 45 or 46 or 47 or 48

50 44 and 49

51 Quality of life/

52 "quality of life".ti,ab.

53 "life quality".ti,ab.

54 personal satisfaction/

55 "personal satisfaction".ti,ab.

56 patient satisfaction/

57 "patient satisfaction".ti,ab.

58 activities of daily living/

59 "activities of daily living".ti,ab.

60 quality-adjusted life years/

61 "quality-adjusted life years".ti,ab.

62 personal autonomy/

63 "personal autonomy".ti,ab.

64 happiness/

65 "happiness".ti,ab.

66 patient preference/

67 "patient preference".ti,ab.

68 fear of death/

69 "fear of death".ti,ab.

70 self-concept/

71 "self-concept".ti,ab.

72 family relations/

73 "family relations".ti,ab.

74 religion/

75 "religion".ti,ab.

76 social support/

77 "social support".ti,ab.

78 financial support/

79 "financial support".ti,ab.

80 positive experience/

81 "positive experience".ti,ab.

82 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66 or 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80 or 81

83 50 and 82

Total papers = 1526

PsychINFO (Ebsco Host)

1 DE "cognitive impairment" or "mental retardation" or "developmental disabilities" or "fragile x syndrome"

2 DE "learning disabilities" or "learning disorders" or "mental disorders" or "rett syndrome"

3 DE "autism" or "cerebral palsy" or "downs syndrome"

4 TI "learning disab*" or "learning difficult*" or "learning problem*" or "learning disorder*" or "learning handicap*"

5 AB "learning disab*" or "learning difficult*" or "learning problem*" or "learning disorder*" or "learning handicap*"

6 TI mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder*

7 AB mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder*

8 TI intellect* disab* or intellect* impair* or intellect* handicap*

9 AB intellect* disab* or intellect* impair* or intellect* handicap*

10 TI development* disab* or multipl* handicap* or “cognitive impairment” or “tuberous sclerosis”

11 AB development* disab* or multipl* handicap* or “cognitive impairment” or “tuberous sclerosis”

12 TI autistic or autism or “cerebral palsy” or “fragile X syndrome”

13 AB autistic or autism or “cerebral palsy” or “fragile X syndrome”

14 TI “Rett* syndrome” or “Lennox Gastaut syndrome” or “Down* syndrome” or “Angelman* syndrome” or “West* syndrome”

15 AB “Rett* syndrome” or “Lennox Gastaut syndrome” or “Down* syndrome” or “Angelman* syndrome” or “West* syndrome”

16 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

17 DE homes for the aged or housing for the elderly or nursing homes

18 TI (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")

19 AB (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")

20 TI "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*"))

21 AB "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*"))

22 TI ((care or convalescent) w1 (home* or center* or centre* or facilit*))

23 AB ((care or convalescent) w1 (home* or center* or centre* or facilit*))

24 TI ((skilled or intermediate) w1 "nursing facilit*")

25 AB ((skilled or intermediate) w1 "nursing facilit*")

26 TI (resident* n2 (care or facilit*))

27 AB (resident* n2 (care or facilit*))

28 TI ((nursing or group or residential) n1 home*)

29 AB ((nursing or group or residential) n1 home*)

30 TI ((longterm or “long term” or long-term) n3 (care or facilit*))

31 AB ((longterm or “long term” or long-term) n3 (care or facilit*))

32 DE “residential facilities” or MH “long term care”

33 TI "residential home*" or "healthcare n2 facilit*"

34 AB "residential home*" or "healthcare n2 facilit*"

35 DE "assisted living"

36 TI "life care cent*" or "continued care cent*" or "extended care facilit*"

37 AB "life care cent*" or "continued care cent*" or "extended care facilit*"

38 TI (MH "halfway houses")

39 TI "halfway houses"

40 AB "halfway houses"

41 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44

42 S16 AND S45

43 TI (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")

44 AB (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")

45 TI (older adj (person* or people or adult* or patient* or inpatient* or outpatient*))

46 AB (older adj (person* or people or adult* or patient* or inpatient* or outpatient*))

47 S47 OR S48 OR S49 OR S50 OR S51

48 S46 AND S52

49 DE ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")

50 TI ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")

51 AB ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")

52 S54 OR S55 OR S56

53 S53 AND S57

54 Limiters - Age Groups: Adulthood (18 yrs & older)
Expanders - Apply equivalent subjects
Search modes - Boolean/Phrase

<u>Total papers = 998</u>

CINAHL (Ebsco Host)

1 MH "cognitive impairment" or "mental retardation" or "developmental disabilities" or "fragile x syndrome"

2 MH "learning disabilities" or "learning disorders" or "mental disorders" or "rett syndrome"

3 MH "autism" or "cerebral palsy" or "downs syndrome" or "intellectual disability"

4 TI learning disab* or learning difficult* or learning problem* or learning disorder* or learning handicap*

5 AB learning disab* or learning difficult* or learning problem* or learning disorder* or learning handicap*

6 TI mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder*

7 AB mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder*

8 TI intellect* disab* or intellect* impair* or intellect* handicap*

9 AB intellect* disab* or intellect* impair* or intellect* handicap*

10 TI “development* disab*” or “multipl* handicap*” or “cognitive impairment” or “tuberous sclerosis”

11 AB “development* disab*” or “multipl* handicap*” or “cognitive impairment” or “tuberous sclerosis”

12 TI autistic or autism or “cerebral palsy” or “fragile X syndrome”

13 AB autistic or autism or “cerebral palsy” or “fragile X syndrome”

14 TI “Rett* syndrome” or “Lennox Gastaut syndrome” or “Down* syndrome” or “Angelman* syndrome” or “West* syndrome”

15 AB “Rett* syndrome” or “Lennox Gastaut syndrome” or “Down* syndrome” or “Angelman* syndrome” or “West* syndrome”

16 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

17 MH homes for the aged or housing for the elderly or nursing homes

18 MH “nursing homes+”

19 MW “nursing home”

20 TI (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")

21 AB (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")

22 TI "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*"))

23 AB "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*"))

24 TI ((care or convalescent) w1 (home* or center* or centre* or facilit*))

25 AB ((care or convalescent) w1 (home* or center* or centre* or facilit*))

26 TI ((skilled or intermediate) w1 "nursing facilit*")

27 AB ((skilled or intermediate) w1 "nursing facilit*")

28 TI (resident* n2 (care or facilit*))

29 AB (resident* n2 (care or facilit*))

30 TI ((nursing or group or residential) n1 home*)

31 AB ((nursing or group or residential) n1 home*)

32 TI ((longterm or long term or long-term) n3 (care or facilit*))

33 AB ((longterm or long term or long-term) n3 (care or facilit*))

34 TI "residential facilities" or "long term care"

35 AB "residential facilities" or "long term care"

36 MH "residential facilities" or "long term care"

37 TI "residential home*" or healthcare n2 facilit*

38 AB "residential home*" or healthcare n2 facilit*

39 MH "assisted living"

40 TI "life care cent*" or "continued care cent*" or "extended care facilit*"

41 AB "life care cent*" or "continued care cent*" or "extended care facilit*"

42 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41

43 S16 AND S42

44 TI (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")

45 AB (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")

46 S44 OR S45

47 S43 AND S46

48 MH ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")

49 TI ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal

autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")

50 AB ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")

51 S48 OR S49 OR S50

52 S47 AND S51

<u>Total papers = 580</u>

SocINDEX (Ebsco Host)

1. SU "cognitive impairment" or "mental retardation" or "developmental disabilities" or "fragile x syndrome"
2. SU "learning disabilities" or "learning disorders" or "mental disorders" or "rett syndrome"
3. SU "autism" or "cerebral palsy" or "downs syndrome" or "intellectual disability"
4. TI learning disab* or learning difficult* or learning problem* or learning disorder* or learning handicap*
5. AB learning disab* or learning difficult* or learning problem* or learning disorder* or learning handicap*
6. TI mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder*
7. AB mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder*
8. TI intellect* disab* or intellect* impair* or intellect* handicap*
9. AB intellect* disab* or intellect* impair* or intellect* handicap*
10. TI development* disab* or multipl* handicap* or cognitive impairment or tuberous sclerosis
11. AB development* disab* or multipl* handicap* or cognitive impairment or tuberous sclerosis
12. SU autistic or autism or cerebral palsy or fragile X syndrome
13. SU Rett* syndrome or Lennox Gastaut syndrome or Down* syndrome or Angelman* syndrome or West* syndrome
14. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
15. SU homes for the aged or housing for the elderly or nursing homes
16. TI (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")
17. AB (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")
18. SU (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*")
19. TI "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*"))
20. AB "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*"))
21. TI ((care or convalescent) w1 (home* or center* or centre* or facilit*))

22. AB ((care or convalescent) w1 (home* or center* or centre* or facilit*))
23. TI ((skilled or intermediate) w1 "nursing facilit*")
24. AB ((skilled or intermediate) w1 "nursing facilit*")
25. TI (resident* n2 (care or facilit*))
26. AB (resident* n2 (care or facilit*))
27. TI ((nursing or group or residential) n1 home*)
28. AB ((nursing or group or residential) n1 home*)
29. TI ((longterm or long term or long-term) n3 (care or facilit*))
30. AB ((longterm or long term or long-term) n3 (care or facilit*))
31. TI "residential facilities" or "long term care"
32. AB "residential facilities" or "long term care"
33. TI "residential home*" or healthcare n2 facilit*
34. AB "residential home*" or healthcare n2 facilit*
35. SU assisted living
36. TI "assisted living"
37. AB "assisted living"
38. TI "life care cent*" or "continued care cent*" or "extended care facilit*"
39. AB "life care cent*" or "continued care cent*" or "extended care facilit*"
40. SU halfway house
41. TI "halfway house"
42. AB "halfway house"
43. S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42
44. S14 AND S43
45. TI (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")
46. AB (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")
47. SU older adults or elderly or seniors or geriatrics
48. S45 OR S46 OR S47
49. S44 AND S48
50. SU ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")
51. TI ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")
52. AB ("Quality of life" OR "Life quality" or "Quality adjusted life year*" or "patient satisfaction" OR "Patient preference*" OR "Activities of daily living" OR "Personal autonomy" OR "Happiness" OR "fear of death" OR "Self-concept" or "religion" OR "family relation*" or "social support" or "financial support" OR "positive experience")
53. S50 OR S51 OR S52
54. S49 AND S53

Total papers = 110

Web of Science Core Collection

"cognitive impairment" or "mental retardation" or "developmental disabilities" or "fragile x syndrome" or "learning disabilities" or "learning disorders" or "mental disorders" or "rett syndrome" or "autism" or "cerebral palsy" or "downs syndrome" or "intellectual disability" or learning disab* or learning difficult* or learning problem* or learning disorder* or learning handicap* or mental* disab* or mental* retard* or mental* deficien* or mental* handicap* or mental* incapacity or mental* disorder* or intellect* disab* or intellect* impair* or intellect* handicap* or “development* disab*” or “multipl* handicap*” or “cognitive impairment” or “tuberous sclerosis” or autistic or autism or “cerebral palsy” or “fragile X syndrome” or “Rett* syndrome” or “Lennox Gastaut syndrome” or “Down* syndrome” or “Angelman* syndrome” or “West* syndrome”

AND

"homes for the aged" or “housing for the elderly” or “nursing homes” or (aged n2 ("care facilit*" or "care home*" or "nursing facilit*" or "residential facilit*")) or "aged nursing home*" or (aged n1 "healthcare facilit*") or "aged residential home*" or (geriatric n2 facilit*) or (geriatric* n1 "care home*") or (elderly n2 (facilit* or "care home*")) or ((care or convalescent) w1 (home* or center* or centre* or facilit*)) or ((care or convalescent) w1 (home* or center* or centre* or facilit*)) or ((skilled or intermediate) w1 "nursing facilit*") or (resident* n2 (care or facilit*))

AND

“older adults” or elderly or seniors or geriatrics OR (gerontol* or ageing or aging or elder* or geriatric* or seniors or "old age" or older or "late* life")

AND

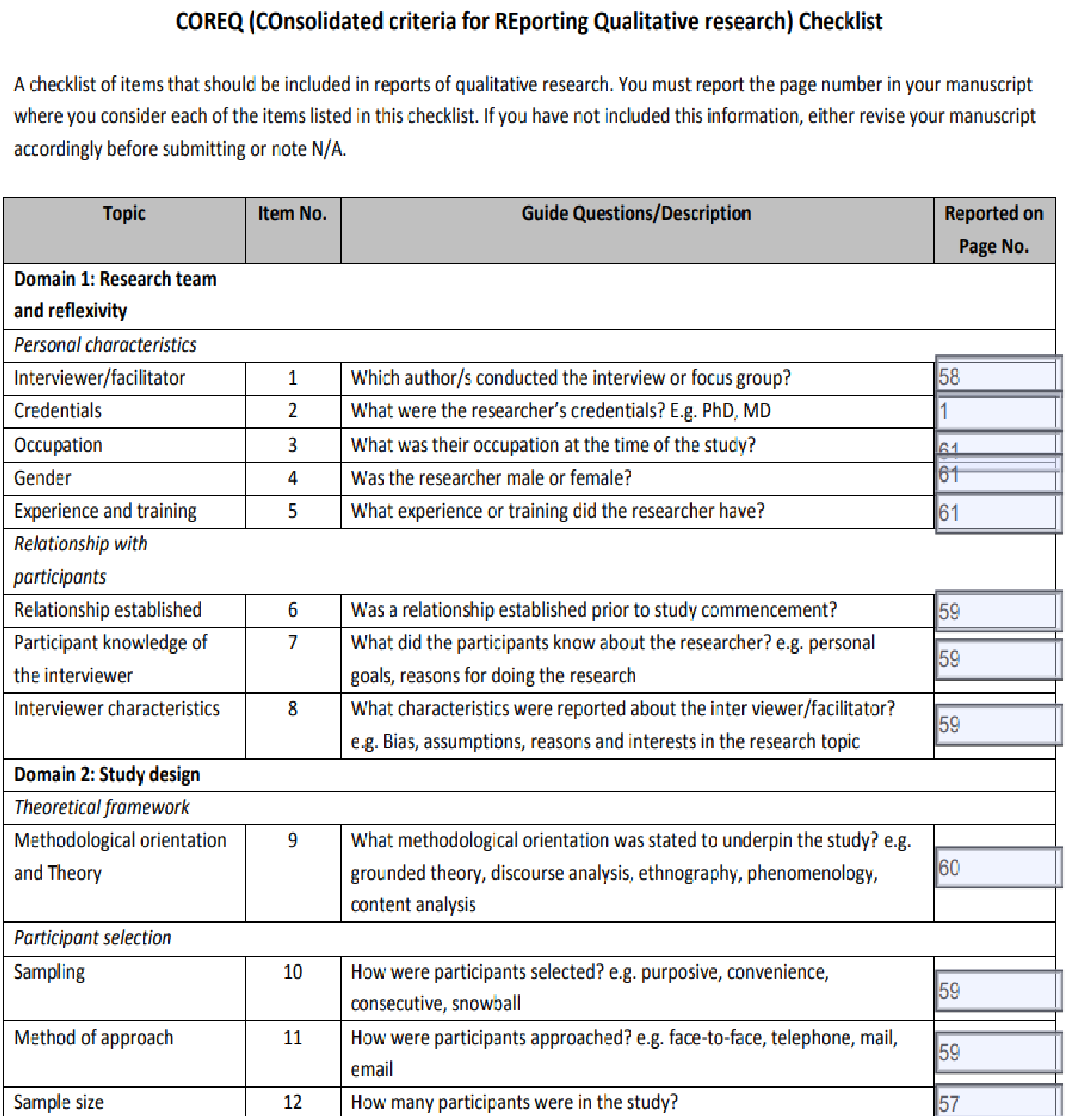
"Quality of life" OR "Client satisfaction" OR "Satisfaction" OR "Life Satisfaction" OR "Activities of Daily Living" OR "Happiness" OR "Self-Concept" OR "Religion" OR "Family relations" OR "Social Support"

Total papers: 523

Appendix Two: Major Research Project

Appendix 2.1 Completed COREQ Checklist

COREQ (COnsolidated criteria for REporting Qualitative research)



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	58
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	61
Gender	4	Was the researcher male or female?	61
Experience and training	5	What experience or training did the researcher have?	61
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	59
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	59
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	59
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	60
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	59
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	59
Sample size	12	How many participants were in the study?	57

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Non-participation	13	How many people refused to participate or dropped out? Reasons?	57
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	60
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	59
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	57
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	58
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	59
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	60
Field notes	20	Were field notes made during and/or after the inter view or focus group?	60
Duration	21	What was the duration of the inter views or focus group?	60
Data saturation	22	Was data saturation discussed?	59
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	60
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	61
Description of the coding tree	25	Did authors provide a description of the coding tree?	61
Derivation of themes	26	Were themes identified in advance or derived from the data?	61
Software	27	What software, if applicable, was used to manage the data?	60
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	62
Data and findings consistent	30	Was there consistency between the data presented and the findings?	68
Clarity of major themes	31	Were major themes clearly presented in the findings?	61
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	61

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Appendix 2.2 Project proposal

Project Proposal can be found using the following link:

https://osf.io/skh4p/files/osfstorage/6505eff9c0a36405c0189815

Appendix 2.3 Ethical Approval Letter

Dear Professor Andrew Jahoda
MVLS College Ethics Committee
Project Title *When I get older: the views of people with mild to moderate intellectual disabilities about life and support in older age*
Project No ***200210196***

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study.
We are happy therefore to approve the project, subject to the following conditions.

1. Project end date as stipulated in original application.

2. The data should be held securely for a period of ten years after the completion of the research project, or for longer if specified by the research funder or sponsor, in accordance with the University's Code of Good Practice in Research: (http://www.gla.ac.uk/media/media_227599_en.pdf)

3. The research should be carried out only on the sites, and/or with the groups defined in the application.

4. Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.

5. For projects requiring the use of an online questionnaire, the University has an Online Surveys account for research. To request access, see the University's application procedure at https://www.gla.ac.uk/research/strategy/ourpolicies/useofonlinesurveystoolforresearch/.

6. You should submit a short end of study report within 3 months of completion.

Yours sincerely

Terry Quinn

FESO, MD, FRCP, BSc (hons), MBChB (hons)

Appendix 2.4 Topic Guide

Topic guide can be found on the following link:

https://osf.io/skh4p/files/osfstorage/6505f369c0a36405d11897c8

Appendix 2.5 Participant Information Booklet

Participant Information Booklet can be found on the following link:

https://osf.io/skh4p/files/osfstorage/6505f4c40fbdf70528313e05

Appendix 2.6 Participant Consent Form

Participant consent form can be found on the following link:

https://osf.io/skh4p/files/osfstorage/6505f4a7cf3dc906e4ad1589