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A Qualitative Exploration of Healthcare Workers' Experiences of End of Life Care for People With an Intellectual Disability

Mary McCarron[1,2] | Eilish Burke[1,2] | Philip Mc Callion[2,3] | Fiona Timmins[4]

[1]Trinity Centre for Ageing and Intellectual Disability, Trinity College, The University of Dublin, Dublin, Ireland | [2]The School of Nursing and Midwifery, Trinity College, Dublin, Ireland | [3]Temple School of Social Work, College of Public Health, Temple University, Philadelphia, Pennsylvania, USA | [4]UCD School of Nursing, Midwifery and Health Systems, Dublin, Ireland

Correspondence: Fiona Timmins (fiona.timmins@ucd.ie)

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Keywords: age-specific care | death | developmental disability | hospice and palliative nursing | intellectual disability | interviews | palliative care | semi-structured interviews

ABSTRACT

Aim: To explore healthcare workers' experiences of end of life care for people with an intellectual disability.

Design: A descriptive qualitative study.

Method: Semi-structured interviews were conducted with 28 healthcare workers who cared for older people with an intellectual disability at their end of life. Data were analysed using thematic analysis and reported according to the COREQ guidelines.

Results: Three major themes emerged: not joining up the dots, living the life desired in one's last days and dealing with death and beyond.

Conclusion: Gaps emerged in the care of the person with intellectual disability. Pain assessment and pain management were particular challenges. End of life care was not always effectively planned, and earlier intervention, including end of life conversations, were needed. More needs to be done in terms of education for healthcare workers, and especially those in the acute care setting and palliative care services who may be unfamiliar with the needs of this cohort.

Implications for the Profession and/or Patient Care: There is little consensus or understanding about the palliative care needs of those with intellectual disability. There are often specific challenges around providing palliative care particularly in relation to healthcare staffs' knowledge and confidence in understanding palliative care needs of this group and indeed communicating and assessing particular needs. Staff require educational preparation and training in palliative care to address the particular needs of this cohort.

Impact: This study revealed that there are gaps emerging in the care of the person with intellectual disability at the end of life. Pain assessment and pain management are particular challenges that require urgent attention.

Patient or Public Contribution: There was no patient or publication contribution in this specific study, although IDS-TILDA has a client representative and advisory committee that advise on all aspects of project design and management.

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Summary

- Although people with intellectual disability are increasingly living longer and experiencing high levels of multiple comorbidity, palliative care has received limited attention among this population.
- There is little consensus or understanding about the palliative care needs of those with intellectual disability.
- There are often specific challenges around providing palliative care particularly in relation to nursing staffs' knowledge and confidence in understanding palliative care needs of this group and indeed communicating and assessing particular needs.
- Overall, there is very little attention paid to the palliative care needs of people with intellectual disability in the mainstream nursing literature.
- This study revealed that there are gaps emerging in the care of the person with intellectual disability at the end of life. Pain assessment and pain management are particular challenges.

1 | Introduction

People with intellectual disabilities have "problems with general mental abilities that affect functioning in two areas: intellectual functioning (such as learning, reasoning) [and] adaptive functioning (activities of daily life such as communication and independent living)" (APA 2022). This definition is understood in the context of social functioning and ability to meet the demands of daily life compared with peers (Psychology Today 2022). The severity of intellectual disability is categorised as mild, moderate, severe, or profound, with most individuals (more than 85%) falling within the mild category (APA 2022). Historically, due to co-existent medical conditions and other factors, the life expectancy of those with intellectual disability was less than the general population (Doyle et al. 2021). While this remains largely the case, the gap is narrowing due to improvements in treatment, lifestyle, and detection (Doyle et al. 2021).

However, despite the knowledge that people with intellectual disability are increasingly living longer (Doyle et al. 2021), and experiencing high levels of multiple comorbidity, approaches to palliative care have received limited attention among this population (Adam et al. 2020; McCarron et al. 2011). As the average age of death before 2000 was 45 years (Doyle et al. 2021), there was less requirement for this type of care. While advanced treatments and lifestyle improvements have resulted in longevity, there are also missed opportunities when it comes to the management of terminal illness (Stirling et al. 2021; Dobrina, Chialchia, and Palese 2020; Flynn et al. 2015).

While there is some understanding of the experience of those with intellectual disability receiving cancer treatment for example, there is little by way of understanding around their specific palliative care needs (Witham and Haigh 2018). The inequity presented by the fact that little attention paid to the palliative care needs of people with intellectual disability in the mainstream nursing literature is not surprising, given that it is well known that health inequities exist among this group, for example in terms of access to cancer treatment and end of life care outcomes (Stirling et al. 2021). However, providing end of life care to people with intellectual disability is nuanced and complex (Kirkendall, Linton, and Farris 2017), most notably by the occurrence of complex multi-comorbidities (van den Bemd et al. 2022; Cooper et al. 2015), lack of screening/late detection of disease (Morris and Julian 2024) dementia, early onset of age-related health problems (Tse, Kwan, and Lau 2018), and communication challenges (Tuffrey-Wijne 2017). This presents unique challenges when caring for this population, and one that most likely exacerbates the existent barriers (Doherty et al. 2020) faced by these individuals when accessing healthcare. Moreover, these omissions in the context of austerity and reduction in services for those with intellectual disability in areas such as the UK (Forrester-Jones et al. 2018; Malli et al. 2018) and global workforce issues (Jackson et al. 2024) may mean that there is a significant amount of missed care that is as yet unexplored in this population. Thus, existent health disparities (Stirling et al. 2021) may be compounded in this cohort.

2 | Background

While there is direction and guidance in relation to palliative care support at end of life in the general population, there are significant gaps in understanding related to the provision of this support to people with intellectual disability and their families (Kang and Barcelona 2023). However, there have been some developments in terms of progressing the nursing profession's understanding and skills, and ultimately improving end of life care, including consensus statements (McCallion et al. 2017; McCarron, Mccallion et al. 2017; Tuffrey-Wijne, Curfs, and Deliens 2016) yet there is much remaining to be developed to address the current inequalities in healthcare provision. Tuffrey-Wijne, Curfs, and Deliens (2016) importantly outlined core principles and consensus, from a European perspective, that sought to support approaches to the inclusion of people with intellectual disabilities in their end of life care planning and ensure more awareness about greater access to mainstream palliative care services. However, the enactment of these recommendations is slow and challenging because of the gaps in staff knowledge, service provision, and policy implementation (Kang and Barcelona 2023).

Indeed, there are often specific challenges around providing palliative care to people with intellectual disability, particularly in relation to nursing staffs' knowledge and confidence in understanding the care needs of those with intellectual disability (Dobrina, Chialchia, and Palese 2020; Dunkley and Sales 2014). Outside of specialist intellectual disability settings, staff can struggle with even the most basic communication with these clients, and so assessing and communicating particular needs at end of life can be challenging (Dobrina, Chialchia, and Palese 2020, Dunkley and Sales 2014). UK oncology nurses, for example, reported discomfort communicating with clients who had an intellectual disability (Flynn et al. 2015). In fact, these nurses reported that caring for these clients was stressful (Flynn et al. 2015). Moreover, these health professionals also reported lacking confidence when dealing with this population (Flynn et al. 2015). Recently, Voss, Francke, and de Veer (2023) found

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that there were very limited referrals to palliative care services across 10 intellectual disability services in the Netherlands. While they found that healthcare professionals reported a high level of competency when caring for these clients, they also identified gaps in knowledge and skills. Results revealed that 24% of staff were "probably not skilled" in relation to collaborating with care organisations that specialise in palliative care (Voss, Francke, and de Veer 2023). This is surprising given the key role that these services play in supporting quality end of life care. The team identified that clear improvements were needed to enhance the health professionals' expertise in supporting end of life care for those with intellectual disability, but skills were also needed in identifying palliative care needs of the clients (Voss, Francke, and de Veer 2023). Due to the dearth of research on this topic, there is an urgent need to address gaps in understanding end of life care for people with intellectual disability in order to inform policy and service. As a first step in developing this awareness, interviewing carers' to understand their experiences of end of life care is important. This can provide in-depth insight into this unknown area of care to establish a basis for future research, policy, and practice.

3 | The Study

3.1 | Aim

This study aims to explore healthcare workers' experiences of end of life care for people with an intellectual disability.

3.2 | Research Question

What are healthcare workers' experiences of end of life care for people with an intellectual disability?

4 | Methods And Methodology

4.1 | Study Setting and Recruitment

4.1.1 | The Study Origins and Context

This research drew indirectly on the dataset of a larger study in the Republic of Ireland (ROI) entitled the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (2024, McCarron, Mccallion et al. 2017). IDS-TILDA is a multi-wave longitudinal study of older adults with intellectual disability designed to explore their ageing profile, physical and behavioural health, health services use, psychological health, social networks, living situations, and community participation including employment (McCarron, Mccallion et al. 2017). It investigates the health and well-being of people with intellectual disability aged 40 years and older in the ROI during 3-yearly cycles (McCarron, Mccallion et al. 2017). Participants for this longitudinal study are derived from National Intellectual Disability Database (NIDD), which the ROI hosts. This is managed by the Health Research Board (Hourigan, Fanagan, and Kelly 2017) and comprises a register of people in the ROI with an intellectual disability (approximately 28,000). IDS-TILDA (2024) retrieves its representative sample (approximately 800) from the NIDD in order to examine the health and social needs of the intellectual disability cohort in the ROI. IDS-TILDA collects data directly from individuals with intellectual disabilities. This current study focuses on people who provide care to these individuals and who were recruited through their association with IDS-TILDA participants. All carers of IDS-TILDA participants who had died ($n = 57$), at the end of wave one of the study, were contacted to take part in this study. Thirty-seven consented to be interviewed (McCarron, Burke et al. 2017), 9 took part in the pilot study, and 28 took part in the main study.

4.1.2 | Operational Definitions

4.1.2.1 | Intellectual Disability. The ROI hosts a National Intellectual Disability Database, managed by the Health Research Board (Hourigan, Fanagan, and Kelly 2017). The estimated population with intellectual disabilities in the ROI (according to this data) is approximately 28,000 (Hourigan, Fanagan, and Kelly 2017), although the national census reports four times that amount (CSO 2022). These discrepancies are likely due to interpretations and could be impacted by the lack of formalised definitions (McConkey, Craig, and Kelly 2019). For the purposes of this study, persons with intellectual disabilities are those enrolled on IDS-TILDA (McCarron, Mccallion et al. 2017) who by default are deemed to have intellectual disabilities by virtue of their registration on the National Intellectual Disability Database (ROI) and subsequent inclusion in IDS-TILDA.

4.1.2.2 | Carers. Following the confirmed deaths of 57 participants identified within the IDS-TILDA (McCarron, Mccallion et al. 2017), carers were identified as family members and/or healthcare staff members who provided support with activities of living for the respective person with intellectual disability at the end of their life, and who consented and were willing to take part. Carers were recruited by means of the IDS-TILDA study (McCarron, Mccallion et al. 2017). Following the confirmed deaths carers of those participants who had died were contacted and invited to take part in this study. Only carers who had supported the individual with intellectual disability, enrolled in IDS-TILDA, for at least 1 year, were included.

4.1.3 | Recruitment

Following the confirmed deaths of 57 participants identified within the IDS-TILDA wave one (McCarron, Mccallion et al. 2017) dataset, carers of those participants who had died were contacted by a gatekeeper by email and invited to take part in this study. These were carers who had supported the individual with intellectual disability for at least 1 year. Prospective carers of these 57 participants were contacted initially by email and followed up (once agreement to participate had taken place) by telephone call. Ultimately, 37 carers consented to be interviewed, of those 9 took part in the pilot interview, but not in the main study. These 28 individuals worked across 17 formalised intellectual disability services in the ROI, across both rural and urban contexts. All of the 28 carers were health care staff, and although family carers were also invited and included, only one took part in the pilot study. Specific demographics related to these healthcare professionals were not collected during the

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study; however, only healthcare assistants, social care workers, registered general nurses (RGNs), or registered intellectual disability nurses (RNID) are employed in the services.

4.2 | Design

4.2.1 | Methodological Approach

Using a descriptive qualitative approach, the current study explored carers' experiences of end of life care for people with an intellectual disability (enrolled on IDS-TILDA, McCarron, Mccallion et al. 2017). The specific aim was to explore the carers' experiences of end of life care for those who had died. A qualitative research design was chosen, as while some information is available on causes of death within this cohort both in the Republic of Ireland (Doyle et al. 2021) and internationally (O'Leary, Cooper, and Hughes-McCormack 2018), little is known about their specific experiences, particularly with regard to receiving and/or access to palliative care services. A semi-structured interview guide was developed specifically for this purpose, which served as the data collection tool (Table 1).

4.3 | Data Collection and Management

Interviews were conducted by a single researcher (PW). All interviews took place at a venue of choosing by the participants. This was either a location convenient to participants or at a participant's house or workplace. During the interviews, only the participant and the interviewer were present. Interviews were recorded and transcribed verbatim. Interviews lasted approximately 30 min. Data saturation occurred. Participants were not known to the researcher before study commencement. The team used the Consolidated Criteria for Reporting Qualitative Research (COREQ) tool (Equator Network 2023) to guide the reporting of the research.

4.4 | Ethical Considerations

Ethical approval for the study was granted by the Faculty of Health Sciences Research Ethics Committee at Trinity College Dublin, Republic of Ireland.

4.5 | Data Analysis

4.5.1 | Thematic Content Analysis

Thematic content analysis was used to analyse the interview data (Graneheim and Lundman 2004). This consisted of repeated reading of each transcript by the research team (PW, COD, KR, JOF, McC, and PMcC). Notes taken by the initial interviewer (PW) were also read by the research team. Preliminary codes were developed independently by the researchers and later finalised and agreed as a group. Each complete transcript was further analysed and coded using NVivo Pro Version 11.4, and this was compared and combined with the aforementioned manual coding. Through systematic content analysis of these emerging codes, by the research team (PW, COD, KR, JOF, McC, and PMcC), emergent themes developed that were further agreed and finalised within the team. Interviewer characteristics were not included in the analysis. Data were anonymised and pseudonyms were used to display quotations.

TABLE 1 | Details of interview guide.

Questions for the interview guide were derived from a variety of sources and included the following items.
Firstly items were used from the validated VOICES questionnaire (Views Of Informal Carers—Evaluation of Services) (Hunt et al. 2019), which contains three open ended questions:
1. What, if anything, do you feel was good about the care?
2. What, if anything, do you feel was bad about the care?
3. Please use the space below if there is anything more you would like to add about the care provided.
Specific items were also drawn from the IDS-TILDA study (Mc Carron et al. 2017) were also included:
4. Since we last talked to him/her, did a doctor ever tell him/her that he/she had any of these conditions?
- A cardiac or cardiovascular disease/Chronic lung disease such as chronic bronchitis or emphysema/
- Arthritis (including osteoarthritis, or rheumatism) Cancer or a malignant tumour (excluding minor skin cancers)/Parkinson's disease/Any emotional, nervous or psychiatric problems/Diabetes/
- Alzheimer's disease or dementia

5. Did he/she have any (other) major illnesses since the last interview/in the 2 years preceding
- His/her death? What illness was that?

I would now like to ask you a few questions about his/her mood during the last year of his/her life.
6. Do you think he/she was depressed during his/her last year of life?
7. How often do you think he/she felt happy during his/her last year of life?
8. And how about the last 3 months of his/her life, how often do you think he/she felt contented or at peace during this time?
A pilot study ($n = 9$) preceded the main study, and following this these further questions, related to rituals after death, were also added to the interview guide:
9. How soon after did a person take their place [replace them] in residence [residential unit or home]?
10. Who was present with the person at the time of death?
11. Who decided what would happen with the person's remains?
12. Who was involved in arranging the funeral service?
13. Who was at the funeral?
14. Where was the person laid to rest/ How far from the usual home?

4.5.2 | Rigour

The researchers aimed to ensure auditability, credibility, confirmability, and fittingness (Polit and Beck 2021) throughout the process. In terms of auditability, a single researcher conducted

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the interviews, and field notes were taken. Approaches to data collection were applied consistently without deviation, including the use of the semi-structured interview guide. Notes were taken by the researcher which supported this audit trail but also aided confirmability, and these were used to confirm the arising codes and themes. Confirmability of the data collected was further established by member checking if the interview transcripts by the participants. Emergent themes are resonant within findings in the literature, and this implies a fittingness outside of this specific context.

5 | Findings

5.1 | Themes

The qualitative analysis identified three major themes: not joining up the dots, living the life desired in one's last days, and a number of sub-themes also emerged (Figure 1).

5.2 | Theme 1: Not Joining Up the Dots

This related to the practicalities of end of life care in formalised institutional settings. This theme reflected many reports of gaps in care for the person with intellectual disability during their end of life care.

5.2.1 | Pain

The recognition and management of pain for people with intellectual disability at the end of life was reported by participants as challenging. Many respondents reported that they found it difficult to confidently assess whether or not the person they were caring for was experiencing pain:

> It was very very difficult to assess his pain as he didn't really show pain

If the person was receiving pain relief, its effects were also difficult to monitor:

> It was very hard to tell with Ellen whether she had pain or not, extremely hard to tell, because she couldn't obviously express.

Many of the respondents reported that they did not know if the person's pain was relieved during the last 3 months of their life. Some reported that they perceived that the client had their pain only partially relieved or not at all. Some mentioned that they used a pain assessment tool. Others observed facial expressions, how the person moved, occurrence of sweating, vocalisations and changes in facial colour. Having a personal relationship with the client appeared to make pain assessment easier. One of the difficulties in assessing pain was that for some there was a learned automatic "yes" or "no" response:

> You'd talk to him and you'd ask him was he in pain [sic] and he'd say no, and that's about all you'd get...

> Not in particular saying, have you got a pain, because we found 99.9% of the time she'd say 'yea, I have a pain'. Whereas, we'd ask 'how are you?' you know things like that. And then if you're chatting, she'll say, 'oh I have a pain'. So we went a little different way around it with her.

Interestingly, several carers reported that when the specialist palliative care became involved in the delivery of care, the healthcare workers perceived that the person's pain was eased and they became pain free.

5.2.2 | Learned Acceptance

Many participants indicated that people with intellectual disability tolerated their pain, in the same way they may have

FIGURE 1 | Subthemes emerging within the three main themes identified within the study.

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done so with previous co-existing disorders (such as epilepsy). Participants believed that some clients were used to a level of suffering due and this led to an acceptance of this. This acceptance was most obvious among those who had spent most of their lives in institutionalised care:

> ...he just accepted his disability all down through the years, he accepted all these horrific seizures he was getting...there was just an acceptance of whatever was happening to him rather than he being aware I think, I don't know how aware he was that he was actually dying but there was just that huge, you know, just acceptance that this is it and this is where I'm at now and, do you know.

5.2.3 | Transitions

Most of the people referred to by the healthcare workers during the interviews died either in their regular residential or community home, or in a residential unit within the same service. Moving residence within the service within the year or months preceding death were uncommon. When they did occur, an emphasis appeared to be placed on maintaining familiar settings, familiar people, and continuity of care for the clients. For example, when individuals were transferred to hospital, they were usually accompanied by a familiar member or staff, if resources allowed:

> If they said right, we're sending him now, have somebody to come with him in the van, you know the ambulance. Maybe, you know, just sit to hold his hand.

Interviewees expressed regret when the person with intellectual disability was transferred to hospital or another unit and they didn't feel it was in the person's best interests:

> But it's a shame, it shouldn't have, that shouldn't have really happened. He should not have been shipped out of his home. Where, you know, he was happy and he was familiar with his surroundings. Especially given the fact that he was confused and everything to begin with.

Not only was the transition expressed as a personal loss for the staff but as several carers expressed the opinion that it had an effect on the health of the person being moved:

> I think we were all very disappointed with the decision to move him out of his home, into another home. Because of staffing, you know. I just, it goes against everything that we'd be trying to achieve, you know.

> Moving clients here is something ... really you know it affects even their physical conditions.

Participants articulated that in situations where accommodating people in their usual home at the end of life, this led to a perception by the staff of a comfortable death. They were assured of familiar surroundings with a level of comfort, privacy, dignity, and a quality of care delivered by the people who knew them best:

> This was her home, she was extremely comfortable and all her personal belongings went in to that room... She was extremely comfortable, and towards the end there was always a staff sitting with her, you know, she was very relaxed...It was familiar surroundings and familiar staff...I think if she was moved anywhere else, it would have been to the detriment really.

5.2.4 | Decisions

Decisions about end of life care were made with the involvement of the individual and families concerned. Participants in the interviews reported that they ensured that they assessed and honoured the wishes of the client, where possible, and in most cases families were also involved in planning and decision-making at the end of life. Although participants reported that this could be challenging, as families may not have had regular contact, they §made great efforts to ensure contact and involvement during this time.

> And it was explicitly her choice to say that she didn't want to move from her own home. We brought her down one afternoon just to see what it was like. And she absolutely said no. So it was very much her own choice to actually stay where she was.

5.2.5 | Conversations About Dying

Many participants spoke of the challenges with conversations about dying with individuals with intellectual disability. Some of this related to the level of disability, which may preclude conversation, but there was also uncertainty as to whether there should be open conversations around death with people with intellectual disability. Among carers' reasons were feelings that the person would not understand or be emotionally ready to cope with such information. They also explained that often the person with intellectual disability had little understanding of their deteriorating health status which led to this reluctance to initiate end of life conversations, which would mean essentially that they would have the responsibility and burden of breaking the news of impending death:

> ... actually it's interesting like, you know, how should we be dealing with it really, should we be telling the person that you're dying, I mean I don't, we've never done that actually.

5.2.6 | General Practitioner/Physician Care

Participants reported that having a regular general practitioner (GP) that knew the individual with intellectual disability, their

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medical history, their story, and how to communicate with them contributed to quality care, good end of life care, and appropriate decision-making:

> ...but she was just so used to [G.P.] coming, because he comes on a weekly basis and he would have been seen her for twenty years...so he would have had a good relationship with her and he knew exactly, yeah.

For many, there were regular GP visits depending on the type of residence they were in and their health needs, with all participants reporting GP visits in the last 3 months of life. These visits could be weekly, two or three times a week, or even daily and there was a sense that they could contact the GP at any stage if they had concerns. Most felt that they had access to good GP care. When out-of-hours GP care was accessed, it was often in a crisis situation and with an unfamiliar GP. Decisions made in these circumstances usually involved admittance of the person with intellectual disability to an emergency hospital department.

> ...[Out of hours GP service] links directly then with the unit, and they make that decision then. They usually come out [to visit the client], but nine times out of ten the person is admitted.

Sometimes, even when end of life plans were already made, for example, with a chosen place of death as the permanent residential home, circumstances dictated that decisions were reliant on out-of-hours GP services:

> So we met with the GP and the family and made a plan for him...But to my dismay one weekend I was off, we ended up calling [out of hours GP service], we have an extremely good GP service here but he happened to be gone that weekend as well. And [out of hours G.P. service] sent him in [to an acute hospital]...So once he went in we didn't get him back and that was a huge disappointment for us all really.

It was interesting to note the language that was used by carers in the few cases when they had negative experiences with the GP services. Several carers spoke of having to 'push',' fight' and 'battle' when they felt that the GP didn't understand the needs of the person with intellectual disability.

> It wouldn't be just specifically to that GP anyway. It'd be just as I say you have to battle with most GPs.

> We just keep fighting with GPs until they listen to you, keep doing it. I suppose

5.2.7 | Rapid Decline

Many of the participants spoke of a rapid decline in health which took place in the last days of the person's life, particularly when people had chronic or terminal illnesses such as end stage cancers, renal failure, pneumonia and advanced dementia:

> It was very quick. Yea and just the end just it was very much like a rollercoaster I suppose. The climb to the top is slow but you know getting there and just hit the bottom very fast.

Many participants spoke of feeling shocked about the deteriorating health and death of the person they were caring for:

> Well I suppose really we're not used to our service users dying, first and foremost. Really, as a rule, we're not. And I suppose, I suppose when someone dies it is always a shock, isn't it, you know.

5.2.8 | Beyond the Medical Model

Several of the participants noted a stereotyping of people with intellectual disability, when interacting more broadly with the general health services. They expressed the view that this often meant that staff they encountered could not separate the illness from the person, and focused more on the intellectual disability label, rather than being alert to possible underlying causes for their symptoms:

> ...was always kind of ah sure they've Down syndrome, that's the way it goes for people. And you know, definitely trying to change that mindset. Because I suppose the further into caring we get, the more you realise there's obviously more to people with Down syndrome than just Alzheimer's, or early onset of it, so. So yea it's something you know, it was a real learning curve I suppose for everyone here that.

5.3 | Theme 2: Living the Life Desired in one's Last Days

Participants reported that staff having a relationship with the person with intellectual disability and having someone close to the person being present at end of life, contributed, in their view, to the provision of high-quality palliative care. These relationships served to maintain normality and a sense of self for the individual.

5.3.1 | Maintaining Normality and Sense of Self

The commitment to delivering high-quality, individualised care which honoured the true self of the person with participants was evident throughout the interviews. Striving to keep people within their usual home, in their usual bedroom was important and most people were reported to have died in their usual home. The suitability, familiarity and security of being in one's own room at the end of life was reported:

> well all I can say is that Bridget was very fortunate, you know...That she died in this room that she loved.

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Maintaining a sense of normality was also achieved through a daily assessment of the ability to continue with one's normal routine such as walking, eating independently, using the bathroom independently, being outside, listening to music, attending the day service and being in the company of other residents and staff.

> So she actually got up out of bed. She sat on the chair, asked us to put on her shoes and then she passed away. When she was in her chair and she had her shoes on, she passed away.

> And she loved, you know, for staff to put on makeup and to do her nails and that. So all those wee things were still kind of carried out for her as long as possible...

5.3.2 | Relationships

Respondents spoke about having a deep sense of caring and attachment for the person with intellectual disability. As a result participants often reported a huge sense of loss when someone was dying, and these healthcare staff experienced grief:

> Do you know, as we always say to us it's like a family member, and that's the relationship we have with the lads...It never gets easier. Not when you work with the clients for as long as we work with them... it's never easy.

As difficult as this time was for the healthcare professionals, they expressed a belief that they were in a privileged position to provide this end of life care:

> It was intense but you know a lovely experience to be...You know to witness and to be with her you know through her final journey. It was lovely for me, a personal journey to see her, I don't know, right through to the end. It was just something I felt that I needed to do like.

5.3.3 | High-Quality Palliative Care

Most of the participants reported that they witnessed a good level of care being provided at the end of life to the clients. They reported a constant presence as being of essential importance. Many carers reported that end of life care manifested in ensuring that someone was by the person's bedside all of the time in their last weeks or days. Two factors appeared to influence—firstly, having a cohesive and determined team and secondly, having the staffing resources. Once the team came together and decided that 24 h care was needed, there was a determination to provide that care regardless of shift patterns or staff shortages. Carers indicated having support at management level, extra staff provided and appropriate equipment available all eased the burden:

> Even though he knew he was getting the care, you know, but we just wanted to go that little extra mile for Edward...like I mean they told us in the current climate like that it was not feasible for Edward to have anybody sitting with him, so we just had to give him as much, if we were on duty we just had to give him as much as we could, you know.

> ...we weren't bothered about shift patterns or anything, you know, because we just wanted to make sure that Bridget got her wish... And there was only one wish, to stay at home.

However, if the person was transferred to hospital the opportunity to provide the same level of care was reported unpredictable. In some cases, the person and the primary host service had the resources to permit a member of their staff to be present with the client 24 h a day. In other cases, this was not possible.

When clients received end of life care in their usual home, the care they received from familiar staff was often supported by specialist palliative care nurses. This was usually triggered when pain levels became unmanageable and consisted of visits and telephone support regarding pain management and comfort care. In many cases, the participants felt "out of their depth" and the palliative care team provided great support and reassurance:

> the Palliative Care Service was fabulous...they were at the end of a phone telling me what to do all night, I don't know how many phone calls I made that night! So there was always somebody there.

> They give us as staff great support and advice on how to manage things. And they support us I suppose the way they would family members, for people who are in their own homes. And they allowed us to participate in all, any planning, or they listened when we said, suggested maybe you could said it a different way.

5.3.4 | Being Present at Death

Participants reported that the clients were mostly accompanied at time of death, by at least one person present at the time of death. Participants expressed a sense of satisfaction knowing that the person was comfortable and peaceful and surrounded by familiar staff and family members:

> With all his family around him, he would have loved, that would have been from what we would have known him; that is what he would have wanted was to have all his family around him.

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In the few cases where there were sudden deaths or the person died alone there was a sense of regret and sadness among the participants:

> But that would be my only, my only regret at the end. I would love to have [sic], if some of us had been there.

5.4 | Dealing With Death and Beyond

This sub-theme addresses what happens around the time of death and afterwards; the funeral arrangements, the rituals that have developed around death, holding the person's place vacant, the impact of the loss, the bereavement support available, the relationship with the family after a death and the lessons learned from the experience.

5.4.1 | Funeral

Very often the participants were involved in funeral preparations, mostly alongside the person's family. Participants believed that it was important that both family members and staff had a role to play in the funeral:

> ...but obviously at the end of the day the family's wishes are what are taken in to account and what are the most important, even if they haven't had that much contact, that's the way it is. But I suppose there's a bit of negotiation there, you know, that it is important to them to have it at home, but it was important to us too that he wasn't just whisked off by the undertaker and–because we knew that there would have been a lot of people, you know, who would have worked with John in different forms down through the years.

The participants reported usually attending memorial services. In many cases the Irish custom of a "wake" (Hardie et al. 2023) was observed, whereby the body was prepared and publicly displayed to allow people to grief. Participants believed that when this took place in the formalised residential setting, it helped staff and other clients to also grieve:

> But they [other clients] were all very much involved and they were very much involved in the funeral as well. So that really helped them, they brought up gifts and someone to say prayers. And all the staff was really involved as well.

One carer spoke of how their service had developed a tradition of a mass in the house to ensure that other clients and healthcare staff received opportunities to grieve:

> We usually have a mass in the house, well that's evolved because initially you see the funerals that were there would be in the village, the funeral mass, or the person went home to their own place to have the mass. And that cut us out of it so what we ended up starting was a farewell mass we used to call it.

5.4.2 | Rituals Around Death

Participants reported unofficial rituals around death which have evolved naturally over time. Having "wake" in the clients usual home was often preferable, allowing healthcare staff and other clients to also grieve. There were also numerous reported practices such as having a table/altar adorned with flowers; keeping photographs up of the deceased person; hosting religious services and remembrance services and placing flowers on the grave at Christmas. One respondent explained that they have worked hard at developing appropriate and respectful procedures around death to support transparency and grieving for the other clients in the services.

> I suppose in a sense we celebrate death. We announce it, we tell people very discreetly individually, or in little groups. We tell them and then we tell the staff. And that is an important system. Because in the past they have told us that staff would know and they [the clients] wouldn't [know] and they'd hear staff talking about it. Imagine finding out that somebody you lived with for forty years [died and you didn't know]. So we tell them first and then we tell the staff. And we have prayers immediately, we say a rosary and we put a picture of the person out on the front desk. We have a table and flowers and a nice picture frame of the person.

5.4.3 | Holding the Space

Most participants reported that within their services the residency of the dead person was permitted to remain vacant, as a mark of respect, often for more than 3 months.

> We were so slow to give his room away... They used every other room but his room I'd say for about four or five months.

Participants reported a belief in the importance of physically holding the space vacant while there was a psychological adjustment to life without the person who had lived there. Actions such as keeping the bed vacant, keeping the deceased's photographs up on the wall and leaving the bedroom door open were all viewed by participants as displaying a respect for the person who had died. It provided an interim pathway for everyone in the residence to adjust, to settle and adjust after the death.

5.4.4 | Impact of Loss

Participants spoke about the need for both staff and other clients (usually within a formalised care residential house setting) to grieve and adjust:

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> ...the house actually needed that length of time for people to adapt to it because it wasn't just a death in the house, it was someone who had lived their final days in, you know, it was a very busy house and then suddenly there was nobody coming to it.

> It was huge. It was absolutely huge because though she was on the periphery, she was there; she was a constant you know. So she, while she wasn't the big talker she was a constant [presence]. And it was huge.

> And she's still talked about you know... she hasn't gone... she had a really big impact...so her death had a big impact

There was also an impact on staff who were grieving:

> Certainly staff were physically and mentally, or emotionally exhausted after. It was like, it turned into a mini nursing home for the last three months, or maybe more all of a sudden. You know, we had no energy, you know I think people were you know were grieving in some shape or form. But we just didn't realise it at the time, like, you know...But it was the just the emotional drainage that we had that we couldn't overcome for a good two months after.

> I think the toughest bit is when you walk into their bedroom and we try and keep their bedrooms as personal as we can so their photographs are all over the wall and their little bits are all around the place, that was the hardest bit...and the staff will always say to me emptying the wardrobes is the hardest bit.

5.4.5 | Bereavement Support

Not only did participants report that they had experienced grief at the loss of a close relationship but they were also supporting other staff and clients with their grief. Participants also reported that healthcare chaplains within the services also supported informally. Participants also mentioned that their employer provided access to a counselling service or psychologist. Formal bereavement support was often provided by healthcare chaplains. Many participants availed of both informal and formal support after the client's death. Some participants reported having formal death review meetings. One example described how they now had a structured process in place of regular meetings in the weeks following the death. These meetings included family members and were open to all healthcare staff who had known the person to include supported staff such as bus drivers. In other settings, a manager organised for an outside health care professional to facilitate a bereavement support meeting and these meetings were all favourably received. Bereavement support for the clients within the services was less formalised.

5.4.6 | Relationships With Family

Participants reported that each family dynamic was different. There were clients who had no family contact, some with intermittent contact especially if relatives were elderly or lived a distant away and there were those with close regular contact. However participants noted that it was common, irrespective of the nature of the contact, that this increased in the final weeks of the person's life. Most families were involved in funeral arrangements:

> He loved them, so he would have been so happy to have had all of them there. And they were fabulous, they would have sang all his favourite songs, and they would have had, you know, been talking about things from the past, all the stories that he would have loved.

Sometimes it was only in the final weeks of the person's life that their family really got to know the services:

> ...they get to know staff, they get to know the places and once they feel the staff are able to look after things they are happy and they like that.

This increased level of contact with families continued after the death, for example, while belongings were being organised and through attendance at one-month anniversary religious services. However, after this contact with families then seemed to end, particularly when the family didn't live locally. Participants reported that there was a perception of loss, that affected both sides, when this happened. Staff lost out on the shared link with the family to the person who had died and the families missed out on the relationship with the service, as phone contact and visits had become part of the pattern of their lives:

> Do you know, it's hard for them after having ...[been] associated with [the service], for ...the thirty years that Kathleen... was in the service, or whatever. To then just completely nothing.

> I think we're much more conscious now of trying to get families involved more. Of making them come up, ringing them every week and say oh will you come up, like we'd our family forum now last week and there was families who would never have thought of coming up came up for it.

5.4.7 | Lessons Learned

Participants were not directly asked what they had learned from their experiences of caring for someone at the end of their life but many willingly shared their reflections. These learned lessons can be broadly described as; preparation, communication and follow through. They are listed in Table 2. For some participants, it had already led to a change in practice. Participants also reported the characteristics of a good and bad death (Table 3).

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TABLE 2 | Lessons learned- preparation, communication and follow through.

Preparation, communication and follow through	
Get families more involved from early on	Ensure excellent communication between staff and shifts
Early introduction to possible future residence	Be insistent/take strong lead/speak up and follow through
End of life plan	Early medical intervention
End of life information for families	Have a good GP and change if necessary
Have conversations with the person with ID about what is happening	Develop chat book' for the person with ID to bring with them when accessing different services which help to prompt conversations
Discuss DNR status	Hold the space vacant for as long as possible when someone dies
Have a protocol and stick to it	Bereavement
Be prepared for emergencies and changing health needs	Formal debriefing
Have a panel of people on call; e.g., to enable a familiar member of staff to go to the hospital if necessary	Bring counsellor in

TABLE 3 | Lessons learned-characterisitics of a good and bad death.

Characteristics of a good death	Characteristics of a bad death
• A private room with adequate space for equipment and carers • Constant presence of family and/or staff • Good G.P. support • Good Palliative Care support • EOL care plan • DNR plan • Resources ◦ Physical—e.g., hoists, comfort chair, family room ◦ Staff—support from management, extra staff, spiritual support • Familiar faces present • Close relationships with staff • Good family involvement • Death reviews • MDTS • Team decisions • Post-death follow-up e.g., anniversary masses, contact with family, Christmas card	• Lots of transitions e.g., hospital visits • Move within 3 months of dying • Left alone • Doctors not following up on investigations • No DR discussion • Inadequate medical intervention • Late diagnosis • Pain not recognised • Crisis decisions made by health care professionals who don't know person • Lack of communication with person about their death • ID staff fighting for medical care • ID staff not fighting enough for medical care

6 | Discussion

6.1 | Good Quality End of Life Care

It is reassuring to note within this study that the end of life journey for those with intellectual disability within these ROI services, appeared to be of high-quality. A key element of this appeared to be the personalised relationship with the client, and the care and attention that this enabled. This is in contrast to identified gaps in service, knowledge and care provision witnessed in other studies where people with intellectual disability can experience "poorer quality of care at end of life" mostly related to the communication challenges that lead to misunderstandings and missed opportunities to identify care needs (Tuffrey-Wijne 2017). A good understanding of the clients' needs and referral to palliative care services seemed to be core components of this seamless care. This contracts with barriers identified within the literature where people with intellectual disability appear to have difficulty receiving or accessing palliative care due to under referral and lack of expertise (related to intellectual disability) among the healthcare workers and communication barriers (Voss, Francke, and de Veer 2023; Irons 2023; Velepucha-Iniguez, Bonilla Sierra, and Bruera 2022). Key insights around facilitating a good death for people with intellectual disability emerged from this study that may be useful to inform care going forward. This will be especially helpful for supporting families in the community, who, as formalised institutionalised care in the ROI diminishes are now being recognised as the sole carers for this population (Brennan et al. 2023).

6.2 | Breaking Bad News

From the interviews with these participants it appeared that end of life care was further complicated as clients did not know or understand their prognosis. This led to an ethical dilemma for participants who were not always sure how to act in this regard.

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This finding is echoed in the literature (Foo et al. 2021). A recent UK-wide survey revealed that just over half of people in services with intellectual disability were told about their illness, and even less (18%) were told that they were going to die (Tuffrey-Wijne et al. 2020). Interviews with palliative care staff, caring for people with intellectual disability revealed that they do not have a consistent approach to being open about death and dying with this group (Foo et al. 2021).

Indeed Forrester-Jones (2013) spoke of managers' caution in choosing not to speak about death within the intellectual disability services. Several studies suggest that this stems from an assumption of a lack of capacity; a desire for protection and not to cause distress (Kirkendall, Linton, and Farris 2017); staff feeling that they lack the skills to disclose bad news (Tuffrey-Wijne, Bernal, and Hollins 2010) and an uncertainty about timing, who communicates and how to approach the subject (Wiese et al. 2012).

Unfortunately, Tuffrey-Wijne, Bernal, and Hollins (2010), a key researcher in this field for more than two decades, found that in particular, doctors often failed to give individuals clear information about their condition or treatment options and instead explained this to family members and worked in a paternalistic fashion. Tuffrey-Wijne, Bernal, and Hollins (2010) suggest that there is a desire to protect people with intellectual disability from the unpleasant truth, with professionals not wanting to cause distress.

These issues are also further compounded the lack of clear institutional policies on whether or not to inform people with intellectual disability about their impending death (Kirkendall, Linton, and Farris 2017). More education and awareness, within formalised intellectual disability settings, about understanding about death and dying in this context and how to have open conversations about death and develop end of life plans is needed, along with clear institutional policies to support this. Researchers in the field conclude that developing and implementing advanced care planning for people with intellectual disabilities is urgently needed (Tuffrey-Wijne, Curfs, and Deliens 2016; Voss et al. 2020; Voss, Vogel et al. 2021). This would provide a platform for enabling useful end of life conversations to occur and facilitate early hospice care (Ronneberg et al. 2015).

6.3 | Gaps in Service Provision-Pain Relief

One key finding of this study was the challenges that participants noted with managing their clients' pain effectively. One of the cornerstones of palliative care is the adequate control of pain and other symptoms. This finding resonates with Adam et al. (2020) recent systematic review which indicated that pain management was one of the key needs of this population. However pain management often relies on verbal self-report which is unsuitable for people who have communication difficulties (Tuffrey-Wijne, Hogg, and Curfs 2007). One identified way of improving end of life care is an early referral to specialist palliative care services to facilitate timely diagnosis and treatment of symptoms (Temel et al. 2010). Certainly specialist palliative care were called upon within this study, and participants reported improvements in pain management. Attention also needs to be given to the development of sensitive pain assessment tools for this population (Tuffrey-Wijne, McLaughlin, and Curfs 2016).

6.4 | Educational Needs and Requirements

In keeping with other literature on the topic, this study indicates a need for additional training and support for staff with regard to conversations at end of life and advanced care planning (Voss et al. 2019, 2020). Overall education and training was identified as a priority requirement within the literature, particularly related to understanding how to improve the quality of life for this cohort, given their nuanced needs and requirements (Voss, Francke, and de Veer 2023). A targeted palliative care educational programme tailored to the needs of staff can increase confidence in palliative care provision (Kim and Gray 2018). One recent evaluation of an advanced care planning palliative care training program for professionals working with people with intellectual disability was very successful in increasing knowledge and skills (Voss, Loxton et al. 2021). Kinley, Denton, and Scott (2018) described a successful "steps to successful palliative care" for people with intellectual disability living in residential care homes. The education focused on assessment, future care planning, good coordination of care, delivery of high-quality care, care in the last days of life and care after death (Kinley, Denton, and Scott 2018). Utilising pre-existing resources can also be useful such as those provided by the Palliative Care for People with Learning Disabilities (PCPLD) Network (2021) and the European Association of Palliative Care (EAPC) Taskforce. The latter comprises an EAPC Taskforce on intellectual disabilities chaired by Tuffrey-Wijne (2012). Other resources that might be useful are the recent development of a tool for identification of people with intellectual disabilities in need of palliative care (Vrijmoeth et al. 2018).

6.5 | Limitations and Future Directions

Given the ongoing reduction of formalised care for people with intellectual disabilities, across Europe, the burden of end of life care will uniquely rest with family caregivers bringing a new set of challenges. It is they that will likely navigate the acute and palliative care services for their family member, and have concurrent challenges, such as coping with ageing in the case of parents, and family responsibilities, in the case of sibling carers. This study provides valuable insights into the experiences of health care workers providing end of life care to individuals with intellectual disability, that will likely inform these developments. However application of the study findings need to be considered in light of its limitations. It is limited by its perspective and focus on health care workers rather than family carers. Moreover the findings relate to people with intellectual disability who live in formal residential settings, rather than a family home. ROI is also one of the few countries internationally with a unique educational preparation for nurses working in the intellectual disability services. As such the provision of residential and supported community care to this cohort is of a specialist nature, informed by the intellectually disability nursing profession, albeit in a multidisciplinary context. This differs greatly from the organisation of care for this

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group in other countries internationally. Ultimately, the qualitative nature of this study is subjective, and further limited by the particular historical and societal developments of intellectual disability services in the ROI. Attitudes towards death and dying reflected in this study are likely linked to the ROI's Roman Catholic past, as evidenced in the rituals that emerged as important in the study. Indeed staffs' overall approach to "dealing with death and beyond", could be said to be located within a Judeo-Christian context. These attitudes would not necessary be reflected of the reactions and approaches of staff in other religious and cultural contexts and environments.

7 | Conclusion

This study described how gaps in the care of the person with intellectual disability and communication challenges affected the quality of care provided at end of life, particularly in relation to pain management, decision-making about end of life care, and emergency hospital admissions. While there has been important attention paid to missed care globally, an exploration of this within the intellectual disability sector has not emerged. It is likely therefore that staff are missing care for this cohort, particularly at their end of life. These gaps need attention going forward, not least because they compound the already existent health inequities experienced by this group. Enabling and empowering people at end of life calls for preparation, conversations and planning, which were often but not always present according to his research. What is needed is a merging of the core beliefs of intellectual disability care with an openness to death and dying. Additional education and training is also needed, for staff across the health care system, and for those with intellectual disability. More attention needs to be paid to early diagnosis, advanced care planning and pain management, and the implementation of policies to support these measures, so that quality end of life care can be consistently supported.

7.1 | Implications for the Profession and/or Patient Care

- End of life care for individuals with intellectual disability needs to be based on emerging consensus statements, and supported by organisational policy that provides guidance on breaking bad news and advanced care planning.
- Care needs to be taken with established methods of communication and assessment for individuals with intellectual disability at end of life, especially with regard to pain management.
- Consideration needs to be given to supporting a good death for individuals with intellectual disability at end of life, including the development and agreement of rituals that may support other clients, family members and staff.

7.2 | Impact

- This study provides some guidance on supporting a good death for individuals with intellectual disability at end of life.
- This study revealed that there are gaps emerging in the care of the person with intellectual disability at the end of life in relation to pain assessment and pain management that need to be addressed in practice.

7.3 | Note on Dissemination

To aid dissemination, the study has also been published as a preprint (McCarron et al. 2021) and in keeping with the requirement of the funders, and to ensure timely dissemination and impact in this field, the main study findings were reported informally elsewhere in online PDF format (McCarron, Mccallion et al. 2017). However neither of the aforementioned dissemination routes preclude official publication in peer reviewed journals (COPE 2023). Moreover, as much of the original discussion and recommendations related to a specific Republic of Ireland context only, the implications of the study findings have been redeveloped within this current paper with a more global audience in mind. As such this material would not be considered redundant or duplicated (COPE 2023).

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data available upon reasonable request.

Peer Review

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References

Adam, E., K. E. Sleeman, S. Brearley, K. Hunt, and I. Tuffrey-Wijne. 2020. "The Palliative Care Needs of Adults With Intellectual Disabilities and Their Access to Palliative Care Services: A Systematic Review." *Palliative Medicine* 34, no. 8: 1006–1018. https://doi.org/10.1177/0269216320932774.

APA (American Psychiatric Association). 2022. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Washington, DC: American Psychiatric Association.

Brennan, D., M. D'eath, N. Dunne, M. A. O'Donovan, P. McCallion, and M. McCarron. 2023. "Irish Social Policy to Family Carers of Adults With an Intellectual Disability: A Critical Analysis." *Journal of Intellectual Disabilities* 27, no. 4: 1013–1031. https://doi.org/10.1177/17446295221115296.

Central Statistics Office (CSO). 2022. "Census 2022 Profile 4-Disability, Health and Carers." https://www.cso.ie/en/releasesandpublications/ep/p-cpp4/census2022profile4-disabilityhealthandcarers/typeofdisability/.

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Committee on Publication Ethics [COPE]. 2023. "Redundant (Duplicate) Publication in a Submitted Manuscript." https://publicationethics.org/sites/default/files/duplicate-publication-submitted-manuscript-cope-flowchart.pdf.

Cooper, S. A., G. McLean, B. Guthrie, et al. 2015. "Multiple Physical and Mental Health Comorbidity in Adults With Intellectual Disabilities: Population-Based Cross-Sectional Analysis." *BMC Family Practice* 27, no. 16: 110. https://doi.org/10.1186/s12875-015-0329-3.

Dobrina, R., S. Chialchia, and A. Palese. 2020. ""Difficult Patients" in the Advanced Stages of Cancer as Experienced by Nursing Staff: A Descriptive Qualitative Study." *European Journal of Oncology Nursing* 46: 101766. https://doi.org/10.1016/j.ejon.2020.101766.

Doherty, A. J., H. Atherton, P. Boland, et al. 2020. "Barriers and Facilitators to Primary Health Care for People With Intellectual Disabilities and/or Autism: An Integrative Review." *BJGP Open* 4, no. 3: bjgpopen20X101030. https://doi.org/10.3399/bjgpopen20X101030.

Doyle, A., M. O'Sullivan, S. Craig, and R. McConkey. 2021. "People With Intellectual Disability in Ireland Are Still Dying Young." *Journal of Applied Research in Intellectual Disabilities: JARID* 34, no. 4: 1057–1065. https://doi.org/10.1111/jar.12853.

Dunkley, S., and R. Sales. 2014. "The Challenges of Providing Palliative Care for People With Intellectual Disabilities: A Literature Review." *International Journal of Palliative Nursing* 20, no. 6: 279–284. https://doi.org/10.12968/ijpn.2014.20.6.279.

Flynn, S., L. Hulbert-Williams, R. Bramwell, D. Stevens-Gill, and N. Hulbert-Williams. 2015. "Caring for Cancer Patients With an Intellectual Disability: Attitudes and Care Perceptions of UK Oncology Nurses." *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society* 19, no. 5: 568–574. https://doi.org/10.1016/j.ejon.2015.03.002.

Foo, B., M. Wiese, B. Curryer, R. J. Stancliffe, N. J. Wilson, and J. M. Clayton. 2021. "Specialist Palliative Care staff's Varying Experiences of Talking With People With Intellectual Disability About Their Dying and Death: A Thematic Analysis of In-Depth Interviews." *Palliative Medicine* 35, no. 4: 738–749. https://doi.org/10.1177/0269216321998207.

Forrester-Jones, R. 2013. "The Road Barely Taken: Funerals, and People With Intellectual Disabilities." *Journal of Applied Research in Intellectual Disabilities: JARID* 26, no. 3: 243–256. https://doi.org/10.1111/jar.12022.

Forrester-Jones, R., G. Murphy, J. Beecham, et al. 2018. *Becoming Less Eligible. Intellectual Disability Services in the Age of Austerity*. UK: NIHR, School For Social Care Research, University of Kent. https://www.sscr.nihr.ac.uk/wp-content/uploads/SSCR-research-findings_RF100.pdf.

Graneheim, U. H., and B. Lundman. 2004. "Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness." *Nurse Education Today* 24, no. 2: 105–112. https://doi.org/10.1016/j.nedt.2003.10.001.

Hardie, P., C. McCabe, F. Timmins, and D. R. Thompson. 2023. "A Qualitative Exploration of Irish Nursing students' Experiences of Caring for the Dying Patient." *Nursing Open* 10, no. 8: 5649–5658. https://doi.org/10.1002/nop2.1810.

Hourigan, S., S. Fanagan, and C. Kelly. 2017. "HRB Statistics Series 37 Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings." https://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2018_pubs/Disability/NIDD/NIDD_Annual_Report_2017.pdf.

2024. "IDS-TILDA." https://www.ucd.ie/issda/data/idstilda/.

Hunt, K. J., A. Richardson, A. E. Darlington, and J. M. Addington-Hall. 2019. "Developing the Methods and Questionnaire (VOICES-SF) for a National Retrospective Mortality Follow-Back Survey of Palliative and End-Of-Life Care in England." *BMJ Supportive & Palliative Care* 9, no. 1: e5. https://doi.org/10.1136/bmjspcare-2016-001288.

Irons, K. 2023. "How Can Social Work Practice Facilitate a Dignified Dying Experience for People With Intellectual Disabilities?" *A Scoping Review. Australian Social Work* 76, no. 1: 60–71. https://doi.org/10.1080/0312407X.2021.1946572.

Jackson, D., H. Aveyard, Y. Commodore-Mensah, et al. 2024. "The Future Is Ours to Shape: Nursing Emerging From the Pandemic With Insight, Optimism and Courage." *Journal of Advanced Nursing* 80: 1–3.

Kang, J. A., and V. Barcelona. 2023. "A Comparison of Conceptual Frameworks to Examine Health Inequities in End-of-Life Care." *Journal of Advanced Nursing* 79: 2025–2041. https://doi.org/10.1111/jan.15393.

Kim, J., and J. A. Gray. 2018. "Palliative Care Experiences and Needs of Direct Care Workers." *Journal of Palliative Medicine* 21, no. 8: 1094–1099. https://doi.org/10.1089/jpm.2017.0555.

Kinley, J., L. Denton, and S. Scott. 2018. "Development and Implementation of the Steps to Successful Palliative Care Programme in Residential Care Homes for People With a Learning Disability." *International Journal of Palliative Nursing* 24, no. 10: 492–502. https://doi.org/10.12968/ijpn.2018.24.10.492.

Kirkendall, A., K. Linton, and S. Farris. 2017. "Intellectual Disabilities and Decision Making at End of Life: A Literature Review." *Journal of Applied Research in Intellectual Disabilities: JARID* 30, no. 6: 982–994. https://doi.org/10.1111/jar.12270.

Malli, M. A., L. Sams, R. Forrester-Jones, G. Murphy, and M. Henwood. 2018. "Austerity and the Lives of People With Learning Disabilities." *A Thematic Synthesis of Current Literature, Disability & Society* 33, no. 9: 1412–1435.

McCallion, P., M. Hogan, F. H. Santos, et al. 2017. "Consensus Statement of the International Summit on Intellectual Disability and Dementia Related to End-Of-Life Care in Advanced Dementia." *Journal of Applied Research in Intellectual Disabilities* 30, no. 6: 1160–1164. https://doi.org/10.1111/jar.12349.

McCarron, M., E. Burke, P. White, et al. 2017. "Experiences of End of Life Care for People With an Intellectual Disability as Perceived by Staff Carers. Findings from the End of Life Interviews of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)." http://www.professionalpalliativehub.com/sites/default/files/Report_Experiences%20of%20end%20of%20life%20care%20for%20people%20with%20an%20intellectual.pdf.

McCarron, M., P. McCallion, E. Burke, and F. Timmins. 2021. "End of Life Care for People With an Intellectual Disability: A Qualitative Exploration of Staff Carers' Experiences." Pre Print. Research Square. https://www.researchsquare.com/article/rs-1008624/v1.

McCarron, M., P. Mccallion, R. Carroll, et al. 2017. *Health, Wellbeing and Social Inclusion: Ageing With an Intellectual Disability in Ireland*. Dublin: The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) 2018. undefined.

McCarron, M., P. McCallion, E. Fahey-McCarthy, and K. Connaire. 2011. "The Role and Timing of Palliative Care in Supporting Persons With Intellectual Disability and Advanced Dementia." *Journal of Applied Research in Intellectual Disabilities* 24, no. 3: 189–198. https://doi.org/10.1111/j.1468-3148.2010.00592.x.

McConkey, R., S. Craig, and C. Kelly. 2019. "The Prevalence of Intellectual Disability: A Comparison of National Census and Register Records." *Research in Developmental Disabilities* 89: 69–75. https://doi.org/10.1016/j.ridd.2019.03.009.

Morris, J., and S. Julian. 2024. "Preventing People With a Learning Disability From Dying Too Young. Nuffield Trust." https://www.nuffieldtrust.org.uk/sites/default/files/2024-03/Nuffield%20Trust%20-%20Learning%20disability_WEB_FINAL_1.pdf.

Network, E. 2023. "Consolidated Criteria for Reporting Qualitative Research (COREQ): A 32-Item Checklist for Interviews and Focus Groups."

13652648, 0, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jan.16556 by Test, Wiley Online Library on [04/03/2025]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

O'Leary, L., S. A. Cooper, and L. Hughes-McCormack. 2018. "Early Death and Causes of Death of People With Intellectual Disabilities: A Systematic Review." *Journal of Applied Research in Intellectual Disabilities* 31, no. 3: 325–342. https://doi.org/10.1111/jar.12417.

Polit, D. F., and C. Beck. 2021. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. 10th ed. Philadelphia: PA, Wolters Kluwer.

Psychology Today. 2022. "Intellectual Disability. Intellectual Developmental Disorder." https://www.psychologytoday.com/ie/conditions/intellectual-disability-intellectual-developmental-disorder.

Ronneberg, C. R., L. Peters-Beumer, B. Marks, and A. Factor. 2015. "Promoting Collaboration Between Hospice and Palliative Care Providers and Adult Day Services for Individuals With Intellectual and Developmental Disabilities." *Omega (Westport)* 70, no. 4: 380–403. https://doi.org/10.1177/0030222815573724.

Stirling, M., A. Anderson, H. Ouellette-Kuntz, et al. 2021. "A Scoping Review Documenting Cancer Outcomes and Inequities for Adults Living With Intellectual and/or Developmental Disabilities." *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society* 54: 102011. https://doi.org/10.1016/j.ejon.2021.102011.

Temel, J. S., J. A. Greer, A. Muzikansky, et al. 2010. "Early Palliative Care for Patients With Metastatic Non- Smallcell Lung Cancer." *New England Journal of Medicine* 363: 733–742.

Tse, M. M., R. Y. Kwan, and J. L. Lau. 2018. "Ageing in Individuals With Intellectual Disability: Issues and Concerns in Hong Kong." *Hong Kong Medical Journal* 24, no. 1: 68–72. https://doi.org/10.12809/hkmj166302.

Tuffrey-Wijne, I. 2012. "Palliative Care for People With Intellectual Disabilities." *International Journal of Palliative Nursing* 18, no. 6: 264–266.

Tuffrey-Wijne, I. 2017. "Palliative Care and Intellectual Disabilities. Intellectual Disabilty and Health." http://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities.

Tuffrey-Wijne, I., J. Bernal, and S. Hollins. 2010. "Disclosure and Understanding of Cancer Diagnosis and Prognosis for People With Intellectual Disabilities: Findings From an Ethnographic Study." *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society* 14, no. 3: 224–230.

Tuffrey-Wijne, I., L. Curfs, and L. Deliens. 2016. "Developing Research, Policy and Practice in Palliative Care for People With Intellectual Disabilities Will Benefit Everyone." *Palliative Medicine* 30, no. 7: 613–615. https://doi.org/10.1177/0269216316648610.

Tuffrey-Wijne, I., J. Finlayson, J. Bernal, L. Taggart, C. K. K. Lam, and S. Todd. 2020. "Communicating About Death and Dying With Adults With Intellectual Disabilities Who Are Terminally Ill or Bereaved: A UK-Wide Survey of Intellectual Disability Support Staff." *Journal of Applied Research in Intellectual Disabilities* 33, no. 5: 927–938. https://doi.org/10.1111/jar.12714.

Tuffrey-Wijne, I., J. Hogg, and L. Curfs. 2007. "End-of-Life and Palliative Care for People With Intellectual Disabilities Who Have Cancer or Other Life-Limiting Illness: A Review of the Literature and Available Resources." *Journal of Applied Research in Intellectual Disabilities* 20, no. 4: 331–344. https://doi.org/10.1111/j.1468-3148.2006.00350.x.

Tuffrey-Wijne, I., D. McLaughlin, L. Curfs, et al. 2016. "Defining Consensus Norms for Palliative Care of People With Intellectual Disabilities in Europe, Using Delphi Methods: A White Paper From the European Association of Palliative Care." *Palliative Medicine* 30, no. 5: 446–455. https://doi.org/10.1177/0269216315600993.

van den Bemd, M., B. W. M. Schalk, E. W. M. A. Bischoff, M. Cuypers, and G. L. Leusink. 2022. "Chronic Diseases and Comorbidities in Adults With and Without Intellectual Disabilities: Comparative Cross-Sectional Study in Dutch General Practice." *Family Practice* 39, no. 6: 1056–1062. https://doi.org/10.1093/fampra/cmac042.

Velepucha-Iniguez, J., P. Bonilla Sierra, and E. Bruera. 2022. "Barriers to Palliative Care Access in Patients With Intellectual Disability: A Scoping Review." *Journal of Pain and Symptom Management* 64, no. 6: e347–e356. https://doi.org/10.1016/j.jpainsymman.2022.08.007.

Voss, H., A. L. Francke, and A. J. E. de Veer. 2023. "Improving Palliative Care for People With Intellectual Disability: A Self-Assessment of Policies, Practices and Competencies in Care Services." *BMC Palliative Care* 22, no. 1: 103. https://doi.org/10.1186/s12904-023-01224-2.

Voss, H., A. Loxton, J. Anderson, and J. Watson. 2021. ""It Was One of Those Complicated Cases": Health practitioners' Perspectives and Practices of Providing End-of-Life Care for People With Profound Intellectual and Multiple Disability." *BMC Palliative Care* 20, no. 1: 177. https://doi.org/10.1186/s12904-021-00873-5.

Voss, H., A. Vogel, A. Wagemans, et al. 2020. "What Is Important for Advance Care Planning in the Palliative Phase of People With Intellectual Disabilities? A Multi-Perspective Interview Study." *Journal of Applied Research in Intellectual Disabilities: JARID* 33, no. 2: 160–171. https://doi.org/10.1111/jar.12653.

Voss, H., A. Vogel, A. M. A. Wagemans, et al. 2019. "Advance Care Planning in the Palliative Phase of People With Intellectual Disabilities: Analysis of Medical Files and Interviews." *Journal of Intellectual Disability Research* 63, no. 10: 1262–1272. https://doi.org/10.1111/jir.12664.

Voss, H., A. G. F. M. Vogel, A. M. A. Wagemans, et al. 2021. "Development, Implementation, and Evaluation of an Advance Care Planning Program for Professionals in Palliative Care of People With Intellectual Disability." *Intellectual and Developmental Disabilities* 59, no. 1: 39–54. https://doi.org/10.1352/1934-9556-59.1.39.

Vrijmoeth, C., C. M. Groot, M. G. M. Christians, et al. 2018. "Feasibility and Validity of a Tool for Identification of People With Intellectual Disabilities in Need of Palliative Care (PALLI)." *Research in Developmental Disabilities* 72: 67–78. https://doi.org/10.1016/j.ridd.2017.10.020.

Wiese, M., R. J. Stancliffe, S. Balandin, G. Howarth, and A. Dew. 2012. "End-of-Life Care and Dying: Issues Raised by Staff Supporting Older People With Intellectual Disability in Community Living Services." *Journal of Applied Research Intellectual Disability* 25: 571–583.

Witham, G., and C. Haigh. 2018. "A Narrative Literature Review Examining Cancer Treatment Issues for Patients Living With Intellectual Disabilities." *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society* 36: 9–15. https://doi.org/10.1016/j.ejon.2018.07.004.

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