

End of Life Care for People with an Intellectual Disability a Qualitative Exploration of Staff Carers' Experiences

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Research Article

Keywords: intellectual disability, older people, death, dying, end of life, palliative, care

Posted Date: November 2nd, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-1008624/v1>

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Abstract

Background: Although people with intellectual disability are increasingly living longer and experiencing high levels of multiple co-morbidity, palliative care has received limited attention among this population. There is some evidence that their needs are unattended and that more could be done to improve care services.

Methods: 28 carers who cared for older people with intellectual disability at end of life were interviewed. Data were analysed using thematic analysis.

Results: One major theme emerged relating to the practical management s of end of life care in formal institutionalised settings. Seven subthemes also emerged: pain, learned acceptance, transitions, decisions, conversations about dying, GP care, rapid decline and challenges with interventions.

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

Introduction

Despite the knowledge that people with intellectual disability are increasingly living longer (Doyle et al 2020), and experiencing high levels of multiple co-morbidity, approaches to palliative care have received limited attention among this population (McCarron et al., 2011). There have been some developments including recent consensus statements (McCallion et al., 2017; McCarron et al., 2017a) but much has yet to be developed. Tuffrey-Wijne et al (2016a) also outlined core principles and consensus from a European perspective seeking to include people with intellectual disabilities in end of life planning and mainstream approaches to palliative care (Bailey et al., 2016). However end of life care for people with intellectual disability is complex (Kirkendall et al., 2016). There are issues related to communication difficulties, limited capacity, and a higher prevalence of dementia, that means carers continue to report that delivering high quality end of life care for people with intellectual disability is an important, if unrecognised, element of their work (Todd, 2013); and one for which they often feel inadequately prepared (Adam et al 2020. Bailey et al., 2016). To better address these known challenges, for people with an intellectual disability requiring end of life care, more needs to be known about the experiences of people with intellectual disabilities and of their carers during the last days of their lives.

There is often a lack of clear institutional policies on whether or not to inform people with intellectual disability about their impending death. Indeed Forrester-Jones (2012) spoke of managers' 'cautious silence' 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 et al.,2016); staff feeling that they lack the skills to disclose bad news (Tuffrey-

Wijne et al., 2010) and an uncertainty about timing, who communicates and how to approach the subject (Wiese et al., 2013). Because of the communication challenges and a misunderstanding of capacity (Adam et al 2020), this silence around death extends to the other residents (Fahey-McCarthy et al., 2009). At the same time staff working in the area of intellectual disability staff report feeling unprepared for end of life care (Todd, 2013). but this does not hinder their motivation to provide that care (Ryan et al., 2011) even when they do not feel adequately prepared (Todd, 2013). Due to the dearth of research on this topic, and the urgent need to address gaps in policy and service, this study aims to explore end of life care for people with an intellectual disability from the perspective of the staff who care for people during this time.

Methods

Study design

This research formed part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (McCarron et al., 2013). 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 et al., 2013). More details on the study design is available in McCarron et al. (2013). A specific protocol was utilized with carers of participants who were recently deceased.

Using a qualitative approach, the study explored end of life experiences as reported by carers. The specific aim was to explore carers' reports of end of life experiences for people with intellectual disability. A validated questionnaire (the VOICES questionnaire) on carer perspectives of end of life care formed the basis of a semi-structured interview which was the primary data collection tool. Carers were family members and/or staff members who supported the person with intellectual disability at the end of life. A pilot study preceded the main study. The full (unpublished) report is available online (McCarron et al., 2017b).

Participants

IDS-TILDA is a nationally representative study of older adults with an intellectual disability aged 40 years and over. Data were drawn from the this dataset, which investigates the health and well-being of people with intellectual disability aged 40 years and older in the Republic of Ireland during 3-yearly cycles (McCarron et al., 2017a). Following the confirmed deaths of 57 participants in the study, carers of those who had died were invited to take part in this study and 37 agreed. They were carers who had supported the individual for at least one year.

Ethical approval

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

Data collection tool and procedure

A semi-structured interview based primarily on the shorter form, 58 item '*The Views of Informal Carers-Evaluation of Services Short Form*' (VOICES-SF) questionnaire (Hunt et al. 2011). Demographic data were obtained on the carers and on the person who had died were obtained from the IDS-TILDA dataset.

Data analysis

SPSS (Statistical Package for the Social Sciences) Version 20, was used to provide quantitative descriptive analysis. Thematic content analysis was used to analyse the open question interview data (Graneheim & Lundman 2004). This consisted of repeated reading of full transcripts, note taking, development of codes, preliminary coding and then coding of each complete transcript using NVivo Proversion11.4. Through systematic content analysis emerging categories and themes were then developed. Credibility was advanced through triangulation with the quantitative data, peer debriefing and constant checking that analyses were grounded in the participants' responses (LoBiondo-Wood et al., 2014).

Result

All 37 participants responded to the quantitative questions included with the VOICE-SF questionnaire and 28 took part in the qualitative interviews. Carers originated from a variety of settings across the Republic of Ireland (ROI), representing 17 intellectual disability services across both rural and urban contexts. All of the 28 carers were staff members, and one family member completed the initial questionnaire.

Gender distribution among the people who had died was equal with 19 (51.4%) males and 18 (48.6%) females. Most had either moderate (n=18, 52.9%) or severe/profound disability (n=15, 44.1%). Those who had died either lived in a residential setting (n=28, 75.7%) or a community group home (n=9, 24.3%). The median age was 64. Most had been unwell for at least one month (n=26, 73.4%). Many (n= 21, 57%) died at their usual home, two died in another residential unit within the same service and 35% (n=13) died in hospital. Nine (32.1%) of the 28 deceased whose carers took part in the semi-structured interview had a diagnosis of dementia. Participants who were interviewed (n=28) reported causes of death as outlined in Table 1.

The qualitative analysis identified three major themes each with related subthemes. One major theme is discussed in this paper, which related to the practicalities of end of life care in formal institutional settings. This was summarized as "not joining up the dots". This theme comprised seven subthemes: pain, learned acceptance, transitions, decisions, conversations about dying, GP care, rapid decline and challenges with intervention.

Not joining up the dots

This theme reflected the numerous reports of gaps in care for the person at the end of life from illness and dying symptoms not being recognised, unnecessary transitions and crisis-led decisions to general

feelings of being unsure in this new era of people with an intellectual disability living longer with differing health needs.

Pain

The recognition and management of pain for people with intellectual disability at end of life proved to be particularly challenging. Many respondents reported that there were to confidently assess whether or not the person they were caring for was experiencing pain. If the person was receiving pain relief its effects were 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."

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

Indeed almost one third of respondents (n=11, 32.4%) reported that they did not know if pain was relieved during the last three months of the person's life. Almost a quarter reported that they perceived that the client had their pain only partially relieved or not at all (n=14, 23.5%). Some mentioned that they used pain assessment tool. Others observed facial expressions, how the person moved, occurrence of sweating, vocalisations and changes in facial colour. Knowing the person 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. As the following carer quotes note, this led to more individually tailored assessments of pain:

"You'd talk to him and you'd ask him was he in pain 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."

Five of the respondents spoke of the high pain threshold of the person sometimes learned over time from self-harm behaviours or painful physical conditions:

"I'm not saying he was never in pain with his bowel...I'd say he was just, his threshold was just so high..."

"So I think for Patrick it was just a normal way of feeling for a long time"

Interestingly several carers reported that when the specialist palliative care became involved there was a greater sense of the person being pain free.

Learned Acceptance

In understanding how people with intellectual disability coped with their pain, their illness and their dying, many respondents spoke of the acceptance that the people they cared for had of their situation. This

acceptance was most obvious among those who had spent most of their lives in institutionalised care:

"Well you see poor Richie came from an era where being in you know it was institutional care what can I say like I mean so I think I suppose he was as involved as much as he was able to be."

"...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".

Transitions

The majority of people in this study died either in their regular residential or community home, or in a residential unit within the same service. Transitions in the year or months preceding death were minimum. When they did occur, an emphasis was placed on maintaining familiar settings, familiar people and continuity of care. For example when individuals were transferred to hospital they were usually accompanied by a familiar member of staff, if resources allowed. Several carers noted that this was not always possible.

"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."

"Well I mean he spent so much time in hospital here, we felt there was nobody with him. That was the only thing at that stage."

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. Not only was the transition expressed as a personal loss for the staff but as several carers noted it had an effect on the other residents and the health of the person being moved.

"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."

"And then she transferred to [another unit], reluctantly, under duress. The staff did not want to let her go. They did not want to you know, because we were afraid of once you kind of go into [unit], which more the dependent unit... And that she loose her skills. But she was losing anyway. But it was just I think we take it real personal ourselves and hold on to people as long as can, you know".

"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."

Being able to accommodate people in their usual home at end of life was believed to be a significant contributor to people experiencing a 'good 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."

Decisions

Wherever possible, end of life care decisions were made with the involvement of family. In most cases family were very involved in planning and decision-making working with the individual with an intellectual disability and with the staff carer. Sometimes staff had to go to great lengths making phone calls and writing letters to include families that hadn't previously been involved. Although a small number (n=5, 15.2%) of staff reported that they would have liked to have been more involved in the decisions made during the three months preceding death, the majority were satisfied that the right decisions about end of life were made and most importantly, 70.6% (n=24) reported that they believed that these decisions reflected what the person with intellectual disability would have chosen as the following quotes illustrate:

"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."

Collaborative decision making was also seen as central to good end of life care:

".....she had her choice, it was, as I said, if we all get our choices when our time comes, you know – she couldn't have, she couldn't have gotten a better death, being honest."

However, one carer noted the quality of end of life care can hinge on one decision that is made in a crisis situation when emotions are highly charged.

"...do you know what I mean like, so he was, life was pretty good. But just, it was just some small little thing that happened and, tiny thing that happened, and it was misinterpreted and he was sent into hospital. And then he was put into intensive care, into HDU."

Another carer noted that decisions had an impact on all of the staff:

"Yeah, he ended up being a couple of weeks in the hospital and he died in hospital. So we were very disappointed about that now. Some of the staff were actually really upset, you know... because they just felt he shouldn't be in here, he shouldn't be, do you know what I mean, he shouldn't be in here dying when he should be in his own home."

Being prepared, thinking ahead, discussing end of life and developing an end of life care plan were not usual practices as demonstrated in this quote in relation to a man in his 80's highlights:

"We had no path of care; we had nothing 'cos he wasn't sick."

Only two respondents specifically mentioned that an end of life plan had been developed with the person with intellectual disability. Although families had not discussed the decision with the person, eight respondents (28.6%) reported that families had decided on do not resuscitate (DNR) status, although staff noted that this was not always supported in the hospital setting:

"and then if he was transferred to an acute setting sure that was it, our DNR has no status whatsoever."

Conversations about Dying

The level of intellectual disability was raised by many carers to explain their view that the person with intellectual disability had little understanding of their deteriorating health status and to explain a reluctance to initiate end of life conversations including on end of life care planning, and being told they were dying. Carers also expressed uncertainty as to whether there should be open conversations around death with people with intellectual disability:

"... 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."

Among carer reasons were feelings that the person would not understand or be emotionally ready to cope with such information. Participants also expressed uncertainty as to whether there should be open conversations around death with people with intellectual disability:

"... 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."

"what I felt was the most important part of it, it wasn't, you know, just going in there telling you look, your time is limited. It was I suppose the reassurance part of it was the most important part... and I hoped that he understood that part of it more than the other part of it."

General Practitioner/Physician (GP) Care

Having a regular GP that knew the person, their 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 carers reporting GP visits in the last three 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. With some, quality end of life care was less obvious, usually due to a limited relationship with the person:

“...another GP took over his practice. And he was younger and less...what would be the politically correct word? Personable, you know. And I mean he’s always busy and always in a rush. And Jane is an elderly gentle lady. And she didn’t want to talk to him and didn’t engage with him really. So it was, his work with her was really, really practical. So there was no relationship as such”.

“there was no relationship there obviously with Catherine, or the GP like. It was just antibiotic prescription again like you know”

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, but nine times out of ten the person is admitted”

“I suppose she was of a different opinion than we were. You know, her opinion was you know, always hospital transfer... But certainly it’s not, you know the wishes of the family, or it wasn’t, you know as an advocate for Catherine. You know she loves familiar staff and that was very important for her. Especially at that vulnerable stage.”

Sometimes, even when end of life plans have been made, it may be the GP on call at that time who determines what decision is made. As one of the carers noted:

“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...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”

"It was frustrating now if I'm honest like. You know constantly kind of battling with the GP like. So I felt her lack understanding of somebody with an intellectual disability wasn't there like. Or it was different more so, I don't know a little bit negative."

Rapid Decline & Challenges with interventions

Many of the carers 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. The pattern of deterioration described by one carer below captured the reports of other carers:

"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."

Almost half of the respondents spoke of a level of 'shock' about the deteriorating health and death of the person they were caring for. As one carer noted:

"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."

There was a concern expressed by carers that key symptoms could be missed either due to being masked by the intellectual disability or being difficult to assess due to communication difficulties or other issues:

"It was just put down to being Patrick"

Often health care practitioners in the community or acute care settings, consulted for advice on worsening conditions, appeared insensitive to symptoms believing that these were related to the intellectual disability rather than the underlying illness. This could result in missed opportunities to provide early intervention at end of life.

"But I fought I got him into the xxx clinic ...you have to get a good GP that's tuned into people".

However when there was a medical emergency health care professionals were found to react quickly to the symptoms regardless of intellectual disability, perhaps as conditions are explicitly observable and measurable, for example cardiac arrest.

Discussion

This study described carers' perceptions of end of life care for people with intellectual disability. In keeping with the literature (Todd et al 2020) most of the clients died in their home, more so in fact than is common in the general population (DeBoer et al 2017). This could indicate a responsive palliative care system, however there was also evidence that accessing care services was challenging and clear gaps in service provision exist. This raises a concern that access to palliative care services is being missed. A key finding of this study were the challenges associated with pain management, and the struggle that

carers experienced with this. Interestingly when specialist palliative care teams were involved this seemed to improve. This finding resonates with Adam et al's (2020) recent systematic review which found that pain management was an essential and often missing element of end of life care for people with intellectual disability. One of the cornerstones of palliative care is the adequate pain control. However pain management often relies on verbal self-report which is unsuitable for people who have communication difficulties (Tuffrey-Wijne et al., 2007). One identified way of improving end of life care, supported by this study's findings, is early referral to the Specialist Palliative Care to facilitate timely diagnosis and treatment of symptoms (Temel et al., 2010). Attention also needs to be given to the development of sensitive pain assessment tools for this population (Tuffrey-Wijne et al 2016b).

However overall there was limited mention of specialist palliative care services, something that is consistent with other reports in the literature (Tuffrey-Wijne et al 2018). Intellectual disability professionals and palliative care services need to work closer together to achieve effective end-of-life care. McLaughlin and colleagues (2014) found that partnership practice was infrequent but when partnership between services existed, it led to better outcomes for people with intellectual disability. However contrary to previous findings (Adam et al 2020, Ronneberg et al 2015), a lack of collaboration between services did not emerge as a barrier within this study. The relationship with the GP was acknowledged as critical with a good relationship between the client and GP, and also between the services something that supported quality of care and life for the person who was dying. However, the carers also expressed frustration when they were obliged to work with on-call and locum GPs with difficulties arising with decision making.

At the same time this study highlighted that the emerging medical needs of people with intellectual disability were often missed. Earlier research (Reiss et al 1982) highlighted this concern about 'diagnostic overshadowing', where clinicians attributed the symptoms of physical ill health to a person's intellectual disability and therefore under-diagnosed. This makes the need for appropriate professional responses, education and improvements in palliative care practice for this cohort even more urgent. More use needs to be made of palliative care educational programmes such as those developed by Fahey-McCarthy et al (2009) and Hahn and Cadogan (2011). Providing training and support for staff, that includes intellectual disability carers, palliative support staff and physicians (Voss et al 2019, 2020) is crucial to providing optimal care (Bekkema et al. 2014). Hahn and Cadogan (2011) suggest that implementing a targeted palliative care educational programme tailored to the needs of care staff can increase confidence in palliative care provision. A recent implementation and 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 et al 2021). Kinley et al (2021) described a successful "steps to successful palliative care" for people with intellectual disability 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 et al 2021).

Palliative care staff can struggle with relating to persons with intellectual disabilities (Ryan et al 2016). However staff education and early referral can prove vital build rapport, trust and familiarity with services

and enable care professionals to gain knowledge of the person's lifestyle and usual behaviour (Tuffrey-Wijne et al. 2007). Hospital staff also need education and training as they are not always confident or especially responsive to the particular needs of this cohort (Wark et al 2017). Cross et al (2012) also suggest the establishment of a development or link worker role to bridge these difficulties. Overall early engagement in palliative care services is crucial (Fahey-McCarthy et al., 2009; McCarron, et al., 2011).

Training is not only required for staff but also for people with intellectual disability because it has been noted that there is limited death education provided to people with intellectual disability (Wiese et al, 2012). More attention is also needed on health promotion, prevention, and early detection of cancers and other disorders among this population (Reppermund 2020). Respondents in this study noted a rapid decline at end of life of people in their care. This fact that is not surprising given that in one study more than half of all reports of palliative care needs (related to people with intellectual disabilities) occurred less than one month before their death *as a first ever report* of symptoms and needs (Voss et al 2019).

Conversations about dying were an identified challenge within this study. Indeed a recent UK-wide survey revealed that just over half of people in services with intellectual disability were told about their illness, but even less (18%) were told that they were going to die (Tuffrey-Wijne et al. 2020). In fact recent interviews with palliative care staff caring for people with intellectual disability revealed that they did not have a consistent approach to being open about death and dying with this group (Foo et al 2021). Improving end of life care begins with conversations. Open communication and collaboration with the person with intellectual disability, their family, other residents, staff members and other health care professionals is the cornerstone to enhancing end of life care. Bereavement research has demonstrated how difficult these conversations are for everyone but the difficulties are greater for those with intellectual disabilities and communication difficulties. Barriers to open communication have been noted in previous studies (Adam et al 2020. Kirkendall et al., 2016) but people with intellectual disability have a fundamental right to know about and be involved in decisions regarding their end of life care (Weise et al., 2012b), and professionals have a duty to provide opportunities for this discussion (Read and Cartlidge, 2012). Unfortunately, Tuffrey-Wijne et al (2010) has concluded health care professionals often failed to give individuals clear information about their condition or treatment options instead explaining issues to family members. Ryan et al (2011) also found that relatives were often used as communication proxies, preventing direct engagement with the person with intellectual disability, effectively acting as gatekeepers of information discussed. Tuffrey-Wijne et al (2010) also suggested that there is a desire to protect people with intellectual disability from an 'unpleasant truth', with professionals not wanting to cause distress. While discussing death with intellectual disability may have challenges (Clayton, 2015), it is important to build relationships, taking time to care and support open communication even when there are challenges (Arrey et al 2019).

Enabling and empowering people at end of life calls for preparation, conversations and planning, features which were not always evident within in this research. Tuffrey-Wijne et al (2016b) provide us with some clear direction on this, by means of an international consensus statement on palliative care norms for people with intellectual disability. however there needs to be clearer direction from a national policy

perspective, additional education and a greater voice for and contribution of people with intellectual disability to policy and practice (Reppermund et al 2020).

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. Enabling and empowering people at end of life calls for preparation, conversations and planning, which were often but not always present in this research. What is needed is a merging of the core beliefs of intellectual disability care with an openness to death and dying and the expertise of palliative care. Additional education and training is needed, for staff across the health care system, and for those with intellectual disability. Early diagnosis, advance care planning and pain management will more consistently support quality end of life care.

Declarations

Acknowledgements

The authors would like to thank the participants for their immense support and cooperation. The contribution of P. Whyte, P. O'Dwyer, K. Ryan, K. & J. O'Farrell to data collection in the original study is also acknowledged.

Authors' contributions

Conceptualising of the study was performed by Mary McCarron, Eilish Burke and Philip McCallion. Mary McCarron, Eilish Burke and Philip McCallion were responsible for data collection and data analysis. Mary McCarron, Eilish Burke, Philip McCallion and Fiona Timmins contributed to conceptual content of the paper. Fiona Timmins updated the literature review, reconceptualised the findings in this context, and wrote the paper. All authors have read and approved the content of the manuscript.

Funding

This project was funded by the Health Research Board (HRB) Ireland and the All Ireland Institute of Hospice and Palliative Care (AIHPC). This funding supported data collection and data analysis for the project.

Availability of data and material

The datasets generated and/or analysed during the current study are not publicly available due to this being qualitative data, some of which is highly sensitive and where, given the small numbers, access to the full dataset may mean a possibility of identifying individuals, but are available from the corresponding author on reasonable request.

Ethics approval and consent to participate

The research was performed in accordance with the guidelines and regulations of the Declaration of Helsinki and after obtaining ethical clearance from the Faculty of Health Sciences Research Ethics Committee at Trinity College Dublin, and each local service provider. All participants provided written and informed consent to participate. The methods were carried out in accordance with the relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

Authors declare no competing interests.

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Tables

Table 1 Carers' reported cause of death

Disorders	N(%)
Unknown	4 (14.3 %)
Cancer	7 (25.0 %)
Pneumonia	7 (25.0 %)
Renal failure	3 (10.7 %)
Dementia	2 (7.14 %)
Pulmonary embolism	1 (3.6 %)
Brain haemorrhage	1 (3.6 %)
Cardiac arrest	1 (3.6 %)
Bowel perforation	1 (3.6 %)
Age-related	1 (3.6 %)