Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

"He'd mind you, you mind him"

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)

HEALTHY HAPPY AGEING

AIIHPC
All Ireland Institute of Hospice and Palliative Care

“He’d mind you, you mind him”
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)

McCarron, Burke, E., M., White, P., O Dwyer, C., Ryan, K., O Farrell, J., McCallion, P.

Message from the Principal Investigator

Advances in public health and social care have enabled people with an intellectual disability (ID) to live longer than ever before. However, as well as enjoying and experiencing a longer life like the general population, many more people with and ID will also now live with chronic, life limiting conditions and increasing levels of multi-morbidity.

The underpinning philosophy of intellectual disability services of person-centeredness is often characterised by the development of long term relationships with the person, their family and peers. Caring for the person who is on their final journey of life and nearing death often involves high levels of emotional engagement, and strong therapeutic bonds which develop between the individual and staff caregivers over an extended period of time.

Death is an inevitable part of life, and just as living well is important, so too is dying well.
The reports here from carers highlight the challenges of providing comfort care to the person with complex disease, who was often unable to verbally communicate their needs. Effectively managing pain and other intractable symptoms, including moral distress arising from conflicting beliefs about the goals of care and optimal place of death, added to the emotional burden of end of life care for the carers and raised concerns about the quality of death for the person with ID. Yet, examples were also offered of what did work: good collaboration between ID services and palliative care services, improved communication with general health care services and being supported to age, live, and die in one’s own home all appeared to contribute to a good death.

‘Dying with dignity is easy to say but hard to watch’ (Keidel, 2002)

For some people with an intellectual disability lack of preparedness and comprehensive approaches to end-of-life care meant they may not have been as well supported to have a good quality of life in their declining years, or a good death at the end. Key suggestions emerged on the critical issues to be considered: addressing communication challenges and connecting up the dots, supporting living as full a life as possible and addressing needs both at death and beyond. Many of the concerns are in common with the general population but the findings here are that communication challenges are greater for people with ID raising particular concerns for the management of pain, that there is a need for greater collaboration among all services providers and a recognition that relationship based care is particularly relevant when as a group, people with an intellectual disability have compressed social networks and fewer supporters. Engagement with families, even where care is services provider-based, is an area for further development and research.

Prof. Mary McCarron.

Professor Mary McCarron
Professor of Ageing and Intellectual Disability
Principle Investigator End of Life Study

Acknowledgement

Our heartfelt thanks are extended to all those family members and carers who shared their experiences of end of life care for those for whom they cared with intellectual disability. Their generosity of time and experience lends richness to this report that will no doubt have impact and advance changes necessary to ensure a comfortable and good death for people with intellectual disability.

Grateful appreciation is also extended to the service providers and their staff who supported, and continue to support the work of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA). Without this support the voices of older adults with intellectual disability would not be heard.

We would like to acknowledge and thank all those who contributed to this report, our field researcher, Janet O'Farrell, research writers and analysts, Dr Patricia White, Dr Éilish Burke, and Claire O'Dwyer, the project's advisory group, Prof. Mary McCarron, Prof. Philip McCallion, Dr Kevin Connaire, Dr. Elizabeth Fahey-McCarthy, Dr. Lawrence Taggart, Dr Philip Dodd, Dr. Suzanne Guerin, Dr. Karen Ryan, Dr Geralyn Hynes, and the editors, Prof. Philip McCallion and Prof. Mary McCarron.

Disclaimer

Please note no actual participant names are used in this report, all names used are pseudonyms for reading flow purposes only, any similarity to any person living or dead is merely coincidental.

Funding Bodies

This project was funded by the Health Research Board (HRB) Ireland and the All Ireland Institute of Hospice and Palliative Care (AIIHPC).

Contents

List of Figures

List of Tables

Executive Summary

Introduction

Life expectancy for people with an intellectual disability (ID) is increasing (Kelly & Kelly 2013), providing new challenges in understanding not only how people are living with illness but also how they are dying. While there is a growing openness to death, end of life planning and palliative care in the general population, the limited research available suggests that a similar trend has not been witnessed for the population with an intellectual disability (Bailey et al., 2016; Todd, 2005; Tuffrey-Wijne et al., 2006). With additional issues of communication difficulties, limited capacity, and a high prevalence of dementia, end of life care for people with intellectual disability is complex (Kirkendall et al., 2016; McCallion et al., 2012; McCarron et al., 2013; Wiese et al., 2012a). Indeed, carers frequently 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 sometimes feel inadequately prepared (Ryan et al., 2011; Bailey et al., 2016).

Despite these known challenges, as well as a growing population of people with an intellectual disability requiring end of life care, there is as of yet too little investigation of:

- The demographic profile, health status, and disease patterns reported by adults with intellectual disability at end of life
- The healthcare utilisation and health care service needs of this population
- The experiences of people with intellectual disabilities and those of their carers during the last days of their lives

Research Aim

Using the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) as the sampling frame, the aims of the study were:

1. To develop a demographic, health status, and healthcare utilisation profile of participants in IDS-TILDA who had died between October 2010 and January 2015

2. To explore the experiences at end of life for those who died, as reported by their carers

Methods

Recruitment and Study Sample

IDS-TILDA is a nationally representative study of older adults with an intellectual disability aged 40 years and over. Among the 753 adults with ID who took part in Wave One of the Study (2010). Between October 2010 and January 2015, the parameters of the End of Life Study, the deaths of 57 participants were identified and confirmed. Demographic, health status and healthcare utilisation for these 57 participants was generated from their most recent IDS-TILDA interview. Carers of 37 (64.9%) of the 57 participants who had died, consented to take part in the End of Life Study. In total 36 staff carers and one family carer participated; n=9 in a pilot study and n=28 in the main study.

Data Collection & Analysis

This is a mixed methods study with both quantitative and qualitative information collected using

- A modified version of the VOICES-SF questionnaire (Views of Informal Carers-Evaluation of Services-Short-Form) informed a semi-structured interview of each carer

- Six health status items from *‘The Irish Longitudinal Study on Ageing’* (TILDA) exit interview were also asked of the carer.
- Six questions regarding post-death rituals

Pilot Study

The aim of the pilot study was to explore the feasibility of using the VOICES questionnaire (Addington-Hall & McCarthy, 1995) in a population of carers of people with an intellectual disability. Nine carers took part in this pilot study, and filled out a paper-based version of the VOICES-SF questionnaire. Data collected during confirmed the feasibility of the using the VOICES in this population. Based on the data which emerged during the pilot phase the three following amendments were made to the study protocol:

1. During the administration of the paper based version of the VOICES questionnaire it emerged that large amount of rich narrative data was not been adequately captured, and given the nature of the questions that it was insensitive to interrupt the participant. Consequently, it was decided that administrating the VOICES-SF through a semi-structured interview which would be recorded and transcribed more adequately captured the perceived experiences of people with Intellectual disability at end of life as reported by their carers.
2. Six items from the TILDA exit interview were added to increase opportunity for comparisons with the general older population in Ireland.
3. Six items were added on post death rituals based on the large amount of data emerging on this topic from the pilot interviews.

Additional ethical approval for the changes to the study protocol resulting from the pilot study was sought and granted.

Semi-Structured Interviews

Based on the recommendations emerging from the pilot study, outlined above, carers of 28 participants took part in semi-structured interviews based on the VOICES-SF questionnaire. These interviews were recorded and transcribed verbatim. Descriptive analysis was conducted on the quantitative data which was manually extracted from the transcripts of the 28 semi-structured interviews. For the qualitative data emerging from these semi-structured interviews, thematic and content analysis was carried out on the interview transcripts.

Ethical consideration

Full ethical approval was received from the Faculty of Health Sciences Trinity College, and from each of the service providers involved in the end of life study. Written informed consent was obtained from each of the participants.

Key Findings

Demographic and health profile of the 57 participants with an intellectual disability who died

Demographics and health profiles of the 57 who died were described and compared with surviving IDS-TILDA participants and with those who died in the TILDA general population study.

- Almost all who died had a moderate (n=26, 50%) or severe/profound (n=25, 48%) level of ID.
- Over two-thirds (n=39) were living in residential centres, approximately one quarter (n=15) were living in community group homes and just over five percent (n=3) were living independently or with family.

- The median age at death was 61 years, considerably lower than the median age reported by TILDA for the general population at 77 years but when those with Down syndrome are excluded (median age of death of 57 years) the median age of death for others with ID was 67 years..
- Over 90% of those who died (n=52) reported multi-morbidity (two or more chronic conditions) with neurological and eye disease the most frequently reported disease pairing.
- Although numbers are small there is a concerning finding that for most of those who died from cancer the diagnosis occurred less than a year and sometimes within a month prior to death.
- The most commonly reported chronic health conditions were eye disease, (n=35, 61.4%), neurological disease (n=32, 56.1%) mental health difficulties (n=31, 54.4%) and gastrointestinal disease (n=28, 49.1%).
- Those with an intellectual disability who died had a greater recorded utilisation of primary healthcare services, but less use of secondary care services such as hospital visits or A & E admissions compared to people who died in the general population TILDA study.
- Other health and social services commonly accessed by those who died included physiotherapy (n=27, 47.4%), speech and language therapy (n=26, 45.6%), occupational therapy (n=23, 40.4%) and psychiatry (n=23, 40.4%). Overall those who died reported accessing more of these services than Wave 2 survivors.
- Nine individuals who died (15.8%) were accessing palliative care services at the time of their most recent IDS-TILDA interview.

Circumstances surrounding death for the 37 End of Life Study participants

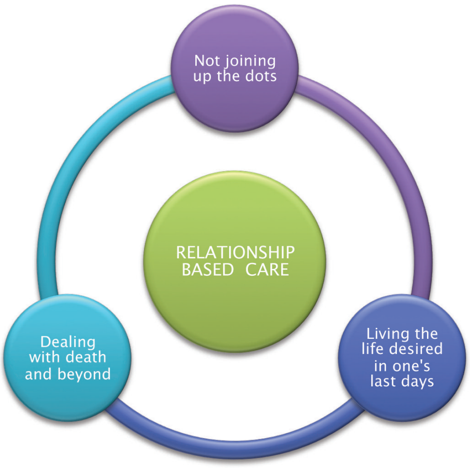
Information on the circumstances surrounding death, including place of death, cause of death, length of illness, and pain management was collected only for the 37 End of Life Study participants. Key findings are highlighted below:

- Over one quarter (n=9) of individuals who died were reported to have been ill for less than one month before they passed away. Eight participants (22.9%) were ill for 1-6 months, approximately half (n=17) were ill for six months or more prior to death, with 11 of these reported to be ill for over a year.
- Pain management emerged as an area of concern, one third of carers (n=11) were not sure how well the person’s pain was relieved in the last three months, while almost a quarter (23.5%) reported that the person’s pain was only partially relieved or not relieved at all. However, 88% (n=22) of carers who responded reported that pain relief in the last two days of life was either good or excellent.
- Over half (n=21) of the IDS-TILDA participants were reported to have died in their usual home or in their family home. This figure was considerably higher than that reported for the general population; just less than one quarter of those who died in the TILDA study died in their usual home. Reported rates of death in hospital were higher among TILDA participants who had died compared to those who had died in IDS-TILDA study; 48.4% versus 35% respectively.
- Cause of death was available only for those who completed the semi-structured interview (n=28). For four people (14.3%) cause of death was unknown. Seven participants (25%) were reported to have died of cancer, while another seven (25.0%) reported pneumonia as cause of death. Other reported causes of death included renal failure (n=3, 10.7%) and dementia (n=2, 7.14%).

Key Findings from the 28 semi-structured interviews
Twenty-eight carers completed the semi-structured interview and thematic content analysis.

Relationship Based Care
At the heart of the qualitative findings and permeating all discussions was a core overarching concept of relationship-based care which in turn supported three themes:
Not joining up the dots
Living the life desired in one's last days
Dealing with death and beyond (see figure 1 below).

Figure 1 Core Theme and Related Sub-themes



Key findings emerging from Theme 1- Not joining up the dots

- This theme identified gaps in care for the person. This included poor pain management, transitions, health care professionals not understanding the needs of the individual with ID, crisis-led decision making, not recognising signs of dying and uncertainty about having conversations about death and about planning for end of life care and not having the skills to engage in conversations about death.
- Some of these subthemes are reflected in some of the following quotes from multiple carers:

"…should we be telling the person that you're dying, I mean I don't, we've never done that actually." (uncertainty about having conversations about end of life care)

"..it was very hard to determine pain in James…..But certainly a lot of pain went unnoticed as well, maybe looking back like you know." (poor pain management)

"..it was just some small little thing that happened and, tiny thing that happened, and it was misinterpreted and he was sent into hospital" (crisis led decision-making and transitions)

- Carers reported that people with ID were not involved in end of life care planning, with the majority of older adults not told that they were dying. This was not only due to a feeling of protectiveness towards the person with ID and a perceived lack of ability of the person with ID to understand death but also because carers did not feel they had the skills and knowledge to have open conversations around death. This is exemplified by the following quotes:

"… nobody sat down to say you are not getting better because I don't think he would have any understanding of that…" (perceived lack of capacity of the person with ID to understand)

"…families would be like, oh they don't need to know that. Or you know don't be saying that you know, it'll only upset them." (feelings of protectiveness)

Key findings emerging from Theme 2 – Living the life desired in one’s last days

- Knowing the person, their story, what was important to them was the ‘bed rock’ of care and was perceived by staff as essential in maintaining the personhood of the person including in their final hours and was demonstrated in the following quotes from carers:

“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” (maintaining normal routines)

“But because that we had the room in the bedroom to have all the equipment that we needed. Kathleen was actually able to pass away here, which was really nice” (supporting people to die in their own homes)

Carers also expressed a sense of privilege at ‘being present’ and sharing the final days and hours with someone they knew so well.

“It was intense but you know a lovely experience to be…You know to witness and to be with her through her final journey.”

- Two key factors emerged which contributed to the quality of care the person received (1) A cohesive and determined team that often when above and beyond the call of duty

“…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.”

(2) Balancing physical and staffing resources
“We were feeling guilty and we were getting up to help her. So just, we were wrecked as well. ‘Cos we were looking after the other five.”

- Overall, there was a high satisfaction level with help received in the last two days of life. Where this was not the case, it was usually due to undiagnosed symptoms, late referrals or an emergency hospital admission.

“They said, you know like that she would’ve passed away very quickly. And she wouldn’t have had any distress. But that would be my only, my only regret at the end. I would always; I would love to have, if some of us had been there.” (about a person who passed away after an emergency hospital admission)

Key findings emerging from Theme 3- Dealing with Death and Beyond

- The majority of funerals were organised by the family alone or with staff. Staff carers described practices and traditions to preserve where they had lived the dignity and memory of the person with ID, e.g., having the wake within the ID setting so that residents, friends and staff have the opportunity to pay their respects.

“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.”

- Family and members of staff were always in attendance at the funeral mass and 85% of the time it was reported other residents/friends attended. Often staff and residents were directly involved in the mass service.

“they [the other residents in the house] 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.”

- For care settings that were not the family home the importance of not filling someone’s space immediately was recognised. Unexpectedly 73% of staff carers reported that the person’s place remained vacant for more than 3 months. Further investigation found that many of those who died were living in congregated settings that were in the process of being closed down meaning beds were not in demand there.

Some of the carers spoke of the need in all situations for the whole house to take time to catch its breath when a death occurs:

“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.”

- The most common form of bereavement support was informal peer support and 44.1% of carers reported that they did not need to access a formal service.

- The increased involvement of family members around the time of death reflected a natural sense of reconnection back to the person’s family and early life. Despite outreach by some services, post-death contact with families declined over time.

“the thirty years that Kathleen maybe was in the service, or whatever…to then just completely nothing.”

- Carers summed up their lessons learned in terms of the need for preparation, communication and follow-through as well as a need for more training in providing end of life care.

“…it comes up at the end of the year when you are doing your staff training analysis, and you would submit what is needed, and what do you see that should be in place, and you’d always put down “end-of-life care” kind of training information for staff”

Conclusions

The findings here confirmed previously reported inequalities for people with ID at end of life, i.e., they are dying at a younger age than the general population, with higher levels of multi-morbidity and dementia (McCarron et al., 2015; Lauer & McCallion, 2015) and potentially of conditions such as cancer that should be diagnosed and treated earlier (McCallion & McCarron 2015).

Building on an overall theme of relationship-based care, three sub-themes emerged that speak directly to critical issues related to end of life care. The theme 'joining up the dots’ highlighted gaps in end of life care for people with an intellectual disability, particularly a lack of the person’s involvement in decision-making about their end of life care, which is at odds with the person-centred care approach that underpins intellectual disability services. A lack of preparedness or awareness that the person was approaching end of life also emerged; a quarter of participants were reported to be ill for less than one month before death. At times, this lack of preparation resulted in crisis-led decision making in emergency situations which sometimes led to decisions that may have not been in line with the wishes of the person with ID. A need was identified for advanced end of life care planning for people with intellectual disabilities, in which the person with ID is at the centre.

The theme "living the life desired in one's last days" confirmed the value of familiar carers providing high quality care to people with intellectual disabilities at end of life (McCarron et al., 2010; Ryan et al., 2014). Carers described activities that went above and beyond in supporting the person with ID to maintain a sense of normality towards the end of life, and to stay where they wanted to be; two key elements of a good death. Over half died in their own homes and for those who died in hospital, carers expressed regret that they could not have been supported at home.

Carers were happy to provide this care but some felt out of their depth with a third of carers reporting that they were unsure if the person with ID was in pain in the last three months of life. Where recommended end of life training for ID staff and greater collaboration with mainstream palliative care services (McLaughlin et al., 2014) occurred, carers reported high satisfaction levels with the care provided.

Just as there has been a move in ID care to support 'ageing in place' (McCallion & McCarron, 2004), there is a need to support 'dying in place', a movement that will require earlier planning about end of life care and earlier referral to palliative care and its associated benefits (Temel et al., 2010).

The theme *'dealing with death and beyond'* related to the funeral rituals, the impact of the person's loss, and the lessons learned from the person's death. Generally, funerals were organised by families, who often ensured that both staff and other residents in the house were involved in the funeral ceremony. Carers reported a sense of loss and grief after the death of the person with ID, and described the impact on the other residents in the house. Carers highlighted a need for bereavement supports for families, staff and residents.

Recommendations

There was considerable richness in the qualitative data gleaned from the End of Life Interviews but there are still questions to be answered. Recommendations for the future include making a greater effort to include the views of family members, both as primary carers themselves when the person dies in the family home, but also as additional informants when the person's home is one that they visit but where they are also part of the care team at end of life. Gathering the perspectives of other informants, such as palliative care services and hospital staff as relevant, and from peers will also help. However, the effort to plan earlier for end of life will hopefully also mean that future researchers will have the prior words and desires of the person who has died to compare actual care against desired care.

Research that helps identify conditions and related symptoms that are potentially terminal for people with ID will both advance efforts to prevent avoidable deaths and will also increase the likelihood that needed conversations about planning for end of life will begin earlier, palliative options will be introduced, and there will time for greater collaboration between ID services, families, palliative care services and the person with ID themselves. There also needs to be work on the development of protocols and pathways to support the sensitive implementation of such care planning and delivery. The VOICES-SF questionnaire proved useful although a need was identified to add questions on contacts with family, palliative care, and other residents and also to establish the timing and extent of end of life planning.

Most of all, the confirmation here of the value of person-centred approaches and of the support people with ID receive when care is relationship based should encourage continued attention to achieving and respecting both.

1 Background and Context

Background and Context

Today in Ireland, there are 27,691 people registered on the National Intellectual Disability Database (NIDD; Kelly & O’Donoghue, 2014) at the end of December 2013. Of these, 27,318 people were in receipt of services, the highest number recorded since the database was first established in 1995. 7,972 (29.2%) of this group were in receipt of full-time residential services, which represented a decline of 1.6% on the 2012 figure, potentially reflecting the impact of deinstitutionalisation policies and practices. The majority (82%) of full-time residents had a moderate, severe or profound level of intellectual disability, were aged 35 years or over (83%), and lived in a community group home (54%) or residential centre (31%).

People with intellectual disability (ID) in Ireland are therefore an ageing population, living and potentially dying in a variety of settings. A great many people with ID today access services, which have a longstanding history and have undergone many changes in approaches, ethos and models of care, leadership, staffing and physical space. People with ID have moved from a position of being viewed as “the needy” to a group with increased rights and visibility in society and acceptable standards of care and residential circumstances have changed dramatically.

As the life expectancy for people with an ID increases (Kelly & Kelly 2011), it provides new challenges in understanding how people are living with illnesses, how they are ageing and how they are dying. In under a century, life expectancy for people with ID has increased from 18 years of age in 1930 to 66 years in 1993 (Braddock 1999). However more recent data suggests that such increases have since stalled (McCarron et al., 2015; Lauer & McCallion, 2015).

However, these changing statistics have not prompted a corresponding rise in appropriate quality healthcare and understanding of morbidity in this population (Innes et al., 2012; Tuffrey-Wijne, et al., 2008; McCarron et al., 2013).

What is known is that when compared to the general population, people with ID have higher mortality rates, higher multi-morbidity rates (McCarron et al., 2013) and higher prevalence and earlier onset of Alzheimer’s and dementia (McCarron et al., 2011, 2014, 2017). Of particular concern is emerging data on what are termed avoidable deaths.

Heslop and collegaues (2014) reported the results of the Confidential Inquiry into premature deaths of people with ID in the UK. This study drew attention in particular to the quality of health care being offered to people with ID in local communities, as compared with the general population. Avoidable deaths from causes amenable to change by good quality health care were found to be more than twice as common in people with ID (37%; 90 of 244 deaths) than in the general population of England and Wales (13%). Equally, there were findings that quality health care would have reduced this elevated mortality, while contributory factors to premature deaths included problems in advanced care planning, living in inappropriate accommodation, adjusting care as needs changed and carers not feeling listened to. If these contributory factors were concerns in disease progression then they are likely also to be of concern at end of life.

Findings from the research in this field of the limited inclusion of people with ID in end of life care planning (Shogren et al., 2006; Tuffrey-Wijne et al., 2007; Wagemans et al., 2010; Bekkema et al., 2014) confirms that barriers and differential access continue for people with ID at end of life. To date, there has been a lack of clear policy on informing people about death and people with ID are not usually told about their own death. Forrester-Jones (2012) spoke of managers’ ‘cautious silence’ in choosing not to speak about death. Several studies from the literature suggest that this stems from:

a) a sense of protecting the person who is dying and not wanting to cause them any unnecessary distress (Kirkendall et al.,2016)
b) an assumption of a lack of capacity
c) staff feeling that they lack the skills to disclose bad news (Tuffrey-Wijne et al., 2009)
d) an uncertainty about timing, who communicates and how to approach the subject (Ellison & Rosielle, 2008; Wiese et al., 2013).

Because of communication challenges and a misunderstanding of capacity, this silence around death extends to the other residents in out of home placements and medical staff and hospice/palliative care staff outside of ID services feel unprepared to assist (Fahey-McCarthy et al., 2009).

Despite ID staff feeling unprepared for end of life care, it has been reported that it does not hinder their motivation to provide that care (Todd, 2005; Ryan et al., 2011). Bekkema and colleagues (2014) found that staff spoke positively about providing end of life care but acknowledged feeling they did not have adequate training. Staff regarded the provision of end of life care as an important, if unrecognised element of their work (Todd, 2013).

A systematic review of 61 relevant studies from Ireland, the U.K., the U.S., Belgium, the Netherlands, Australia and New Zealand carried out in advance of this study (O'Farrell, 2016) identified four key areas of concern: (1) Training and Support (2) Partnership in service provision (3) Quality of relationships and (4) Communication and decision making.

1. Training and support

Understanding the training and support needs of all staff, including palliative care staff and ID support staff is crucial to understanding care provision. The Bekkema et al. (2014) study demonstrated, in line with much of the literature (McLaughlin et al, 2014; Hahn & Cadogan, 2011; Botsford, 2010), that ID support staff at all levels wish to engage in more training in providing quality end of life care, in this case particularly in supporting those that they support to deal with their impending death. Ryan and colleagues (2010) noted that ID staff find providing palliative care rewarding, particularly when a 'good death' is experienced by the person with ID and consequently the staff, while stress is experienced staff feel unprepared to provide care because of a lack of knowledge, skills and appropriate resources. This lack of preparation and awareness results in participants feeling emotionally burdened and guilty because the quality of care is compromised. Ryan and colleagues (2010) observed that although ID and palliative care staff are motivated to provide the best possible care to the patient, they perceive themselves as inadequately trained and prepared for this role.

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. With this in mind, Fahey-McCarthy and colleagues (2009) have created a training programme for carers in ID services supporting adults with ID and dementia. This included treating the person holistically, covering medical symptom management along with bereavement care, culturally competent caring and specific issues around ID and dementia. When asked, staff that underwent this training agreed that it supported ageing in place and the preparation for a "good death". This included support for staff, peers, and family in their grief and bereavement, mirroring palliative care in the ID care environment.

Training is not only required for staff but also for people with ID. An emerging theme from the literature is the limited death education that is delivered to people with ID (Wiese et al, 2012b; Ryan et al., 2011). Healthcare professionals require skills and knowledge to effectively provide palliative care for people with ID and should also work in partnership with their family carers.

2. Partnership in service provision

While staff may have expert knowledge about key issues such as communication difficulties and patients’ multiple pathologies, they are often new to the field of palliative care and sometimes struggle with ensuring to provide proactive palliative care (Crawford et al., 2010). Morton-Nance and Schafer (2012), highlight the benefits of ID professionals and palliative care services working together to achieve effective end-of-life care. McLaughlin and colleagues (2014) however, found that partnership practice was infrequent and there were unmet educational needs that impinged on this. When partnership between services existed, it was noted that this led to better outcomes for people with ID, allowing them to die in place. Specialist palliative care services reported limited and late referrals of people with intellectual disabilities, as has been noted in other studies, which was a constraint to collaboration. Cross et al (2012) suggest the establishment of a development worker role for ID and end of life care to bridge these difficulties, however the practicalities due to funding and staffing resources are questionable. Nevertheless, it is clear that this engagement must be supported at all levels, including managerial to be a meaningful and effective partnership, enhancing end of life care for people with ID.

3. Quality of relationships

Ryan et al. (2014) explored relationships between people with ID and palliative care professionals and ID care staff, bridging the literature between palliative care and the changing approaches in ID care from person centredness to relationship-centredness (Nolan et al. 2006). Staff interviewed clearly valued the relationships they had with service users. Palliative care and ID staff emphasised trust, continuity of relationship and of knowing the individual in developing high-quality relationships. Interestingly, palliative care staff were found to struggle more with these areas when they were providing care to people with ID and in building authentic relationships, which in turn affected care negatively. Authentically “being there” with the person through the phases of dying, death and beyond death were viewed as more positive experiences by those caring for people with ID (Todd, 2013). Tuffrey-Wijne et al. (2008) emphasise the importance of early referral to palliative care services to help build rapport, trust and familiarity with services but also for the palliative care professionals to gain knowledge of the patient’s lifestyle and usual behaviour. It is fundamental to effective palliative care provision that those providing are confident, competent, and appropriately skilled, but also open to forming warm and authentic meaningful relationships with all people, including those with ID.

4. Communication and decision making

Read and Cartlidge (2012) stressed that professionals have a duty to provide opportunities for discussion with people with ID. Unfortunately, Tuffrey-Wijne and collegues (2010) 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 and colleagues (2010) suggest that there is a desire to protect people with ID from the unpleasant truth, with professionals not wanting to cause distress. Discussing death for people with ID is not without its challenges (Clayton , 2015). Ryan and collegaues (2011) found that relatives were often used as communication proxies, preventing direct engagement with the person with ID, effectively acting as gatekeepers of information discussed. The quality of palliative care for people with ID is strongly linked to the communication skills of ID and palliative care staff and their openness and comfort engaging with the person and supporting broader discussion with all parties, but centrally the person with ID. There are also more specific communication challenges to be addressed in the area of pain management.

One of the cornerstones of palliative care is the adequate control of pain and other symptoms (Sepúlveda et al., 2002). Self-report is the most common form of pain assessment, all the more challenging when working with people who have communication difficulties (Tuffrey-Wijne et al., 2007); highlighting another area for improvement of communication.

All four of these challenge areas are not unique to the ID field and reflect current issues in palliative care research both in Ireland and internationally (McIlfatrick & Murphy, 2013). What is unique is that there is an opportunity in Ireland to examine end of life care and consider these challenges by following up on participants in the Intellectual Disability Supplement to the Irish Longitudinal study on ageing (IDS-TILDA; McCarron et al., 2011; Burke et al., 2014) who subsequently die. IDS-TILDA is a multi-wave longitudinal study of older adults with ID designed to explore their ageing profile, physical and behavioural health, health services use, psychological health, social networks, living situations and community participation including employment. Since Wave 1, the deaths of 57 participants occurred, providing the opportunity to explore their end of life experiences. This study aims to develop a profile of participants who had died since Wave 1 and Wave 2 of the IDS-TILDA study, explore their experiences at end of life as reported by their carers, consider pain and other care research areas still largely unexplored for the end of life for people with ID, and test the usefulness of a specific instrument, the VOICES questionnaire.

2 Methodology

Design

This research is part of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). A mixed methods approach, incorporating both qualitative and quantitative data collection and analyses advanced understanding end of life care of older adults with intellectual disability in Ireland from the perspective of their carers. A validated questionnaire on carer perspectives of end of life care formed the basis of a semi-structured interview which was the primary data collection tool.

Aims

The aims of the study were:

1. To develop a demographic, health status, and healthcare utilisation profile of participants in IDS-TILDA who had died between October 2010 and January 2015
2. To explore the experiences at end of life for those who died, as reported by their carers

Participants

The participants in this study were all carers of individuals who died from Wave 1 and Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study of Ageing (IDS-TILDA). The inclusion/ exclusion criteria are presented in Table 1.

Table 1 Inclusion/exclusion criteria for carer participants

Inclusion Criteria	**Exclusion Criteria**
Aged 18 and over	**Aged less than 18 years**
Provided direct physical and/or emotional care in the last year of life	Did not provide care in the last year of the person's life
Knew and cared for the person who died for at least 1 year	Knew and cared for the person who died less than 1 year
Knew the person well, including their personal, health and social circumstances and preferences in this time	Did not know the person well and did not know their health and social circumstances and preferences in this time
Family member, friend, paid ID staff member, healthcare provider, volunteer care provider	The person died less than 6 months ago, in line with VOICES recommendations
The person died at least 6 months ago, in line with VOICES recommendations	

All participants who died up until January 2015 (N=57) were included when analysing demographic profiles, health status, and healthcare utilisation. Of the 57 persons identified, 61.4% (n=35) completed Wave One only, and 38.6% (n=22) completed Wave Two (see Table 2). Data from each person's most recently completed IDS-TILDA questionnaire was used (see table 1).

Carers of 37 of the deceased participants were approached and agreed to complete either the pilot study or the full qualitative interview. Carers of nine of those who died completed the pilot study and 28 completed the qualitative interview.

Table 2 IDS-TILDA participants who died by January 2015 – EOL study participation

	Total (N=57)	Completed Wave 1 (n=35)	Completed Wave 2 (n=22)
	n (%)	n (%)	n (%)
Completed qualitative interview	28 (49.1%)	17 (60.7%)	11 (39.3%)
Completed pilot	9 (15.8%)	8 (88.9%)	1 (11.1%)
Did not complete any element of EOL	20 (35.1%)	10 (50.0%)	10 (50.0%)

Respondent Carers

'*Carers*' refers to family members and/or staff members who supported the person with intellectual disability at the end of their lives. Carers of 37 (64.91%) of the 57 deceased participants took part in the End of Life study. The majority of carers were staff (n=36, 97.2%) with one family member (2.8%) participating in the pilot study and none in the full interview. In the case of staff members, the staff had to have worked with the person with intellectual disability for at least one year in order to take part. Carers were from 17 intellectual disability services across both rural and urban contexts.

Pilot Study

The aim of the Pilot Study was to explore the feasibility of using the VOICES questionnaire (Addington-Hall & McCarthy, 1995) in a population of carers of people with an intellectual disability. Nine carers took part in this pilot study, and filled out a paper-based version of the VOICES-SF (short-form) questionnaire. Participants were from three services in both rural and urban contexts. Data collected during confirmed the feasibility of the using the VOICES in this population. However, pilot findings resulted in three amendments to the study protocol:

1. During the administration of the paper based version of the VOICES questionnaire it emerged that large amount of rich narrative data was not been adequately captured, and given the nature of the questions that it was insensitive to interrupt the participant. Consequently, it was decided that administrating the VOICES-SF through a semi-structured interview which would be recorded and transcribed more adequately captured the perceived experiences of people with Intellectual disability at end of life
2. Six items from the TILDA exit interview were added to increase opportunities for comparisons with the general older population in Ireland
3. Six items were added on post death rituals based on the large amount of data emerging on this topic from the pilot interviews

Additional ethical approval for these changes to the study protocol was sought and granted.

Semi-Structured Interview and Questionnaire

The semi-structured interview was based primarily on the *'The Views of Informal Carers- Evaluation of Services Short Form' (VOICES-SF)* questionnaire, amended slightly according to Irish health service utilisation requirements and intellectual disability service specific items. This study used the shorter form of the validated VOICES questionnaire *(VOICES-SF)* which consists of 58 items (Hunt et al. 2011). It was administered as a semi structured interview, with the closed questions generating quantitative data whilst the open questions yielded a rich qualitative narrative.

The VOICES questionnaire has been developed over a number of decades to capture information on quality of care, service use and unmet needs as people approach end of life (Addington-Hall & McCarthy 1995; Addington-Hall et al., 1998; Burt et al. 2010). It has been administered as a face to face interview and as a postal and telephone questionnaire to multiple respondents examining experiences at end of life. It is also used in the UK by their Department of Health and the NHS to inform policy and practice in relation to end of life care (National Survey of Bereaved People (VOICES): England, 2015) and Hunt and colleagues (2011). However, it has not previously been used with carers of those with intellectual disability. Evaluation of data gathered in the pilot study confirmed the suitability of the VOICES-SF questionnaire in this population.

Changes were made to the VOICES questionnaire to delineate between general community based health care services and intellectual disability service based health care services, in order to specify location of the healthcare services accessed. The term "usual home" was utilised rather than home in recognition of the fact that the deceased may have had a family home and an intellectual disability service residential or community group home. Establishing the person's usual home allowed the baseline home location of the person to be determined. Additional questions regarding change in intellectual disability service home were also added reflecting intellectual disability service care and changes in this. Changes were made to the healthcare utilisation section reflecting the Irish specific context, e.g. items changed to community or public health nurse, Irish Cancer Society Night Nurse and community intervention team.

Physical and Emotional Health Measures

As part of the IDS-TILDA pre-interview questionnaire, participants and/or proxies were asked to report whether or not they had received a doctor's diagnosis of one or more of 12 chronic health conditions. Ten of the 12 conditions included in the PIQ were taken from the Charlson Co-Morbidity Index (Charlson et al., 1994). These were: heart disease, endocrine disease, eye disease, hypertension, joint disease, lung disease, gastrointestinal disease, liver disease, cancer and stroke. For the purpose of the IDS-TILDA study, two additional conditions were also included: neurological disease (cerebral palsy, epilepsy, multiple sclerosis, Parkinson's disease, spina bifida, muscular dystrophy, Alzheimer's disease, dementia, organic brain syndrome or senility, and serious memory impairment) and mental health problems (emotional, nervous, or psychiatric condition which included hallucinations, anxiety condition, depression, emotional problems, schizophrenia, psychosis, mood swings and manic depression).

Additional health status items were drawn directly from the TILDA "exit" interview, carried out with proxy bereaved friends and family after the deaths of TILDA Wave 1 participants. These questions provided opportunities to directly with the general older Irish adult population. These questions were:

1. 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

2. Did he/she have any (other) major illnesses since the last interview/in the two 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.

3. Do you think he/she was depressed during his/her last year of life? Yes/No

4. How often do you think he/she felt happy during his/her last year of life?
   Never/sometimes/often/always

5. And how about the last three months of his/her life, how often do you think he/she felt contented or at peace during this time? Never/sometimes/often/always

Post-death rituals

Based on data which emerged from the pilot study, six questions regarding post-death rituals were added to the semi-structured qualitative interview. As these questions were added after the Pilot Questionnaire, data for these questions is available only from the 28 carers who completed the full qualitative interview.

Questions added regarding post-death rituals

1. How soon after did a person take their place in residence?
2. Who was present with the person at time of death?
3. Who decided what would happen with the person’s remains?
4. Who was involved in arranging the funeral service?
5. Who was at the funeral?
6. Where was the person laid to rest/ How far from usual home?

Data Collection

Demographic, health, and healthcare utilisation data collected at the person’s last IDS-TILDA interview provided a descriptive picture of those who died. Pilot interviews (n=9) and semi-structured interviews (n=28) with carers of individuals who died from the IDS-TILDA study were conducted in staff carers’ place of work and with the one family member at an agreed convenient location. Carers (n=9) in the pilot study filled out a paper-based version of the VOICES-SF. The 28 full semi-structured interviews were conducted by the same data collector and were recorded and transcribed verbatim.

Data Analysis

Retrospective Quantitative Analysis of IDS-TILDA interview data

SPSS (Statistical Package for the Social Sciences) Version 20, was used to complete a retrospective quantitative descriptive analysis of the most recently completed IDS-TILDA interview data comprising demographics, health and healthcare utilization for each person who died.

Quantitative data analysis of the VOICES-SF questionnaire

All 37 participants responded to the quantitative questions included in the VOICE-SF questionnaire. For the nine pilot participants, this was filled out on the paper based questionnaire. For the 28 semi-structured interviews, this data was extracted manually from the interview transcripts. SPSS version 20 was used to carry out descriptive analysis on these data.

Qualitative data analysis

Content analysis was used to analyse the qualitative data. This consisted of repeated reading of full transcripts, note taking, development of codes, preliminary coding and then coding of each complete transcript using NVivo Pro version 11.4. Through systematic content analysis, emerging categories and themes were then developed. Credibility was obtained through triangulation with the quantitative data, peer debriefing and constant checking that analyses were grounded in the participants’ responses (LoBiondo-Wood et al., 2014).

Ethical Issues

Ethical approval was granted by Faculty of Health Sciences, Trinity College Dublin and the relevant ID services. All carer participants provided informed consent.

3 The demographic and health profile of those who died

Introduction

In this chapter the demographic, health status and healthcare utilisation of the 57 IDS-TILDA participants who died between October 2010 and January 2015 are presented. Data was generated from participants’ most recent IDS-TILDA interview, which took place in the 1-2 years preceding their death. Comparisons are made between those who died and the surviving Wave 2 IDS-TILDA cohort. Comparisons are also drawn between IDS-TILDA participants who died, and deceased participants from the general population study TILDA (Nolan et al., 2014), where possible.

Demographic profile of IDS-TILDA individuals who died

The demographic characteristics of IDS-TILDA participants who died between Wave 1 (2010) and January 2015 are reported in Table 3. There was an even gender distribution. Most individuals who died were described as having a moderate (n=26, 50%) or a severe/profound (n=25, 48.1%) level of ID. Over two-thirds of individuals who died were living in residential centres (n=38, 67.9%), approximately one quarter were living in community group homes (n=15, 26.8%) and just over five percent were living independently or with family (n=3, 5.4%). A total of 17 (29.8%) individuals who died had Down syndrome. The median age at death was 61 years (Range: 45-85 years) but when those with Down syndrome are separated (median age of death: 57 years) the mean increased to 67 years. In the general population, TILDA (Nolan et al., 2014) report the median age of death was 77 years.

Table 3 Demographic characteristics of individuals who died (N=57) compared to Wave 2 survivors (N=696)

Characteristic	**Individuals who died (n=57)**		**Wave 2 Survivors (n=696)**	
	n	**%**	**n**	**%**
Gender				
Male	28	49.1%	307	44.1%
Female	29	50.9%	389	55.9%
Level of ID*				
Mild	1	1.9%	154	24.6%
Moderate	27	50.9%	293	46.7%
Severe/ Profound	25	47.2%	180	28.7%
Living circumstances				
Independent/with family	3	5.3%	113	16.7%
Community Group Home	15	26.3%	292	43.1%
Residential	39	68.4%	272	40.2%
Cause of ID				
Down syndrome	17	29.8%	130	19.2%
Other/unknown	40	70.2%	466	80.8%
Age at last interview				
40-49	9	15.8%	198	29.2%
50-64	27	47.4%	341	50.2%
65+	21	36.8%	140	20.6%
Age at death**				
44-49	5	10.6%	--	--
50-64	22	46.8%	--	--
65+	20	42.6%	--	--
Median age at death (n=47)**	**Median**	**Range**		
	61	45-85	--	--

*Not all participants identified their level of ID

**Age at death was not available for all participants

As may be seen in Table 3 there was a smaller proportion of people with mild ID among the individuals who died (n= 1, 1.9%) compared to the Wave 2 survivors (n=154, 24.6%). Just three (5.3%) of individuals who died lived independently or with family, compared to 16.3% (n=113) of the surviving cohort. There was also a greater proportion of individuals who died living in residential centres (68.4%, n=39) relative to the Wave 2 cohort (n=272, 40.2%).

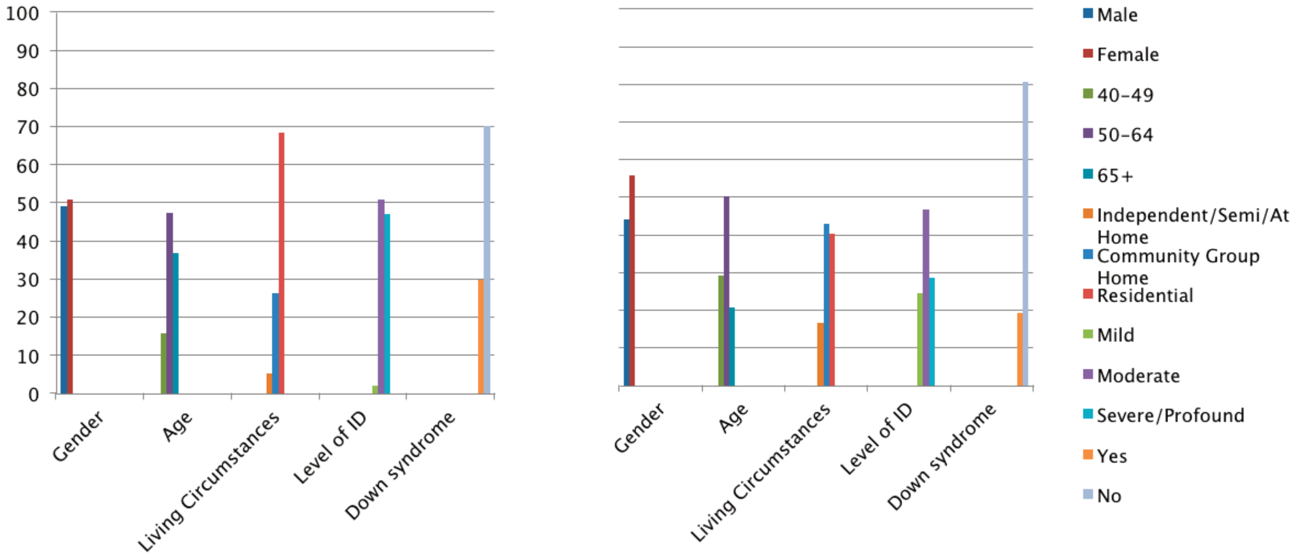


Figure 2 Demographic profile of those who died (N=57) Figure 3 Demographic profile of Wave 2 Survivors (N=696)

Age of death in people with and without Down syndrome

The median age of death for people with Down syndrome in this study (n=17) was 57 years. As presented in Figure 4, the number of individuals who died with Down syndrome peaked in the middle 50-64 year age category (n=13, 86.7%), whilst there was a steady increase in the number of people in each category for people with ID of other aetiology with the greatest number there (n=19, 59.4%) in the 65 years and over category.

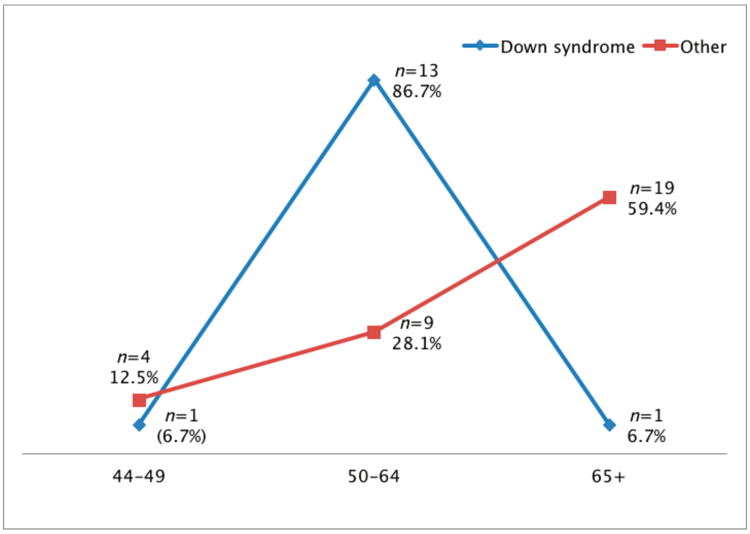


Figure 4 Age category at time of death of persons with Down syndrome compared to persons with ID of other aetiology (n=47)*

*Age at death was not available for all participants

Health Status of Individuals who died

The health conditions reported by individuals who died in their last interview are outlined in Table 4. The most commonly reported conditions were eye disease (n=35, 61.4%), neurological disease (n=32, 56.1%) and mental health difficulties (n=31, 54.4%).

Table 4 Health conditions reported at last interview by those who died (N=57)

Individuals who died (n=57)	n	%
Eye disease	35	61.4%
Neurological disease	32	56.1%
Mental health difficulties	31	54.4%
Gastrointestinal disease	28	49.1%
Joint disease	20	35.1%
Endocrine disease	16	28.1%
Heart disease	14	24.6%
Hypertension	10	17.5%
Lung disease	10	17.5%
Stroke	7	12.3%
Cancer	7	12.3%
Liver disease	1	1.8%

The frequency of health conditions of the deceased participants (N=57) compared to the surviving Wave 2 cohort (N=696) are presented in Figure 5. Almost all health conditions were more prevalent amongst the individuals who died. The most notable differences were the higher prevalence of neurological disease (56.1% compared to 36.5%) and the higher prevalence of heart disease (25% compared to 2.4%) and hypertension (17.9% versus 4.4%) among the individuals who died. A higher proportion of individuals who died who reported having cancer (10.7% compared to 2.4%).

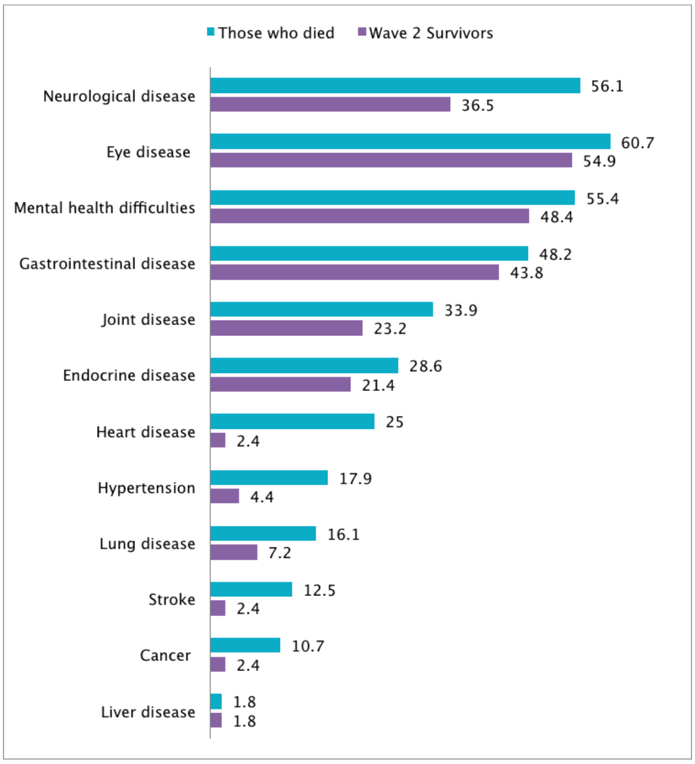


Figure 5 Health conditions reported at last IDS-TILDA interview by those who died (N=57) compared to Wave 2 survivors (N=696)

Neurological conditions

Given the high prevalence of neurological disease among individuals who died compared to Wave 2 survivors (56.1% compared to 36.5%), neurological conditions were broken down into type of condition to investigate the nature of these differences. As reported in Table 5 and Figure 6, there was a higher proportion of epilepsy among individuals who died (n=25, 43.9%) than among the Wave 2 survivors (n=210, 31.0%). More notably, there was also a greater proportion of people with dementia among the individuals who died (n=17, 29.8%) compared to Wave 2 survivors (n=40, 5.9%). A total of 14 individuals who died (14.6%) reported a doctor’s diagnosis of both epilepsy and dementia. Of those with Down syndrome, 12 (70.6%) reported a doctors diagnosis of epilepsy, 13 (76.5%) reported a doctor’s diagnosis of dementia, and 12 (70.6%) reported a doctor’s diagnosis of both dementia and epilepsy.

Table 5 Prevalence of neurological conditions among individuals who died (N=57) compared to Wave 2 survivors (N=696)

	Individuals who died (N=57)		Wave 2 survivors (N=696)	
	n	%	n	%
Dementia	17	29.8%	40	5.9%
Epilepsy	25	43.9%	210	31.0%
Parkinson’s disease	2	3.5%	5	.7%
Cerebral Palsy	0	0	39	5.8%

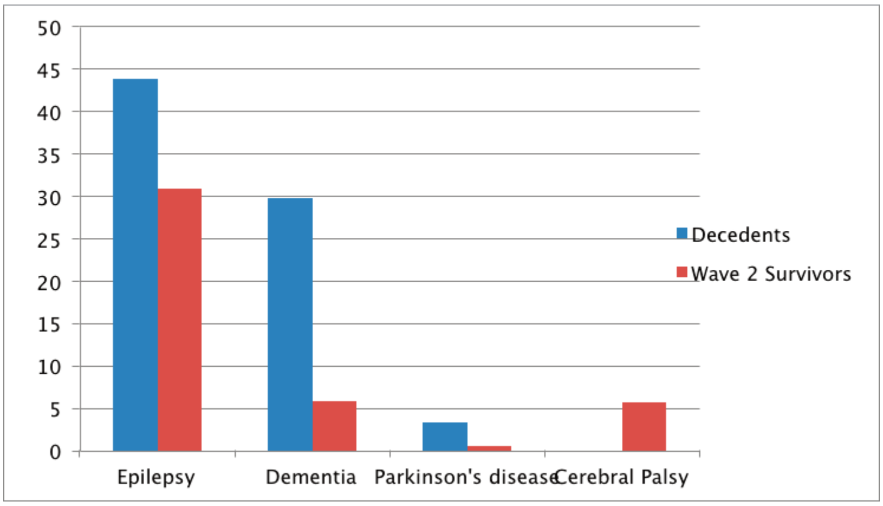


Figure 6 Breakdown of neurological conditions reported by individuals who died (N=57) compared to Wave 2 survivors (N=696).

Disease Pairs

The majority of participants (n=52; 91.2%) reported multimorbidity (having two or more chronic conditions). This was slightly higher than the proportion of Wave 2 survivors who reported multimorbidity (n=546, 80.5%). The disease pairs reported by individuals who died at the time of their last IDS-TILDA interview are presented in Table 6. The most frequently reported disease pairs were eye disease and neurological disease (n=23, 40.4%) and eye disease and mental health difficulties (n=18, 36.1%).

Table 6 Disease pairs reported by individuals who died at their last IDS-TILDA interview (N=57)

Disease Pairs	**n**	**%**
Eye disease and neurological disease	23	40.4
Eye disease and mental health difficulties	18	31.6
Eye disease and joint disease	16	28.1
Neurological disease and mental health difficulties	16	28.1
Endocrine disease and mental health	11	19.3
Eye disease and heart disease	9	15.8
Eye disease and lung disease	8	14.0
Eye disease and hypertension	5	8.8

Healthcare utilisation

Primary and secondary healthcare utilisation in last year of life

The primary and secondary healthcare utilisation of individuals who died compared to Wave 2 survivors and general population TILDA individuals who died (n=155) are presented in Table 7. Almost all individuals who died (98.2%, n=56) and Wave 2 survivors (n=559, 95.1%) reported a GP visit at their last interview. This was slightly higher than the proportion of TILDA deceased who reported a GP visit (87.1%). A greater proportion of individuals who died (n=17, 33.3%) reported a hospital admission at their last interview compared to Wave 2 survivors (n=89, 13.9%). However, a higher proportion of TILDA participants reported a hospital admission (59.4%) compared to both IDS-TILDA deceased and survivors. A greater number of TILDA deceased (44.5%) also reported an A&E visit than both IDS-TILDA individuals who died (n=20, 35.1%) and Wave 2 survivors (n=139, 21.3%).

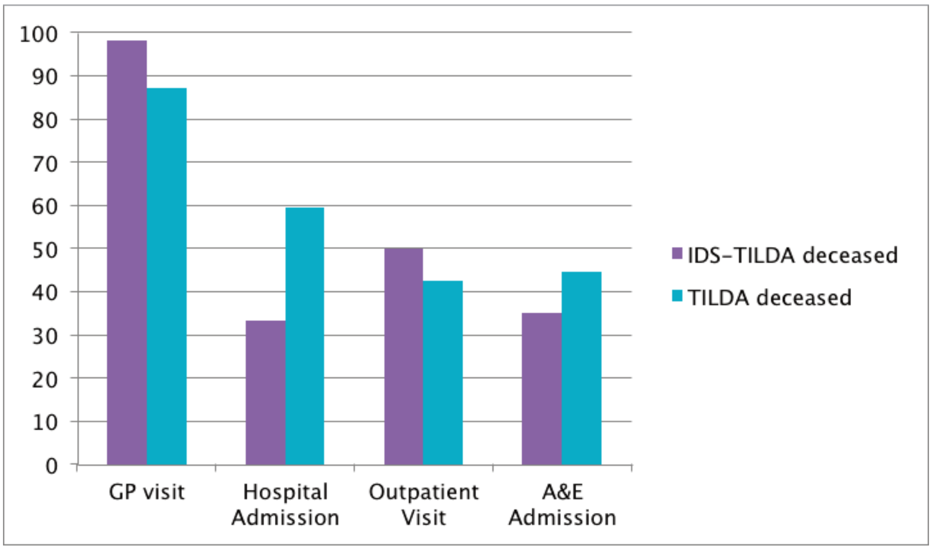
Table 7 Primary and secondary healthcare utilisation reported by individuals who died (N=57), Wave 2 survivors (N=696) and TILDA deceased (N=155) at last interview

	Individuals who died		Wave 2 survivors		TILDA deceased*
	n	%	n	%	%
GP visit	56	98.2	559	95.1	87.1
Hospital Admission	17	33.3	89	13.9	59.4
Outpatient visit	26	50.0	319	51.3	42.6
A & E visit	20	35.1	139	21.3	44.5

*Source: Nolan et al., 2014

As summarised in Figure 7, whilst a greater number of IDS-TILDA deceased accessed primary healthcare, a higher proportion of TILDA deceased reported hospital stays and A &E visits.

Figure 7 Primary and secondary healthcare utilisation by those who died in the IDS-TILDA study compared TILDA participants who died



Access to other healthcare services

Other health service utilisation reported by individuals who died at their last interview are outlined in Table 8. Commonly accessed services included physiotherapy (n=27, 47.4%), speech and language therapy (n=26, 45.4%), occupational therapy (n=23, 40.4%), and psychiatry (n=23, 40.4%). A total of nine individuals who died (15.8%) had been accessing palliative care services at the time of their last interview.

Table 8 Healthcare services accessed by individuals who died at last interview

	Individuals who died (n=57)		**Wave 2 survivors (n=674)***	
	n	**%**	**n**	**%**
Physiotherapy	27	47.4	160	23.7
Speech and Language Therapy	26	45.6	181	26.9
Occupational therapy	23	40.4	153	22.7
Psychiatry	23	40.4	266	38.2
Social work	14	24.6	136	20.2
Neurology	9	15.8	71	10.2
Public Health Nursing	9	15.8	73	10.8
Palliative Care	9	15.8	4	0.6
Psychology/ Counselling	13	22.8	102	14.7

*Data on healthcare utilisation was not available for all Wave 2 survivors

Services accessed by individuals who died compared to healthcare utilisation of Wave 2 survivors is presented in Figure 8. Overall, individuals who died accessed a greater number of services. In particular, there were a greater proportion of individuals who died accessing physiotherapy (47.4% compared to 23.7%), speech and language therapy (45.6% versus 26.9%) and occupational therapy (40.4% compared to 22.7%).

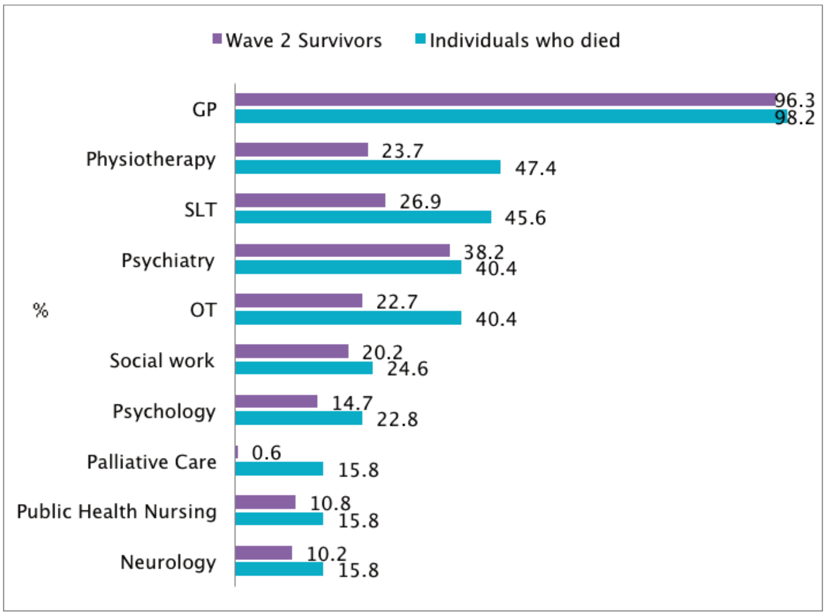


Figure 8 Healthcare utilisation of individuals who died (N=57) compared to Wave 2 survivors (n=674)

Conclusion

In this chapter the demographic characteristics and the health profile of the 57 persons who died were presented. Comparisons were drawn between the characteristics of those who died and those of the living IDS-TILDA participants as well as with participants in TILDA for healthcare utilization. Key findings included an earlier age of death among people with Down syndrome; a higher prevalence of almost all health conditions amongst those who died, in particular neurological disease, heart disease and cancer as compared with IDS-TILDA survivors. On healthcare utilization, those with an intellectual disability were less likely that those who died in the general population to access hospital stays and A&E use. More work is needed to understand the extent to which lower rates of A&E use and hospital stays represent different and effective approaches to care at end of life. The high rates of eye disease, neurological disease and mental health concerns among people with ID who were subsequently dying encourages care plans that address multi-morbidity. Taken together, the findings have important implications for policy and service provision, and highlight the complex needs of older adults with ID at the end of life.

4. Circumstances Surrounding Death

Introduction

In this chapter the circumstances surrounding death, including length of illness and place of death for the 37 participants whose carers took part in the End of Life Study are outlined. The demographic characteristics of the subsample who took part in the End of Life Study (N=37) compared to all of the deceased participants (N=57) are also presented, in order to explore the representativeness of this subsample.

Demographic Profile of Participants in the End of Life Study

The person’s place of death and carer’s reported length of illness was available only for the individuals who died who took part in the End of Life Study (N=37). The demographic characteristics of these individuals (n=37) compared are listed below. These are largely reflective of the characteristics of the overall sample of individuals who died (n=57), however none of the three participants (5.4%) who lived independently or with family were involved in either element of the End of Life Study.

Table 9 Demographic profile of the subsample of individuals who participated in the End of Life Study (n=37) compared to all of those who passed away (n=57)

sample of	**End of Life Study**			**Overall**
	Participants (n=37)		**Individuals who died (N=57)**	
	n	**%**	**n**	**%**
Gender				
Male	19	51.4	28	49.1
Female	18	48.6	29	50.9
Level of ID*				
Mild	1	2.9	1	1.9
Moderate	18	52.9	27	50.9
Severe/profound	15	44.1	25	47.2
Residence				
Independent/with family	0	0	3	5.3
Community group home	9	24.3	15	50.9
Residential	28	75.7	39	68.4
Down syndrome				
Yes	11	29.7	17	29.8
No	26	70.3	40	70.2
Age at death**	Median	Range	Median	Range
	64	45-85	61	45-85

*Level of Intellectual Disability was not available for all participants
**Age at death was not available for all participants

Length of illness

As outlined in Table 10, just over one quarter of individuals who died (n=9) were reported to be ill for less than one month before they passed away. Eight participants (22.9%) were ill for 1-6 months and approximately half the participants were ill for six months or more prior to death, with most of these (n=11) reported to be ill for over a year.

Table 10 Length of Illness (n=35)*

	n	%
Not ill, died suddenly and unexpectedly	2	5.7%
Less than 24 hours	1	2.9%
One day or more but less than one week	3	8.6%
One week or more but less than one month	3	8.6%
One month or more but less than six months	8	22.9%
Six months or more but less than one year	7	20.0%
One year or more	11	31.4%

*Not all participants reported length of illness

Place of death

Figure 9 and Figure 10 show the breakdown of place of death for IDS-TILDA and TILDA deceased. Place of death was reported for 37 deceased. A total of 21 (57%) died in their own home or their family home. Two died in another residential unit within the same ID service campus setting. 35% (n=13) died in hospital. In contrast, only a quarter of TILDA deceased were reported to have died in their own homes (24.5%), with a greater proportion (48.4%) dying in hospital. A higher proportion of TILDA participants died in nursing homes (9.7%, compared to 3% (n=1) for IDS-TILDA deceased. Finally, thirteen percent of TILDA participants passed away in a hospice whilst none of the IDS-TILDA participants were reported to have died there.

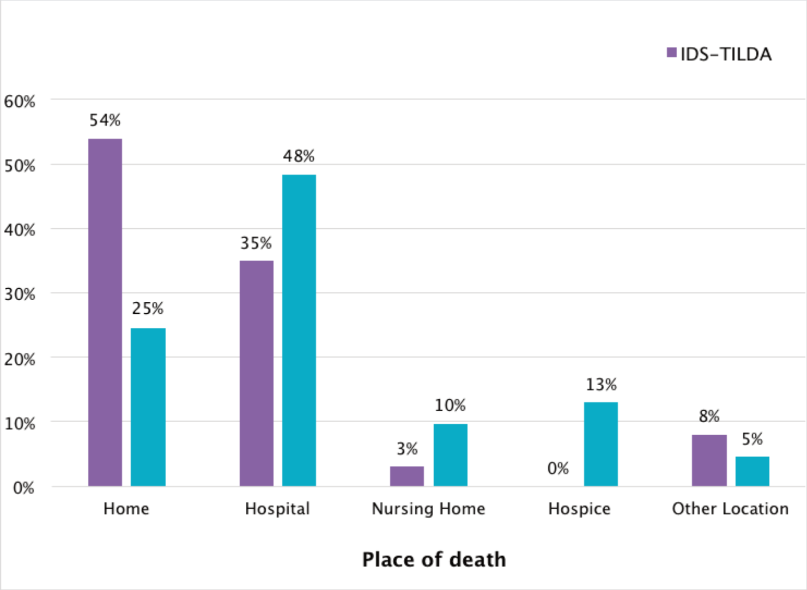


Figure 9 Place of death of IDS-TILDA individuals who death (n=37)

Cause of death

Cause of death was available only for the individuals who died for whom carers completed the semi-structured interview (n=28) as this question was not included in the pilot study (n=9). For four of these people (14.3%) cause of death was unknown. One quarter of participants (n=7) were reported to have died from cancer. Another seven individuals who died (25%) were reported to have died from pneumonia. As may also be seen in Table 11, three people (10.7%) died of renal failure, two people died of dementia (7.1%) and five (17.9%) died of other causes.

Table 11 Carer's reported cause of death (n=28)*

	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

*Cause of death was only asked of the 28 carers who took part in the semi-structured interview

The types of cancer reported by those who died from cancer were leukaemia (n=2), gastrointestinal cancer (n=1), colon cancer (n=1), prostate cancer (n=1), pancreatic cancer (n=1) and ovarian cancer (n=1). Three of those who died of cancer also reported a doctor's diagnosis of dementia (42.9%) at their last IDS-TILDA interview. Only two of those (28.6%) of those who died of cancer reported ever having received treatment for their cancer. Length of illness was reported for five of the seven people who died of cancer. One person was reported to be ill for one month or more but less than six months, one person was reported to be ill for more than six months but less than a year, and three people were reported to be ill for one year or more.

A total of nine (32.1%) of the 28 deceased whose carers took part in the semi-structured interview had a doctor's diagnosis of dementia. Of these nine people with dementia, carers reported cause of death as cancer (n=3), pneumonia (n=3), end stage dementia (n=2) and a bowel perforation resulting from a distended stomach (n=1).

Conclusion

In this chapter the circumstances surrounding deaths of people with intellectual disabilities were presented. Despite the high-rates of chronic conditions and multi-morbidity reported, over a quarter of the individuals with an intellectual disability were reported to be ill for less than one month before they died. That not everyone with a diagnosis of cancer for more than a year had been receiving any treatment prior to death suggests they were not considered good candidates for such treatment. Unestablished is whether this was due to the stage of disease or to persons with intellectual disability being seen assuitable for treatment. Data on cause of death indicated they died from a range of health conditions, including cancer and dementia. Over half died in their own homes, a rate considerably higher than that reported for the general older population. All of this has important implications: providing high quality palliative care to people with ID in their own homes will best support them as they reach end of life.

5 Qualitative Findings from the Semi-Structured Interviews

Introduction

Analysis was based on 28 semi-structured interviews with ID staff members. There were no family members in this subsample. The majority (75%) were staff in the usual home, a further 14.3% were keyworkers and the remaining 10.7% were staff (usually management) from the broader ID service.

Relationship Based Care

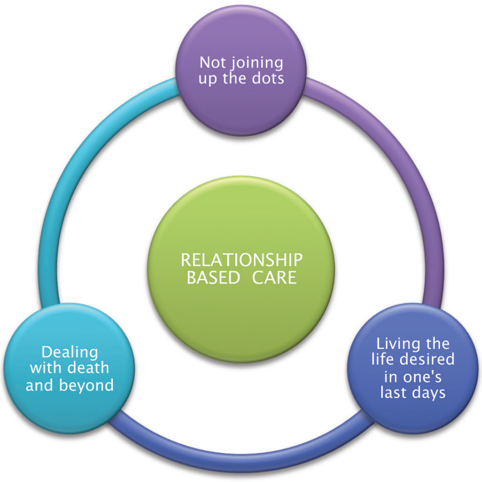
The overarching theme evident in every interview was a commitment of staff to deliver high quality end of life care based upon and benefiting from the relationship that had been developed with the person with ID over years and sometimes decades.

The hallmark of good palliative care is best summed up in the often cited quote from Cecily Saunders *‘you matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die*’ (1993).

Drawing upon the bedrock of their relationship the person with an intellectual disability carers universally described their commitment throughout the dying process to support a good death and in what they said exemplified their dedication to such a hallmark for care.

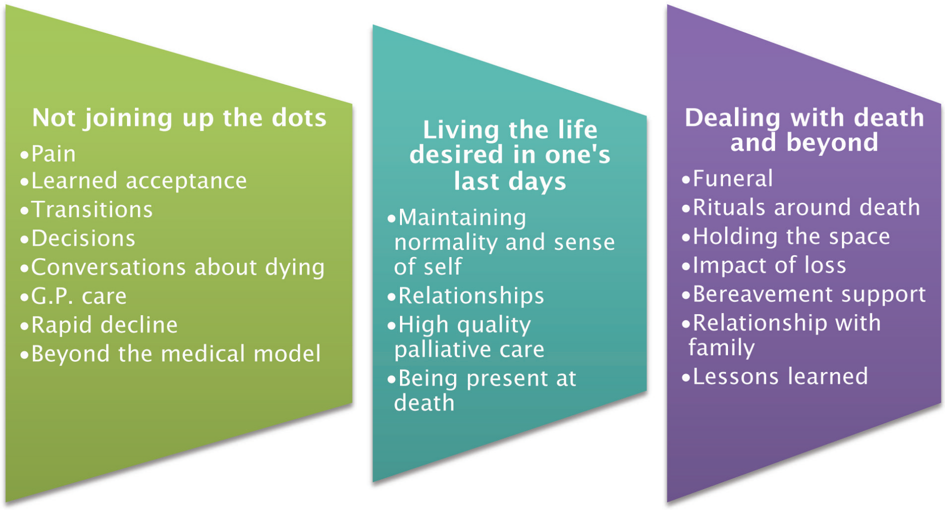
From ‘Relationship Based Care” three sub-themes emerged (see figure 11).

Figure 10 Overarching theme and three sub-themes



These sub-themes will be discussed with their corresponding sub-categories (see figure 12).

Figure 11 Sub-themes and subcategories



Theme 1: Not joining up the dots

Introduction

The title of this sub-theme came from the numerous accounts of gaps in care for the person with ID at the end of life. This was multifactorial, from illness and dying symptoms not being recognised, unnecessary transitions and crisis-led decisions to a general unsureness of this new era of people with an ID living longer with differing health needs.

Pain

The recognition and management of pain proved to be a difficult area of care, with many respondents unable to say with certainty if the person they were caring for was experiencing pain or had their pain well managed.

> *“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 hard to determine pain in James…..But certainly a lot of pain went unnoticed as well, maybe looking back like you know.”*
>
> *“It was very very difficult to assess his pain as he didn’t really show pain”*
>
> *“But then I hope that he wasn’t in pain. But I know he was, you know, so.”*

In fact, almost a third of respondents (32.4%) reported that they did not know if pain was relieved during the last three months of the person’s life (see table 12). Almost a quarter had their pain only partially relieved or not at all (23.5%). This potentially is a substantial number of people who are experiencing pain at the end of their life.

Table 12 Level of pain relief during the last three months of life (n=34)*

	n	%
Does not apply- (s)he did not have any pain	8	23.5%
Completely, all/some of the time	7	20.6%
Partially	5	14.7%
Not at all	3	8.8%
Don’t know	11	32.4%

*Level of pain relief was not reported for all participants

What was apparent was the awareness of the participants’ in looking for symptoms of pain and how it was different for each person. They spoke of using pain tools (e.g. Abbey Pain Scale, DisDAT), observing facial expressions, how the person moved, sweating, vocalisations, changes in facial colour and simply through knowing the person.

One of the difficulties in assessing pain was that for some there was a learned automatic ‘yes’ or ‘no’ response to the question ‘do you have pain?’. As the following quotes form several different carers 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 particularly 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.”*

> *“It was the communication really is the tricky one. It was really difficult for him ‘cos you know if you sat him down and a cup of tea with him, or had a glass of water. It was as if all his pain disappeared, which wasn’t the case obviously. But you know he mightn’t complain again about it.”*

Five of the respondents spoke of the high pain threshold of the person with ID, sometimes learned over time from self-harm behaviours or painful physical conditions with different carers stating:

> *“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”*

> *“…or else he’d a very high pain threshold, but he seemed, you know, never seemed to be in any pain.” (man with colon cancer)*

Learned Acceptance

In understanding how people with ID coped with their pain, their illness and their dying, a fifth of respondents spoke of the acceptance that the people they cared for had of their situation. Quotes from two different carers highlighted that this acceptance was most obvious among those who had spent most of their lives in institutionalised care with few opportunities for personal choice.

> *"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 own home or in a residential unit within the same ID service campus. Transitions in the year or months preceding death were kept to a minimum. When they did occur, it highlighted the importance of familiar settings, familiar people and continuity of care. In the last three months of life, carers reported that 63.9% (n=23) of people with ID had a hospital stay. Thirteen carers rated their satisfaction with hospital care. Nine (69.2%) rated it as either excellent or good and the remaining 4 (30.8%) rated hospital care as poor or fair. When asked about the person being treated with dignity and respect by the hospital staff, eleven responded and only one (9.1%) said this happened never/ only sometimes, with the remaining 10 (90.1%) reporting that people were treated with respect and dignity always or most of the time. Where people were transferred to hospital and resources permitted they were usually accompanied by a familiar member of staff. Here 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 ID was moved 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 own home at end of life was believed to be a significant contributor to people experiencing a 'good death'. They were assured of a 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

Closely linked to transitions is how decisions were made about a person's end of life care. Wherever possible, end of life care decisions were made with the involvement of family. In most cases family were very involved participants 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 heretofore hadn't been involved. In the majority of cases it appears that there was a reciprocal recognition and appreciation of the relationship of the staff and of the family in the life of the person with ID resulting in an organic collaborative approach to decision making. A small number (n=5, 15.2%) of staff carers reported that they would have liked to have been more involved in the decisions made during the three months preceding death. The majority of respondents were happy that the right decisions about end of life were made - most importantly, 70.6% (n=24) reported that they were the decisions that the person with ID would have wanted as the following quotes from different carers illustrate:

"And giving Seán a choice oh my god was, but you had to, it was our job to give him a choice."

"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."

Another stated that this collaborative decision making was 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."

There were exceptions and as one carer noted the quality of end of life care can often 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 the consequences of decisions like this 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."*

Not addressed in staff carer comments was the impact on family members and on the person's peers.

Being prepared, thinking ahead, discussing end of life and developing an end of life care plan were not normal practices as 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 ID. Eight respondents (28.6%) reported that families had decided on a DNR status for their relative. It appears that families had not discussed this decision with the person with ID, even when in one case staff felt that the person had the capacity to understand the implications of their status. A further complication noted by one carer was

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

Finally, even when desired, several carers as the following quote illustrates that in the last few days or weeks of a person’s life when specialist palliative care became involved and there was a greater sense of the person being pain free. For example, when asked if they thought the person with ID was involved enough in their own care, one carer responded:

“Ahm, that is difficult! Because he wouldn’t have expressed, he wouldn’t have had the cognitive ability to”.

Conversations about Dying

Of the 37 individuals whose carers participated in the pilot and in the full interviews, 52.9% (n=18) had a moderate level of ID and 44.1% (n=15) had severe/profound ID - only one (2.9%) was described as having a mild level of ID. Level of intellectual disability was raised by many carers to explain their view that the person with ID had little understanding of their deteriorating health status and to explain a reluctance to initiate end of life conversations. This helped explain why the majority of people with ID were not involved in their end of life care planning, were not told they were dying or were spoken with about the prospect of death. Yet 40% were thought of as certainly or probably knowing that they were going to die (see Table 13).

Table 13 Did s(he) know (s)he was likely to die? (n=35)*

	N	**%**
Yes, certainly	3	8.6%
Yes, probably	11	31.4%
Probably not	4	11.4%
No, definitely	6	17.1%
Not sure	11	31.4%

*Not all participants responded to this question

Participants also expressed uncertainty as to whether there should be open conversations around death with people with ID.

“ … 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.”

Some of the barriers for family members and staff were feelings the person would not understand or be emotionally ready to cope with such information described by several carers as:

"… nobody sat down to say you are not getting better because I don't think he would have any understanding of that…"

"…families would be like, oh they don't need to know that. Or you know don't be saying that you know, it'll only upset them."

"so we didn't want to kind of, I suppose, as I say like, give him that sense of fear like, that this is what's ahead Edward, you know, because we felt if we had expressed that to him I think he would have lost the will…so we just kind of kept it as simple with Edward as possible."

From the interviews almost two thirds of the respondents felt that the person with ID had some understanding and experience of death but this did not translate into having conversations about end of life. The following is a carer quote with which many others agreed:

"It's hard to know with him. He knew what death was but did he think of his own death I don't think so…"

However, there were some examples where staff and family members had spoken with the person about their deteriorating health and that they were dying. The most important aspect of these conversations was the reassurance that they would be cared for in their familiar surroundings

"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

There was a connection between the GP/person with ID relationship and the quality of care. Elements of the relationship such as knowing the person, their medical history, their story and how to communicate with them contributed to quality 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 100% of 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 'we can ring our GP at any stage if we've concerns about someone'. Approximately three quarters of the respondents felt that they had access to good GP care. For the remaining quarter, as noted in the quotes below from different carers, poor GP care was equated with the lack of a relationship. When rating the care received form the GP in the last three months of life 85.3% reported excellent or good GP care, with the remaining 14.7% reporting fair/poor care. The majority (94.1%) of respondents felt that the person with ID was treated with respect and dignity either always or most of the time.

"…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 gentile 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 ID 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. As the quotes below indicate, 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 ID.

"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

Approximately 40% spoke of a rapid decline in health which took place in the last days of the person's life. What is noteworthy about this is that these deaths occurred in people who had chronic or terminal illnesses such as end stage cancers, renal failure, pneumonia and advanced dementia and were usually receiving palliative care. The pattern of deterioration described by one carer below was consistent with reports of other carers who reported rapid decline:

"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."

It is worthy of further investigation that perhaps what was happening for such carers was that they did not have an understanding of the dying process.

Beyond the Medical Model

The gaps that have appeared in the care of people with ID at the end of their lives raises questions about how they are portrayed and understood within the wider health care system. There is a contention that for people with ID that there is the danger of missing key symptoms for fear of returning to the era of medicalisation.

“I mean I know we’re moving away from a medical model and, you know, we don’t think in terms of being sick, they have an intellectual disability, they're normal, you know what I mean, everything else is the same but still at the same time that they do have things that do need, you know, that extra bit of support.”

Several of the respondents recognised that the stereotyping of people with ID still exists. This results in not being able to see the illness from the person and being blind to possible underlying symptoms. Carers took on the role of challenging these stereotypes.

“…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.”

“But I fought I got him into the Galway clinic and I’m. You know so it’s just, you have to get a good GP that’s tuned into people. I think elderly people with a disability they flow through them. So I think for him it wasn’t, it was just put down to being Patrick”.

The reverse of this integration of person and disability could be seen where there was a medical emergency and a sudden death. In these situations, health care professionals had to react quickly to the symptoms they were presented with and the fact that it was a person with ID was secondary. The paradox being that in these situations when the person with ID was treated from ‘a medical model’ it was considered appropriate.

Conclusion

This theme described how gaps in the care of the person with ID 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. The relationship with the GP was acknowledged as critical with examples of the benefits of a good relationship for quality of care and life for the person who was dying and frustration particularly when carers were working with on-call and locum GPs. Communication difficulties in general and with GPs impacted the person with intellectual disability who often had his/her own communication challenges but were as likely to arise from disjointed relationships between the intellectual disability services and general health services. In these situations the needs and wishes of the person with intellectual disability were lost and not understood. In some cases it may even have led to crisis decision making and late diagnoses of serious conditions.

Theme 2: Living the Life Desired in One's Last Days

Introduction

The relationship the person with ID had with someone who had been involved for a long time in their care proved to be critical to good end of life care. The interviews conveyed a gentle but deliberate shift in the orientation of care to maintaining normality and a sense of self, and someone close to the person being present throughout their journey was the hallmark of high quality palliative care.

Maintaining normality and sense of self

The commitment to delivering high quality, individualised care which honoured the true self of the person with ID was evident. Striving to keep people within their usual home, in their normal bedroom was important and the quantitative results showed that 57% of people with an ID died in their usual home. This contrasts with data from the general population in the TILDA study, where only 24.5% died in their home. Carers reported that six people with ID had expressed where they would like to die. Of these 6, the response was unanimous - in their usual home. The importance of the suitability, familiarity and security of being in one's own room at the end of life was undisputed:

"This was her home for twenty years and it was great to be able to keep her rather than sending her somewhere else that she wouldn't know and people wouldn't know her and she wouldn't know the area and..."

"But because that we had the room in the bedroom to have all the equipment that we needed. Kathleen was actually able to pass away here, which was really nice like…"

"It was just as if Bridget was at home with her family, and we, and we were the ones that were just going in and out doing her personal stuff and everything..."

"it meant a lot to Edward to be in his room like because it was his space, his safe and security there really…"

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

Maintaining a sense of normality was also achieved through a daily assessment of the ability to continue with one's normal routine e.g. 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 the last, only the last week actually that she was kind of staying in the bed every day, up until that we had her in her chair and when she was well enough she would be out in the garden when we had barbeques stuff like that, so she'd come out in her chair."

"Like she used to see everybody coming up and down, she used to go 'good morning'. They'd come over to her, you know she knew these people all her life. And it was very important for her to be there to see them. Like the household staff would be in and they were cleaning, she would help them to do little bits. And she wanted to see that going on. But she was still doing that and still asking questions about that… and there wasn't a level of fear, that's the way I found it was really good."

"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, until you know we kind of decided you know comfort and peace now is what she, is what she needs then at that stage, so."

"if he couldn't walk up to us he'd get in to a wheelchair and come up to us, you know, he needed to be with us all of the time because again he was king of the castle and 'no matter how sick I am today like I'm going to be in that kitchen with them'."

"…he liked to see people, and he loved flowers, so we would always have, flowers would have been a huge thing that people would have associated with him. So there would always have been flowers brought to him if he couldn't go out for them, and, you know…So as much as possible everything was kept in his normal kind of routine and setting."

Ironically, an interesting consequence of striving to provide normality for the person at end of life was the confusion it led to with some of the other residents who had fixed ideas about how a dying person behaves:

"…because towards the end we were very honest with them [other residents], I was like no, she's not getting better, but this is where she wants to be, she's comfortable, she's not in any pain…but then they would see her coming up for her breakfast or her lunch or something ...Yeah, and they thought we had it wrong, you know, because a dying person doesn't get up for breakfast, you know...Doesn't sit in her chair while her visitors come...And watch [television] in the evenings...The caricature of a dying person like wasn't there, like suddenly we were saying one thing and next thing Bridget would appear, you know, it was confusing for people ."

Relationships

Respondents spoke about having a deep sense of caring and attachment for the person with ID. Defining the relationship proved difficult with staff saying 'we're not friends' or 'we're not family' but it was a lot more than a staff-client relationship. It was an intimate, caring relationship that had developed over years. It was also a loving professional relationship. The most commonly used words to describe the relationship were: knowing, caring, comfortable, close, love, familiar, family, advocate and loss. An essential element of the relationship was how well they knew the person with ID – possibly best described as the level of attachment they had.

"..she was here surrounded by her peers, there was staff who cared for her, and she had a very close relationship, and I suppose the difference between a general hospital and a residential area is that the staff have a huge relationship with the service user – they know the person inside out, they know them the best, you know, and I think they were able to support her better here than anywhere else"

"And even though we are staff, we're not friends, at the same time we are the people that they know for so many years…You know, the people that they feel comfortable with, the people that they have had the outburst with and we're still there… whatever sort of a relationship it is but it's still someone they know and familiar with and be comfortable with and they know what you're going to do and how you're going to react and there's no surprises, do you know what I mean, and that's important in a relationship as well".

"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 like… Do you know, you do get bonds with them and it is, it's never easy."

There was a huge sense of loss when someone was dying. For some respondents the grieving process occurred before the person died as they began to witness changes in the abilities and the loss of the person they had known. Sometimes it was the simplest change that had the biggest impact e.g. a proud lady no longer caring about her physical appearance or someone no longer asking for their favourite drink or television programme.

"Like his Guinness he had. Oh he'd nearly cry if you wouldn't give him his Guinness….Yea and the Guinness stopped when he got sick you know… It would've been, yea that's why we found it so sad to look at him like that. It wasn't our Michael you know".

"So it was extremely hard to see her at that stage."

"Like I've dealt with bereavement at different stages over the years like you know.
Too many years at it…But you never get blasé about it. Each one has their own mark on you"

"He'd mind you, you mind him, you mind him…And that's a huge loss for them[other residents]... A huge loss for them, for us and all, yea it was, it is 'cos he was great."

As difficult as this time was for the carers, there was a sense that they were in a privileged position to provide this end of life care. It was the final gift they could give to the person they had known for so long.

"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, so..".

"Everyone was very sad about the situation. But in a kind of a weird way we were very glad that he came back here. And that we were able to see it out…We always felt that he shouldn't have been moved out. And that he did belong here. So we were glad I suppose that we were able to kind of provide the last bit of care for him".

High quality palliative care

Overall 94.3% of carers perceived that there was a good or excellent level of care provided in the last three months of the person's life with only one person rating it as fair or poor. The most important element to this was being present. Many carers identified having someone by the person's bedside all of the time in their last days or weeks was an essential part of care. Two factors appeared to play a role in providing this quality of care; firstly, having a cohesive and determined team and secondly, having the physical and staffing resources. Once the team came together and decided that 24 hour 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".

Teamwork and staff "going the extra mile" to ensure a good quality of death was evident.

"the staff had said we're out of our depth, so we need training, we need support, we need – but also the physical effort of trying to do it for one person alone, because it's a low support community group home, but it was impossible, so we literally had to throw as much as we could at it in order to make it happen because I think once we made the decision as a team… and in fairness to our funders as well, of course we met with them and said this is going to take, we were told do what ye have to do and come back and talk to us afterwards, and that was the attitude, it was, there was, whatever was needed, like night shifts, extra staff put in, anything that we had we put in"

"…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."

This was more than standard care, it was one-on-one comfort care where someone was sitting in the same room, present with the person; chatting, doing some paperwork, holding their hand but always offering that steady reassurance to the person at end of life that they were not alone.

"… the staff knew her so well, they'd just sit chatting to her. And if they were doing something, they'd go down, down beside her bed and they'd do their notes or whatever."

In meeting the increasing needs of one person it was a challenge to maintain the same level of care for everyone else within the service.

"We were feeling guilty and we were getting up to help her. So just, we were wrecked as well. 'Cos we were looking after the other five."

When family members were present it was a support for the staff. And several carers commented how family members found comfort in the level of care they witnessed.

However, when the person with ID had been transferred to hospital the opportunity to provide the same level of care was unpredictable. In some cases, the person had their own room and the ID service had the resources to allow a member of staff to be present 24 hours a day. In other cases, the person was on a ward and did not have constant family or ID staff members present. Staff endeavoured to visit the hospital but in some instances this was only possible during normal visiting hours and was not considered adequate to provide the level of personal care needed. Some staff reported they were upset when they saw people they cared for being left unshaven, unfed or unchanged because the level of their disability was not understood or hospital staff did not have the time to provide that level of personal care. There was a strong sense of protectionism and staff felt they needed to be there as an advocate for the person with ID, to help them to communicate their needs and wishes and to explain and reassure them of what was happening. Carers also reported hospital staff were often grateful for having the extra help.

"Yes because we were even able to put a nurse in with him in the hospital, when he was in there, you know. Because we'd be afraid he'd be anxious."

"Well I suppose not really in personal caring because the nurses in there would have done all of that but I suppose just to be for her to have a familiar voice because I mean in the big hospital life they wouldn't know her. We would be able to communicate on her behalf really because she wouldn't have she wouldn't be able to communicate for herself you know so we would voice her be her voice yes…"

"no he had no dignity and respect in the hospital at all…he was treated dreadfully, absolutely dreadful. In relation to dressing him, care of him…thank god that [we] were there. But anytime we would've left, no he didn't get any of the proper care."

"They were very good, yea they let us in there was no cutting us out. Even when they were administering anything, or turning, we could stay in the room. No problem no, no in fact they found it helpful."

One way of easing the transition to hospital was by ensuring there were some familiar items in the room, as this quote illustrates:

> *"It [life book] actually went to the hospital with him with two of his favourite photographs, you know. All these things would go with him, just so that you know when you wake up in hospital it's so strange. So I went in one night and his pictures were on the window and he'd his little book next to the bed, you know."*

One service had worked hard at developing links with the local hospital and explaining about communication issues which proved helpful for the next admission:

> *"[The hospital] would communicate with us and we had written on their forms, very clearly, you know how she communicated. And what requirements and additional support need she had. And who to contact here. So that worked really, really well. They were really good at that. We had that worked out. And we worked hard at that … And that was really helpful …because I suppose we had a relationship and it worked really well."*

When the person with ID was facilitated to stay in their usual home at the end of life, the care they received from familiar staff was often supported by specialist palliative care nurses and 35.1% reported accessing palliative care services. This was usually triggered when pain levels became unmanageable and consisted of visits and telephone support regarding pain management and comfort care. Given the similar underlying approaches of ID and specialist palliative care nursing, these were effective collaborations. However, this is a new area and often referrals were made in the last days when little time was available to build relationships. In numerous cases, it was the first time that there had been a death in the house and staff could feel 'out of their depth'. However the support from the palliative care team was instrumental in reassuring ID staff and of the nine carers who commented on satisfaction levels with palliative care services, seven (77.2%) found them excellent/very good. The remaining two who weren't satisfied commented that it was due to the difficulty in accessing palliative care services and not the care itself.

> *"the Palliative Care Service was fabulous, and even though we had a very unmanageable situation, 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 to how 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"*

The support from the GP also contributed to the holistic end of life care that the person with ID received. In fact, in two different services, GPs praised the ID staff for the palliative care that they were delivering without even realising it was 'palliative' care.

> *"He was complementary towards us like I mean he recognised that it was pretty difficult now … Because at one stage it was asked by somebody would the hospice team be coming in and he [GP] says why would the hospice team come in he says aren't ye able to do you know, so he had that much faith in us you know"*

> *"And even from the point of palliative care, like he [GP] always encourages us because, you know, there's good nurses here like, to encourage us that we're just as good for palliative care as bringing in a palliative care team, do you know what I mean."*

When asked in general about care in the last two days of life, twenty people responded, and regardless of the setting, 95% reported that people were treated with respect and dignity most/all of the time and just one reported that the person with ID was sometimes or never treated with respect and dignity. There was a high satisfaction level with help received in the last two days of life, with 90.6% agreeing there was enough help to meet personal care needs, 90.3% agreeing that they had enough help with nursing care and finally 80.6% agreeing that the bed and surrounding environment had adequate privacy. Table 14 shows the support received from carers in the last two days to relieve physical and psychological pain.

Table 14 Support from carers in last two days

	Good/excellent n	%	Fair/poor n	%
Relief of pain (n=25)*	22	88.0%	3	12.0%
Relief of symptoms other than pain (n=24)*	22	91.7%	2	8.3%
Spiritual support (n=23)*	21	91.3%	2	8.7%

*Not all participants responded to these questions

Being present at death

With the emphasis of care on being present during the final days and weeks, the majority (88.9%) of people with an ID had at least one person present at the time of death (see Table 15 below).

Table 15 People present at time of death: (n=27)*

	n	%
Staff only present	9	33.3%
Family only present	2	7.4%
Staff and family present	11	40.7%
Staff, family and other friends/residents present	1	3.7%
Staff and other residents/friends present	1	3.7%
No family, friends, or familiar staff present	3	11.1%

*Not all carers responded to this question

Respondents expressed a sense of privilege to be present at the moment of death, 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"

"and we were all in to hold his hand and talk to him. And he hadn't the pain was gone off his face and the fear was gone."

In the few emergency and sudden deaths when the person died alone there was a sense of regret and sadness.

"They said, you know like that she would've passed away very quickly. And she wouldn't have had any distress. But that would be my only, my only regret at the end. I would always; I would love to have, if some of us had been there."

Conclusion

Dying at home, surrounded by family or familiar staff has been reported to be the preferred model of care for people with intellectual disability both in this study and in previous research (McCarron et al., 2008; Todd, 2013). This allows the person to be supported by the people who know them best, as well as supporting them to experience and maintain a sense of normality during their last days. Findings from our study indicate that staff in intellectual disability services in Ireland are providing high quality end of life care, going the extra mile and pulling out all the stops to support a good death. However, they often feel out of their depth, and lack of staffing and availability of appropriate resources causes challenges. A need for end of life care training for staff with specific emphasis on the unique care for people with intellectual disability has emerged, as well as increased collaboration with specialist palliative care services. There is also a need to better understand and support care and participation by families when the person no longer lives in the family home. The growing ageing of people with intellectual disabilities in Ireland mean there are important service provision and policy implications.

Theme 3: Dealing with death and beyond

Introduction

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.

Funeral

As can be seen from Table 16 below, the majority of funerals were organised by the family alone (35.7%) or with staff (32.1%). 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.”

Table 16 Who organised funeral? (n=28)*

	n	%
Family	10	35.7%
Staff	7	25.0%
Family and staff	9	32.1%
Person who died had input into funeral arrangements prior to death (supported by staff)	2	7.1%

*Only carers who took part in the semi-structured interviews (n=28) were asked this question

There appeared to be a sequence of events which naturally fell into place for many where the person with ID would be waked or have the removal from their usual home and the funeral mass and burial would be within their family parish. Having the wake within the ID setting meant that other residents, friends and staff had the opportunity to pay their respects, to spend time with the family and it normalised the process of dying and death ‘like there was no kind of hiding it away’. Indeed, carers described touching rituals that had evolved e.g. staff laying out the body, candles being lit, prayers or mass being said, time being spent honouring the person’s memory and a guard of honour from other residents and staff as the person left for the last time. There was a sense of dignity and pride from the interviews in carrying out these final rituals.

“…it’s the last thing you do for someone and you know, you do it as best you can”

From there, staff always attended the funeral mass and 85.2% of the time other residents/friends also attended. It was reported that in three cases there were no family members present. Where family members included staff and residents in the funeral mass by carrying up gifts or saying prayers it was appreciated.

“So but they 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 they were no longer excluded from the final arrangements.

“We usually have a mass in the house, well that’s evolved because initially you see the funerals that were here 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.”

Deciding upon the final resting place was the decision of the family 77.8% of the time, staff on their own 11.1% of the time with just one joint decision and two people with ID indicating where they wished to be buried themselves. It is not surprising therefore that the majority of people were laid to rest in a family plot (81.5%), or their own plot (14.8%). In one case it wasn’t possible to locate family or the family plot and the person was buried locally.

“ …so he’s actually buried behind us here in the graveyard. Yeah, because we kept him close to us. I suppose really we didn’t sort of ask him either where would he like to be buried, but here was his home so we felt, he felt the love here.”

One consequence of the final resting place being the family plot is that it usually was not near the residence. This curtailed the visits to the grave for both staff and other residents, something that can be an important practice when someone dies.

Often the next stage in the processes after a death is carrying out the wishes in the will. Only three (10.7%) of the people with ID had made a will, 20 (71.4%) had not and in five cases it was unknown whether there was a will or not. Respondents felt that many of the people with ID wouldn’t have had the capacity to make a will – their financial situation wouldn’t have had any meaning to them so responsibility fell to the family as next of kin. One ID service however had a policy around discussing wills with the person with ID and their families:

"And the family did take her to the solicitor's and that was part of her, an action from her PCP . You know that she would make her will. And because of her age and just because her mobility and you know. We do approach that subject with all of our service users. Some don't want to hear, some families don't want to hear about it. But in her case they were happy to take it on board."

Rituals around death

Some services have written policies in place for when people die which give guidelines for staff about what to do when someone dies e.g. who needs to be contacted and in what order. What is not documented though are the rituals which have evolved naturally over time. Alongside having the person waked in their usual home are numerous other practices e.g. a table/altar with flowers, keeping photographs up of the deceased person, having a "farewell" mass before the person leaves for the church, having a mass a month later, anniversary or remembrance masses and placing flowers on the grave at Christmas. One respondent explained that they have worked hard at developing appropriate and respectful procedures around death as many of their residents would not have the experience of a death being acknowledged, rather it was something that was hidden.

"I suppose in a sense we celebrate a death. We announce it, we tell people very discretely 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 wouldn't and they'd hear staff talking it. Imagine finding out that somebody you lived with for forty years, you 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. "

Holding the space

After the person had died, 73% of staff reported that the person's place remained vacant for more than 3 months (see Table 17). When the place was taken up within three months, it was usually from within the residence. All of the carers recognised the importance of physically holding the space vacant while there was a psychological adjustment to life without the person and in most residences there was an unwritten rule of allowing a month or two to pass before anyone moved into the room.

Table 17 How soon after was the person's place taken in the residence? (n=26)*

	n	%
Less than 3 months	7	26.9%
3 months or more but less than 6 months	3	11.5%
6 months – 1 year	6	23.1%
Place not taken	10	38.5%

*Not all carers responded to this question

Details such as keeping the bed vacant, keeping photographs up on the wall and leaving the bedroom door open were all viewed by carers 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 breathe after the ordeal of a death and to learn to be a new different type of home

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

Impact of loss

Some of the carers spoke of a need for the whole house to take time to catch its breath when a death occurs. They described that suddenly the dynamics of the house were changed and it can appear quiet and different.

....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. And it was a 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”

However, normal routine is soon re-established and life goes on as going to a day service continues, meals are eaten at the usual times and television programmes continue. Most of the staff felt that many of the residents did not have the capacity to understand that a death had occurred. But some reported that there were a few after effects for residents; feeling nervous or worried that they could be next, associating the room with death and a reluctance to go into the room. This was particularly pronounced for residents when they had been sharing a room with the person who had died.

There was also an impact on staff who were grieving and often physically and emotionally exhausted. There were reports that nobody had time off and everyone carried on with their daily work which now included the practical tasks that need to be completed when someone dies.

“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. Because you know a part of it, we were all you know praised of the work that we did and achieved and the family was very complimentary of everything. But it was the just the emotional drainage that we had that we couldn’t overcome for a good two months after like.”

“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.”

Bereavement support

Not only are the staff grieving the loss of a close relationship but they are also supporting each other and the other residents. The most common form of bereavement support was informal peer support and 44.1% reported that they did not need to access a formal service for support. Some of the chaplains from the services provided an informal but organised bereavement support. Most of the staff were aware that their employer provided access to a counselling service or psychologist. Almost a quarter of the respondents (23.5%) spoke with someone from a formal service about their grief, with a further 5.9% expressing a wish they that would have liked to (Table 18). For those who would have liked extra support, they relied on the support of other staff members “we just I suppose muddled on through”.

Table 18 Contact with health and social services, the Intellectual Disability Service or from a bereavement service for bereavement support (n=34)*

	n	%
Yes	8	23.5%
No, but I would have liked to	2	5.9%
No, but I did not want to anyway	15	44.1%
Not sure	3	8.8%
No but it was not clear if they wanted to talk to someone or not	6	17.6%

*Not all carers responded to this question

Only three respondents 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 include family members and are open to everyone who had known the person, extending beyond the staff directly involved to include auxiliary 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 person's peers was less organized and consistently delivered and was most often in the form of informal staff-led support.

Relationship with family

Each family relationship was different. There were people with ID 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. One trend was that in the final days and weeks of the person's life, the level of contact and number of visits increased. As reported earlier, families were involved in over two thirds of the funeral arrangements (table 16). This level of involvement reflected a natural sense of reconnection at the time of death back to the person's family and early life. Staff carers showed great respect for families and their role as next of kin, even when staff were excluded by families in decision making and funeral arrangements. As two different carers stated:

"but obviously at the end of the day the family's wishes are what, what are taken in to account."

"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 and understand their life and how well cared for they were. Two different carers reported:

"they were happy you see basically the families 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".

"They discovered things the day that she was being waked in the unit they never knew – like one sister actually sat and all she did was cry, because she didn't really know her, even though she came in to see her, she was the one who came in to see her most, more often."

This increased level of contact with families continued e.g. while belongings were being organised and one month anniversary masses attended. However, post-death contact with families then seemed to end, particularly when the family didn't live locally. Staff carers felt there was a loss from 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. As one staff member noted:

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

One consequence from dealing with family through the death and dying of their relative was an awareness of the importance of greater links between the service and family at all times and not just when there was a deterioration in health. Staff carers also recognised that the onus is on the service to develop and maintain the relationships with family.

"I think we're much more conscious now of trying to get families involved more. Of making them come up, of 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."

"Families mightn't bother they might say, well sure I haven't heard, they must be alright. But we try and have it that there's family involvement that you're ringing. Nothing wrong, just ringing, just want to say 'hello' and you know if there's anything you needed to ask me. It's just a little phone call and it only takes maybe five minutes."

Lessons learned

Participants were not directly asked what they had learned from their experiences of caring for someone at end of 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 19 . For some participants, it has already led to a change in practice.

Table 19 Lessons learned by carers

Preparation, Communication and Follow Through

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

In summary, a list of characteristics of a good and bad death are presented in Table 20. From the carers’ accounts of end of life experiences, it became clear which factors led to a good death and those which led to a bad death. Very often, experiences of dying had characteristics of both e.g. when a person had been admitted to hospital in a crisis situation but was then able to return to their usual home and spend their final days with familiar carers.

Table 20 Reported characteristics 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	Lots of transitions e.g.hospital visits Move within three months of dying
Constant presence of family and/or staff	Left alone
Good G.P. support Good Palliative Care support	Doctors not following up on investigations
EOL care plan DNR plan	No DNR discussion
Resources: • Physical - e.g. hoists, comfort chair, family room • Staff – support from management, extra staff, spiritual support	Inadequate medical intervention Late diagnosis Pain not recognised
Familiar faces present Close relationships with staff Good family involvement	Crisis decisions made by health care professionals who don’t know person
Death Reviews	Lack of communication with person about their death
MDTs Team decisions	ID staff fighting for medical care ID staff not fighting enough for medical care
Post-death follow-up e.g. anniversary masses, contact with family, Christmas card	

Conclusion

This theme described the rituals that took place after the person with intellectual disability had died and the impact the death of the person had on everyone in the house. In most cases, family and staff worked together to organise the funeral and other residents in the house were included. It was clear that staff supported each other and other residents in the house during this period of mourning; however few accessed formal bereavement services. Staff also outlined the lessons learned from each death, and highlighted a need for training in end of life care.

6 Conclusions

More people with ID died at home than has been reported by TILDA for the general population and the majority of people with ID had a carer present at the time of death. However, the quantitative results also confirmed that inequalities still exist in morbidity and mortality rates. Consistent with other reports (McCarron et al., 2015; Lauer & McCallion, 2015) those with an ID were found to die at a younger age and have a high level of multi-morbidity. For those with Down Syndrome there was an even lower age at death and a higher prevalence of dementia. Nevertheless there was, overall, high satisfaction levels with G.P., hospital and palliative care despite some cases reported of poor quality of care and a lack of respect and dignity for the person with ID.

The qualitative analysis of the interviews identified examples of high quality end of life care including collaboration between ID services and palliative care providers, involvement of family, staff carers and the person with ID themselves and good cooperation with GPs and hospitals. However, it also identified gaps in the continuity of care with other healthcare services, in the knowledge and experience of death and dying among carers and in the communication and planning around end of life. Even with these gaps, in most cases practice and traditions were reported which preserved the dignity and memory of the person with ID.

Relationship centred care has always had particular relevance for intellectual disability care settings where relationships have developed over long periods of time (Nolan et al., 2006). The related research describes care that is more than person-centred care. It embraces years and decades of knowing and working with someone and the authenticity of those relationships as the cornerstone of quality care at the end of life (Ryan et al., 2014). Again, the findings here support the value of such relationship based care and its contribution to a good death.

Attention to detail by carers right up to the moment of death was remarkable. This continued after death with an importance given to having the person waked in their usual home and then of holding their room vacant for as long as possible. This sense of the residence/home needing time to find its new identity emulated the reorganisation or assimilation tasks of mourning reported more generally when time is needed ‘to adjust to a world without the deceased’ (Worden 2008) .

This research took place within an Irish setting where many of the rituals in relation to death and funerals still centre on religious practices. It came easy to the staff to use/return to these customs and where there had been several deaths it provided a guided pathway for residents to follow in the days around the death. Having repeated rituals and supported involvement of residents in funeral arrangements has been shown to reduce questions and challenging behaviours (Sheldon, 1998). Whereas non-involvement could lead to delayed grief or a prolonged grief reaction (Forrester-Jones & Broadhurst, 2007).

Having a detailed discussion about the death of someone close is not an easy task and although it had been a minimum of six months (and usually more) since the death of the person with ID, the interviews proved upsetting for some carers. There was a real sense of a personal loss and a bereavement. Given the close relationship and level of attachment with the person who had died this was both an appropriate response and not unusual for the carers of people with ID (Ryan et al., 2010). We were privileged to have the carers share what they remembered and thought about the death of the person with ID as they continued to process their own grief.

The theme “Not Joining up the Dots” addressed where there can be gaps in end of life care including poor pain management, bad decision making and a lack of communication about dying. We know that people with an intellectual disability have a high level of multi-morbidty (McCarron et al., 2013) but it is less known how this is manifested in disease trajectories at end of life. Carers were often shocked at the suddenness of death. Whether this was due to a lack of experience in recognising the signs of dying or is indicative of underlying complications is unknown. This sense of shock is a common first stage in theories of grief e.g. Kubler Ross (1969). It may be that carers were experiencing the same grief reaction of shock that loved ones in the general express, even when there has been a progressive deteriorating illness. The findings here encourages further research to better understand the timing and trajectory of death and the further understanding of the uniqueness of death when caring has been over many years.

One identified way of improving end of life care has been an earlier referral to Specialist Palliative Care (Temel et al., 2010) to facilitate timely diagnosis and treatment of symptoms, and support for carers’ distress (Cheng et al., 2005; Temel et al., 2010). Such a need for ID services to link in earlier with specialist palliative care has been previously identified (Fahey-McCarthy et al., 2009; McCarron, et al., 2010). The study here adds to our understanding of this need and in particular encourages earlier planning about end of life care as a means to advance both the participation of the dying individual in planning their later care, and the person-centeredness of the approach to care.

The philosophy underpinning ID care centres on empowering and enabling. This has a restorative rhetoric to it (Todd, 2013) which can seem at odds when caring for someone at end of life. There is a need to define what good care is for a dying person with ID. 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 ID care with an openness to death and dying. There has been a move in ID care to support ‘ageing in place’ (McCallion & McCarron, 2004), perhaps we now need to discuss ‘dying in place’.

The interviews highlighted that people with ID have medical needs and these may not be related to their intellectual disability but rather to the normal ageing process. However, general healthcare services continue at times to stereotype and attributing symptoms to intellectual disability may slow diagnosis of conditions and delay consideration of palliative approaches. Earlier research, e.g., Reiss, Levitan & Syzszko (1982) has highlighted this concern about diagnostic overshadowing, where clinicians attribute the symptoms of physical ill health to a person’s intellectual disability and therefore under-diagnose the presence of illness and today the need for response, education and changed practice is even more urgent. Several of the carers also challenged their ID service to change as they respond to the changing profile of people with ID – they are living longer, experience more independence, and are more accustomed to having choices about their lives – end of life care must also reflect these achievements.

Improving end of life care begins with conversations. Open communication and collaboration with the person with ID, their family, other residents, staff members and other health care professionals is the cornerstone to enhanced 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. The findings here confirmed previous concerns that the majority of people with ID are not being told when they are dying (Todd, 2004; Tuffrey-Wijne et al., 2006). Carers reported being uncertain about having open conversations around death with people with ID and unsure if the person had the ability of to understand death. These barriers to open communication have been noted in previous studies (Wiese et al., 2012b; Kirkendall et al., 2016). Despite these barriers, people with ID have a fundamental right to know about and be involved in decisions regarding their end of life care (Weise et al., 2012b). It is a particularly concerning challenge that despite this lack of conversations being highlighted for many years, the findings here suggest that not much progress has been made. Carers in this study demonstrated that they were willing, able, but sometimes felt unprepared to deliver some aspects of end of life care to people with ID, particularly as regards to pain management in the last days. These findings closely mirror results by Ryan and colleagues’ research (2011) and those of Fahey-McCarthy and colleagues (2009). An area for particular attention is if people with ID are not made aware of their terminal prognoses then necessarily they will have limited inclusion in end of life care planning (Shogren et al., 2006; Tuffrey-Wijne et al., 2007; Wagemans et al., 2010; Bekkema et al., 2014). For many of the people with an intellectual disability described here there was no formal discussion. Such discussions are a natural extension of the regular Person Centred Planning (PCP) process that occurs in other phases of the person's life. Here the discussions should address: (a) what and who is important to persons now, (b) how they want to live their life, and (c) what supports will be necessary in the light of dementia diagnosis (McCarron et al, in press).

Despite the strain and difficulties in proving end of life care for the first time or in complex cases, responses of carers demonstrated skill in adapting and meet the changing needs of people at end of life. The similarity in the underlying person-centred care of ID and palliative care (McCallion & McCarron, 2004) helped those carers extend existing practice. From the carer interviews, more education is needed on understanding about death and dying, pain management, how to have open conversations about death and develop end of life plans. Findings here also support that research is needed to understand the style and content of collaborative working between the two specialities (Todd, 2006; Ryan et al., 2010). Some work has already occurred, a partnership framework has been developed (McLaughlin et al. 2014) and curricula have been developed (Fahey-McCarthy et al., 2009). The education and training needs to include opportunities for shared learning between specialist palliative care and intellectual disability using exchange placements and joint roles (McLaughlin et al. (2014).

Limitations

The qualitative analysis was based on proxy, subjective, retrospective accounts of end of life experiences and although the deaths occurred in a nationally representative sample of people with ID there are challenges in claiming generalizability in such a small sample. However, using a mixed methods approach and data from IDS-TILDA, the validity for some of quantitative and qualitative results was cross checked. The detailed accounts of end of life experiences from the 28 interviews also provided diverse narratives yet with core similar themes. The 37 carers of individuals who died who completed any part of the End of Life Interview (pilot or interview) represented a subsample of the 57 individuals who died since Wave 1 of IDS-TILDA. Although similar in all demographic statistics, people in residential facilities were over-represented whilst there was an under-representation of people living with family/independently. All of the 28 interviewees were staff members. Work is needed to better include family members who support palliative care in family homes and to include visiting family members as additional informants when care is by staff carers.

Final Comments

This study has further profiled the experiences of people with intellectual disability at end of life and has confirmed again the higher morbidity rates and lower age at death in this population. It remains concerning that little planning for end of life care in general was found to be occurring and more specifically people with ID were still not included in discussions around death. The core principle of ID care of people being supported to make choices about their life must now extend to choices about their death.

The willingness of carers to provide an optimal level of end of life care was indisputable. This was in spite of their perceived concerns about being inadequately prepared. Their support was grounded in the relationship that had grown and developed over time. Such relationship based care also forms the basis for supportive palliative care for persons ID.

Recommendations

There was considerable richness in the qualitative data gleaned from the End of Life Interviews but there are still questions to be answered. Recommendations for the future include making a greater effort to include the views of family members, both as primary carers themselves when the person dies in the family home, but also as additional informants when the person’s home is one that they visit but where they are also part of the care team at end of life. Gathering the perspectives of other informants, such as palliative care and hospital staff as relevant and from peers will also help. However, the effort to plan earlier for end of life will hopefully also mean that future researchers will have the prior words and desires of the person who has died to compare actual care against desired care.

Research that helps identify conditions and related symptoms that are potentially terminal for people with ID will both advance efforts to prevent avoidable deaths and will also increase the likelihood that needed conversations about planning for end of life will begin earlier, palliative options will be introduced, and there will time for greater collaboration between ID services, families, palliative care services and the person with ID themselves. There also needs to be work on the development of protocols and pathways to support the sensitive implementation of such care planning and delivery. The VOICES-SF questionnaire proved useful although a need was identified to add questions on contacts with family, palliative care, and other residents and also to establish the timing and extent of end of life planning.

Most of all the confirmation here of the value of person-centred approaches and of the support people with ID receive when care is relationship based should encourage continued attention to achieving and respecting both.

References

Addington-Hall, J. & McCarthy, M. (1995). The Regional Study of Care for the Dying: methods and sample characteristics. Palliative Medicine, 9, 27–35.

Addington-Hall, J., Walker, L., Jones, C., Karlsen, S. & McCarthy, M. (1998). A randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in the year before death. Journal of Epidemiology Community Health, 52, 802–807.

Bailey, M., Doody, O., & Lyons, R. (2016). Surveying community nursing support for persons with an intellectual disability and palliative care needs. British Journal Of Learning Disabilities, 44(1), 24-34.

Bekkema N., de Veer A. J. E., Hertogh C. M. P. M., & Francke A. L. (2014). Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple case study. Journal of Intellectual Disability Research, 58, 368– 380.

Botsford, A. L. (2004). Status of end of life care in organizations providing services for older people with a developmental disability. American Journal Of Mental Retardation: AJMR, 109(5), 421-428.

Braddock, D. (1999). Aging and developmental disabilities. Demographic and policy issues affecting American families. Mental Retardation, 37, 2, 155-161.

Burke, E., McCallion, P & McCarron, M. (2014). Advancing Years, Different Challenges: Wave 2 IDS-TILDA. Findings on the ageing of people with an Intellectual Disability. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

Burt, J., Shipman, C., Richardson, A., Ream, E. & Addington-Hall, J. (2010). The experiences of older adults in the community dying from cancer and non-cancer causes: a national survey of bereaved relatives. Age Ageing, 39, 1, 86-91.

Cartlidge, D., & Read, S. (2010). Exploring the needs of hospice staff supporting people with an intellectual disability: A UK perspective. International journal of palliative nursing, 16(2), 93-98.

Charlson, M., Szatrowski, T.P., Peterson, J., & Gold, J. (1994). Validation of a combined comorbidity index. Journal of Clinical Epidemiology, 47(11), 1245-1251.

Cheng, W.W., Willey, J., Palmer, J.L., Zhang, T., & Bruera, E. (2005). Interval between Palliative Care referral and death among patients treated at a Comprehensive cancer centre. Journal of Palliative Medicine, 8, 1025–32.

Clayton, J. (2015). Removing dying and death 'double taboo' for people with intellectual disability. Media release, August 7th 2015 http://www.hammond.com.au/news/removing-dying-and-death-double-taboo-for-people-with-intellectual-disability.

Crawford, H. (2010). Learning disabilities and dying. Journal of Palliative Medicine, 13(4), 361.

Cross, H., Cameron, M., Marsh, S., & Tuffrey-Wijne, I. (2012). Practical approaches toward improving end-of-life care for people with intellectual disabilities: Effectiveness and sustainability. Journal Of Palliative Medicine, 15(3), 322-326.

Ellison, N.M. & Rosielle, D. (2008). Palliative care for adults with developmental disabilities. Journal of Palliative Medicine, 11, 1262–1263.

Fahey-McCarthy, E., McCarron, M., Connaire, K., & McCallion, P. (2009). Developing an education intervention for staff supporting persons with an intellectual disability and advanced dementia. Journal Of Policy And Practice In Intellectual Disabilities, 6(4), 267-275.

Forrester-Jones, R., & Broadhurst, S. (2007). Autism and Loss. London: Jessica Kingsley.

Hahn, J. E., & Cadogan, M. P. (2011). Development and Evaluation of a Staff Training Program on Palliative Care for Persons With Intellectual and Developmental Disabilities. Journal Of Policy & Practice In Intellectual Disabilities, 8(1), 42-52.

Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014). The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. Lancet, 383(9920), 889-895.

Hunt, K.J, Shlomo, N., Richardson, A., et al. (2011). VOICES redesign and testing to inform a national end of life care survey. Southampton: University of Southampton, 2011.

Innes, McCabe & Watchman, 2012 : Caring for older people with an intellectual disability: A systematic review. Maturitas, 72, 4, 286-95.

Keidel, G.C. (2002). Burnout and compassion fatigue among hospice caregivers. American Journal of Hospice and Palliative Care, 19(3), 200-205.

Kelly, C. & Kelly, F. (2011). Annual Report of the National Intellectual Disability Database Committee 2010. Dublin: Health Research Board.

Kelly, C. & O'Donoghue, A. (2014). Annual Report of the National Intellectual Disability Database Committee 2013. Dublin: Health Research Board.

Kelly, C., & Kelly, F. (2013). Annual Report of the National Intellectual Disability Database Committee 2012. Dublin: Health Research Board.

Kirkendall, A., Linton, K. & Farris, S. (2016). Intellectual Disabilities and Decision Making at End of Life: A Literature Review. Journal of Applied Research in Intellectual Disabilities, July.

Kübler-Ross, E. (1969). On Death and Dying. New York: Macmillan.

Lauer, E., & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. Journal Of Applied Research In Intellectual Disabilities, 28(5), 394-405.

LoBiondo-Wood, G., Brown, C.G., Knobf, M.T., Lyon, D., Mallory, G., Mitchell, S.A., . . . Fellman, B. (2014). Priorities for oncology nursing research. Oncology Nursing Forum, 41, 67–76.

McCallion, P. & McCarron, M. (2004). Ageing and intellectual disabilities: a review of recent literature. Current Opinion in Psychiatry 17, 349-352.

McCarron, M., Carroll, R., Kelly, C., & McCallion, P. (2015). Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012. Journal Of Applied Research In Intellectual Disabilities: JARID, 28(5), 406-413.

McCarron, M., Fahey-McCarthy, E., Connaire, K. & McCallion, P. (2008) Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Dementia and Palliative Care. Dublin: School of Nursing and Midwifery, Trinity College Dublin.

McCarron, M., McCallion, P., Fahey-McCarthy, E. and Connaire, K., (2010). Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia. Journal of Policy & Practice in Intellectual Disabilities, 7, 2, 143-152.

McCarron, M., McCallion, P., Reilly, E., & Mulryan, N. (2014). A prospective 14-year longitudinal follow-up of dementia in persons with Down syndrome. Journal Of Intellectual Disability Research: JIDR, 58(1), 61-70.

McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017). A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. Journal Of Intellectual Disability Research: JIDR, doi:10.1111/jir.12390

McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion P. (2013). Patterns of Multimorbidity in an Older Population of Persons with an Intellectual Disability: Results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA). Research in Developmental Disabilities, 34, 521–527.

McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S., & McCallion P. (2011). Growing older with an intellectual disability in Ireland in 2011: First results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing. Dublin: Trinity College Dublin.
McIlfatrick, S.J. & Murphy, T. (2013). Palliative care research on the island of Ireland over the last decade: a systematic review and thematic analysis of peer reviewed publications. BMC Palliative Care, 12, 33.

McLaughlin, D., Barr, O., McIlfatrick, S. McConkey, R. (2014). Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study. Palliative Medicine, 28, 1213-1221.

Morton-Nance, S. & Schafer, T. (2012). End of life care for people with a learning disability. Nursing Standard, 27(1), pp. 40-7.

Nolan, M., Davies, S. & Brown, J. (2006). Transitions in care homes: towards relationship-centred care using the 'Senses Framework'. Quality in Ageing – Policy, Practice and Research 7(3), 5-14.

Nolan, A., O'Regan, C., Dooley, C., Wallace, D., Hever, A., Cronin, H., Hudson, E., & Kenny, R.A. (2014). The Over 50s in a changing Ireland: Economic Circumstances, Health and Wellbeing (2014). Dublin: TILDA: The Irish Longitudinal Study on Ageing, Trinity College Dublin.

O'Farrell, J. (2016). Exploring end of life for older adults with intellectual disabilities in Ireland: care received through the social justice lens. Unpublished thesis. Dublin: Trinity College.

Office for National Statistics (2015). National Survey of Bereaved People (VOICES) 2014. England: Office for National Statistics.

Reiss S, Levitan G, Szyszko J. (1982). Emotional disturbance and mental retardation: diagnostic overshadowing. American Journal of Mental Deficiency, 86, 670–574.

Ryan, K., Guerin, S., & McEvoy, J. (2016). The nature and importance of quality of therapeutic relationships in the delivery of palliative care to people with intellectual disabilities. BMJ Supportive & Palliative Care, 6(4), 430-436.

Ryan, K., Guerin, S. & Dodd P. (2011). End-of-life care for people with intellectual disabilities: paid carer perspectives. Journal of Applied Research Intellectual Disability, 24, 199–207.

Ryan, K., McEvoy, J. & Guerin, S., (2010). An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities. Palliative Medicine, 24, 6, 566–572.

Saunders, C. (1993). Care of the Dying. Oxford: Oxford University Press.

Sepúlveda, C., Marlin, A., Yoshida, T. & Ullrich, A. (2002). WHO 2002 Palliative Care: The World Health Organization’s Global Perspective. Journal of Pain and Symptom Management 24, 2, 91-96.

Sheldon, F. (1998). ABC of palliative care. Bereavement. BMJ (Clinical Research Ed.), 316(7129), 456-458.

Shogren, K. A., Wehmeyer, M. L., Reese, R. M., & O’Hara D. (2006). Promoting self-determination in health and medical care: a critical component of addressing health disparities in people with intellectual disabilities. Journal of Policy and Practice in Intellectual Disabilities, 3, 105–113.

Temel, J.S., Greer, J.A., Muzikansky, A., Gallagher, E.R., Admane, S., Jackson, V.A., et al. (2010). Early palliative care for patients with metastatic non- smallcell lung cancer. New England Journal of Medicine, 363, 733–742.

Todd S. (2004). Death counts: The challenge of death and dying in learning disability services. Learning Disability Practice, 7, 10, 12–15.

Todd S. (2005). Surprised endings: The dying of people with learning disabilities in residential services. International Journal of Palliative Nursing, 11, 2, 80–82.

Todd, S. (2013). ‘Being there’: the Experiences of Staff in Dealing with Matters of Dying and Death in Services for People with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 26, 215–230.

Tuffrey-Wijne I., Whelton R., Curfs L., & Hollins S. (2008). Palliative care provision for people with intellectual disabilities: A questionnaire survey of specialist palliative care professionals. Palliative Medicine, 22, 3, 281–290.

Tuffrey-Wijne, I., Bernal J., Jones, A., & Hollins, S. (2006). People with intellectual disabilities and their need for cancer information. European Journal of Oncology Nursing, 10, 106–16.

Tuffrey-Wijne, I., Bernal, J., & Hollins, S. (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(3), 224-230.

Tuffrey-Wijne, I., Hogg, J. & Curfs, L. (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, 331–344.

Wagemans, A., Van Schrojenstein Lantman-de-Valk, H., TuffreyWijne I., Widdershoven, G., & Curfs, L. (2010). End-of-life decisions: an important theme in the care for people with intellectual disabilities. Journal of Intellectual Disability Research, 54, 516–524.

Wiese, M., Dew, A., Stancliffe, R. J., Howarth, G., & Balandin, S. (2013). 'If and when?': The beliefs and experiences of community living staff in supporting older people with intellectual disability to know about dying. Journal Of Intellectual Disability Research, 57(10), 980-992.

Wiese, M., Stancliffe, R.J., Balandin, S., Howarth, G., Dew, A. (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.

Worden, J.W. (2008). Grief Counselling and Grief therapy: A handbook for the mental health practitioner (4th ed.). New York: Springer.