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Title

Communicating about death and dying with adults with intellectual disabilities (ID) who are terminally ill or bereaved: a UK-wide survey of ID support staff

Authors

Irene Tuffrey-Wijne *(Kingston University & St George's, University of London)*
Janet Finlayson *(Glasgow Caledonian University)*
Jane Bernal *(University of South Wales)*
Laurence Taggart *(University of Ulster)*
Claire Lam *(Kingston University & St George's, University of London)*
Stuart Todd *(University of South Wales)*

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Key words

Intellectual disabilities, truth disclosure, breaking bad news, communication, death and dying, bereavement.

ABSTRACT

Background: Illness and death are part of life for everyone, including people with intellectual disabilities (ID). This study investigated the extent to which staff communicate about death with people with ID facing terminal illness or bereavement.

Method: Staff who support people with ID in the UK (n=690) completed an electronic survey. Detailed data were obtained from staff where a client had died in the past 12 months (n=111), was terminally ill (n=41), or had been bereaved (n=200). Analysis included descriptive and chi-squared statistics.

Results: 52.6% of people with ID who were terminally ill were told about their illness, and 18.1% were told they would die. Of those experiencing an anticipated bereavement, 32.4% of staff said no-one talked about this with them beforehand. A quarter of staff had received training on end-of-life or bereavement.

Conclusion: Death affects many people with ID. Staff require training and support in communicating death.

INTRODUCTION

The focus within intellectual disability (ID) services is on enabling people with ID to live high quality and meaningful lives. However, there is growing awareness of the fact that these services are dealing not only with living, but also with dying, death and bereavement. In this paper we examine the extent to which staff working within services that support people with ID engage in death-related conversations, the challenges they face, and their perceived training needs.

Death, dying and people with ID

There have been questions raised about the extent to which ID services are prepared to deal with issues around death and bereavement effectively, with a range of studies reporting a lack of staff confidence (Dunkley & Sales, 2014; Lord, Field, & Smith, 2017). A critical feature of readiness involves effective communication around death and dying. This includes the ability to support a person's involvement in end-of-life decision making, as well as a willingness to discuss the impact of a significant bereavement.

In western societies, there is a strong emphasis on the importance of frank and open discussions between doctors and patients about diagnosis, prognosis and treatment options, with enabling patient involvement in decision making increasingly featuring in policy frameworks (Department of Health, 2011; National Health Service, 2019; National Palliative and End of Life Care Partnership, 2015). Since the 1990s, clinical practice and broader social views in the UK have favoured open awareness (where both the patient and the family know that the person is dying); a significant change from the 1960s, when closed awareness (where the family knows the patient is dying, but the patient does not) was more common (Seale, Addington-Hall, & McCarthy, 1997). A 2009 review of the evidence around disclosure of prognosis, including 13 studies from the UK, Australia, Canada, the US and Korea, found that all patients wanted honesty from their professional team, and the vast majority wanted prognostic information (Innes & Payne, 2009). In a UK survey of bereaved carers (n=1422), 70% of carers reported that the deceased person was aware that they were likely to die. As many as 93% of people with cancer were reported to have known that they were likely to die, whilst 60% of people dying of other conditions had known this (K. J. Hunt, Shlomo, & Addington-Hall, 2014). However, an ID-sensitive version of the same survey was sent to staff who had supported people with ID who had died (n=157); 78% reported that the deceased person was 'not aware' or 'probably not aware' that they were likely to die, and 24% of staff were unsure whether the person had been aware of their approaching death (Hunt et al., 2019). Those who were reported to have capacity were more likely to have been aware that they were likely to die (45%, vs 18% of those who lacked capacity), but this is still a significantly lower proportion than in the survey of the general population. It seems, therefore, that if a terminally ill patient has ID, there is still a reluctance to inform the person of their impending death, in contrast to what is happening (and advocated as best practice) for the general population.

Whether, how much, and how to communicate with people with ID about their own mortality are increasingly important questions for ID services. People with ID constitute approximately 2% of the population, which is an estimated 1.3 million people in the UK (Emerson & Hatton, 2008). The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) found that around two thirds of 247 people with ID who had died, lived in a residential care setting (Heslop et al., 2013). The philosophy of giving people with ID a 'home for life' means that many will not just live, but also die within their residential and supported living settings. Many of these deaths will be sudden or unexpected deaths. The CIPOLD inquiry found that 43% of deaths of people with ID were unexpected, defined as 'a death which was not anticipated as a significant possibility 24 hours before the death' (p34). The level of sudden deaths reported in the study by Hunt et al (Hunt et al., 2019) was almost twice as high as in the wider population, and considerably fewer people with ID had been ill for more than a year before their death (20% vs 45%). Anticipated deaths are deaths following on from a period of irreversible terminal illness or decline, where death is the expected outcome (Bennett & Maynard, 2012). The lower level of anticipated deaths in ID services has implications for end of life conversations: if a death is not anticipated, it is not possible to create open awareness, to plan and implement end of life care, or to involve the person in end of life decisions.

One would expect that an anticipated death of a person with ID in a particular home or setting is a low frequency occurrence, which could further contribute to the unpreparedness of staff to talk about dying. However, the level of anticipated dying within ID services is likely to rise. This is an ageing population, and if this ageing population is supported successfully to live in the same place within ID settings (rather than move into generic nursing homes, for example), there will be growing numbers of people with ID within such settings who will die from terminal conditions associated with older age (Irene Tuffrey-Wijne, Hogg, & Curfs, 2007).

Bereavement and people with ID

For the purpose of this study, bereavement is defined as the death of a relative, friend or housemate. Bereavement is a universal experience. A Canadian study of 1,208 representative adults found that 96% had suffered a bereavement, and as many as 78% were actively grieving at the time of data collection (Wilson, Cohen, MacLeod, & Houttekier, 2014). We have found no studies that look into the prevalence of bereaved individuals within ID services, but it is likely that very many adults with ID (including younger adults) will experience several significant bereavements. In fact, parental bereavement may well have determined the move into an ID residential or supported living setting. Since the median age of death for people with ID in England is 59, which is significantly lower than the general population (Norah Fry Centre for Disability Studies, 2019), people with ID may well experience the deaths of peers or friends at a younger age than people from the general population. Those who attend day services for people with ID or live in shared accommodation with other people with ID are likely to experience the death of a friend or housemate at some point. Staff working in such services may therefore have to provide support to several bereaved people with ID at the same time.

Supporting people with ID through death and bereavement

The extent to which people with ID are helped to understand that they themselves are facing death is likely to affect their ability to prepare for their own dying or be involved in decisions around their own end-of-life care (Voss et al., 2017). The opportunity for involvement in discussion and personalised care planning is a key aspect of UK national policy guidance, which states that "these discussions should be between the person nearing the end of life, those important to them (as they wish) and their professional carers" (National Palliative and End of Life Care Partnership, 2015) (p.14). There is limited research evidence about the implications of the practice of not informing people with ID that they are going to die. One study found that people with ID coped better with death and dying if they are helped to understand what is happening (Tuffrey-Wijne et al., 2011; Tuffrey-Wijne, 2013a). In contrast, the possibility must also be considered that open discussion of a terminal prognosis may cause harm (Tuffrey-Wijne et al., 2013) and that greater understanding of death may increase people's fear of it (Stancliffe et al., 2016).

Death-related communication is also of relevance for people with ID who experience the death of others. Disclosure of expected death leads to being able to 'anticipate' the death, i.e. 'to feel or know beforehand'. It is recognised that a time of anticipatory grieving can be important in enabling people to absorb the reality of the coming death and to give time to prepare, to say goodbye, and to plan for the future. Lack of preparation for the death of a loved one is a risk factor for complicated grief processes, both within the general population (Lobb et al., 2010) and for people with ID (Blackman, 2003).

Supporting someone at the end of life and through bereavement is challenging, requiring skills and confidence around end-of-life care and death-related communication. There is a growing body of qualitative literature to demonstrate that paid carers, professionals and families struggle with talking about dying with people with ID. Many tend to adopt non-disclosure of expected death to people with ID diagnosed with a life-limiting (terminal) illness (Jane Bernal & Tuffrey-Wijne, 2008; Todd, 2004; Tuffey-Wijne & Rose, 2017; Tuffrey-Wijne, 2013a). Several studies have shown that support staff want to continue to care for people with ID near the end of life, but lack confidence and skills (Ryan et al., 2011; Todd, 2013; Wiese et al., 2013). Even when people with ID are informed about their illness, the issues are highly complex when they have cognitive impairments and communication difficulties. For example, they may be informed that they have a life-limiting illness in a way that does not aid their understanding or does not encourage further discussion (Tuffrey-Wijne, 2010). In the above-cited survey of deaths within ID services, where staff reported that the majority of decedents with ID were not aware that they were dying (Hunt, Bernal, et al., 2019), almost all staff agreed that non-disclosure was appropriate, but the reasons for non-disclosure were not described (Bernal et al., 2016).

In terms of disclosing the death of a loved one (such as a parent), it was not unusual in the late 20th century for such news to be withheld from people with ID (Oswin, 1991), or for them to be excluded from death-related rituals such as funerals (Hollins & Esterhuyzen, 1997). Though this exclusion is likely to be less common nowadays, there is a body of qualitative literature to demonstrate that when people with ID have a close friend or family member with a life-limiting illness, they are often not informed that the person is dying (Forbat & McCann, 2010; Tuffrey-Wijne et al., 2012). An Australian study found that staff who support people with ID may be less prepared to talk about pre-mortem concerns (such as dying) than post-mortem ones (such as funerals) (Wiese et al., 2013).

In summary, whilst the need for truth disclosure and open awareness about anticipated death is undisputed for the general population, this situation is much less clear for people with ID. There is evidence of a tendency to protect people with ID from the knowledge that they are going to die, as well as a relatively high incidence of situations where neither the person nor the staff who support them are aware of impending death. Little is known about the frequency with which staff working in ID services are confronted with issues around death and bereavement, the challenges they face with regards to death-related communication, the extent to which they talk about dying, or the reasons for (not) talking about dying with the people they support.

Consistent international findings with regards to the mortality and end-of-life support needs of people with ID (I. Tuffrey-Wijne et al., 2015) (Voss et al., 2017) indicate that this topic has international relevance. Researchers outside the UK have also noted the importance of focusing on death-related communication with people with ID, with studies conducted in Australia (Stancliffe et al., 2016; Wiese, Stancliffe, Dew, Balandin, & Howarth, 2014), the Netherlands (Bekkema, de Veer, Hertogh, & Francke, 2014; Wagemans et al., 2013), Switzerland (Wicki & Hättich, 2017) and Ireland (K Ryan, Guerin, Dodd, & McEvoy, 2011), for example. Our study therefore adds to a small but growing international body of knowledge.

Aims

The aim of this study was to explore whether, and how, supported living and residential care staff in ID services within the UK communicate about death with people with ID who face terminal illness or bereavement.

The research questions were:

- What proportions of supported living and residential care staff have worked with a person with ID who is dying, has died, or has been bereaved in the previous 12 months?
- For staff who, during the past 12 months, supported a person with ID who had died an expected death or who was diagnosed with an irreversible terminal condition: To what extent did staff communicate with this person about their diagnosis and prognosis?
- For staff who, during the past 12 months, supported a person with ID experienced the death of a close friend or relative: To what extent did staff communicate with this person about the death?
- For all staff: What are their support and training needs with regards to death-related communication?

METHODS

Sample

An anonymous electronic questionnaire was developed, to be completed by one staff member per team or home that was part of an independent provider of residential care or supported living services for adults with ID in the UK (England, Scotland, Wales and Northern Ireland). There were three stages to the sampling procedure.

1. A sample of 59 third sector supported living and residential service providers was identified through personal networks, internet searching, and snowball sampling (where participating services suggested other services to be invited as participants), and a top level manager contacted by email or telephone. Of these, 25 providers (42%) agreed for their organisation to take part. They completed a short questionnaire to collect basic descriptive data about their organisation and the contact details of middle managers.
2. Middle managers (n=728) were contacted by email or telephone. They were asked to select at random one care worker per team or residential facility or supported living scheme, and forward the participant information sheets plus the link to the electronic

questionnaire. In order to monitor response rates, they were asked to inform the research team how many staff they had sent the survey link to; 214 middle managers (29%) responded to this request. Between them, they reported that 1130 frontline staff were sent the questionnaire.

3. A total of 723 questionnaires were returned anonymously; after excluding participants who abandoned the questionnaire after the opening questions, 690 valid questionnaires were analysed (61% response rate).

Data collection tool

The electronic questionnaire survey was developed using SurveyMonkey software (SurveyMonkey, 2016). Some questions were based on existing surveys, including VOICES (K. Hunt, Richardson, Darlington, & Addington-Hall, 2019) and the Last Days of Life Survey (Northway et al., 2018), but most questions were developed specifically for this study, partly based on the results of a preliminary staff interview study on the same topic (Tuffrey-Wijne & Rose, 2017). All respondents were asked to provide basic demographic data about themselves and descriptive data about the number of adults with ID they supported. They were asked how many adults with ID had died, had a diagnosed terminal illness, and were bereaved during the past 12 months. Depending on their answers, they were then automatically routed to one of four relevant sections of the survey, answering detailed questions about [a] one person with ID who had died (where the death had been expected by the respondent); [b] was currently terminally ill; or [c] had been bereaved (see definitions in Table 1). If none of these were relevant, the respondent was routed to [d] the final section with general questions only, to be answered by all respondents. Staff who had supported someone with ID who had died a sudden or unexpected death, were not asked further questions about this person, as many of the questions were around the extent to which the possibility of impending death was discussed with people before they died. See details in Table 1.

The survey included mostly closed questions (multiple choice). The final section contained a series of statements (using 5-point Likert scales) and closed questions, to measure the support and training needs of support/care workers. At the point of data analysis and reporting, respondents in groups [a] (expected death) and [b] (terminally ill) were grouped together, as these questions differed only in grammar and not in content, in order to be sensitive to the individual circumstances, e.g. [a] “How old was s/he when s/he died?” versus [b] “How old is s/he?”

The survey was developed with the input of a research advisory group, which included people with ID, family carers and service providers. It was laid out as attractively as possible and featured photographs and encouraging statements from research advisors with ID. It was trialled with 39 stakeholders and adapted in light of their feedback.

Respondents in groups [a] (expected death), [b] (terminally ill) and [c] (bereaved) took on average around 30 minutes to complete the survey; those in group [d] (none of the above) took around 5 minutes. The full survey is available from the authors upon request.

The data were collected between 1 July and 31 December 2017.

Respondent profile

Respondents came from all parts of the UK, including 535 (78.1%) from England, 53 (7.7%) from Wales, 66 (9.6%) from Scotland and 31 (4.5%) from Northern Ireland. Every UK region was represented and broadly resembled the general population distribution. Of the staff who gave further details about themselves, 132 staff (19.4%) were male and 496 staff (72.9%) were female (missing or preferred not to say = 52, 7.6%); 310 staff (45.0%) were younger than age 45 and 327 staff (47.4%) were over age 45 (missing or preferred not to say = 53, 7.7%). The majority of respondents had worked with people with ID for a considerable length of time, with 152 staff (22.0%) reporting 5-10 years' experience and 294 staff (42.6%) reporting over 10 years' experience. Between them, the respondents reportedly supported 6,039 people with ID (mean: 8.8 people with ID per respondent).

Data analysis

Data was inputted automatically using Survey Monkey software, and then exported into an IBM SPSS version 25 data set for analysis. Frequency and descriptive statistics were mainly used to report findings. Pearson's Chi-squared tests were used to test for associations between key responses relevant to the research questions. The findings and their implications were discussed with the research advisory group.

Ethics

Ethical approval was obtained from the Faculty Research Ethics Committee at Kingston & St George's University of London and from the Office for Research Ethics Committees Northern Ireland (REC reference 17/NI/0198). No identifiable information about the respondents or the adults with ID they supported was collected, and the statutory requirements for conducting research about adults with ID in each of the UK countries was strictly adhered to at all times.

RESULTS

Numbers of staff supporting people with ID who experienced death, terminal illness or bereavement

Table 2 gives a summary of the numbers of staff who reported that people with ID within their care had died, were terminally ill, or have been bereaved within the previous 12 months. About a quarter of respondents (162, 22.4%) reported that at least one of the people they supported had died during the previous 12 months; a total of 197 reported deaths. Two thirds (111 out of 162, 68.5%) of staff who had supported one or more people who had died reported that at least one of the deaths had been expected. Fifty-nine staff (8.1%) reported they were currently supporting a terminally ill person. Three-hundred-and-three staff (41.9%) reported that at least one person they supported had been bereaved during the previous 12 months, totalling 685 bereaved people between them.

As a result of the electronic questionnaire's internal logic, 111 staff were given questions about a person with ID who had died an expected death and 41 staff were given questions about a person who was terminally ill (totalling 152 responses, henceforth grouped together and summarised as 'dying'); and 200 staff were given questions about a person with ID who had been bereaved.

Communicating with people with ID who were dying

Table 3 gives an overview of the characteristics of people with ID who were dying (n=152), as reported by the respondents. Asked about the nature of the terminal illness, the most commonly reported answer for this group was 'other', followed by 'cancer' (52, 34.2% and 40, 26.3% respectively).

Staff were not asked whether the person's ID were mild, moderate, severe or profound, as without detailed explanations of each of these terms, they might be interpreted differently by respondents. As the relevance of the person's level of disability, in relation to this study, was around their expressive and receptive language skills, their ability to communicate and to make decisions, and their ability to understand the concept of death, we developed a set of questions that allowed us to calculate a *Communication and understanding* score, as well as an *Understanding death* score for each person (see details with Table 3). Around a quarter of staff (23.7%) reported that the person who was dying had the lowest level of communication and understanding. A quarter of staff (25.0%) reported that the person with ID understood the concept of death fully, with a similar proportion of staff (22.4%) reporting that the person with ID had no understanding of death at all.

Table 4 provides of the extent to which people with ID (n=152) were told about their illness and prognosis, and whether they were perceived to realise that they were likely to die. The person with ID's *Communication and understanding* score (Table 3) was not found to be significantly associated with whether or not they were told about their illness (χ^2=6.36, df=3, p=0.095); in other words, those less able to understand were as likely to be told about their illness or what was wrong with them as those with good understanding. However, they were less likely to be told about the implications of their illness: the *Communication and understanding* score was found to be significantly associated with whether they were told they were not going to get better (χ^2=13.83, df=3, p=0.03), and whether the staff member thought the person with ID realised they were probably going to die (χ^2=27.66, df=3, p<0.001). The person with ID's *Understanding death* score (see Table 3) was found to be significantly associated with whether or not they were told about their illness (χ^2=21.84, df=4, p<0.001), that they were not going to get better (χ^2=16.02, df=4, p=0.003), and whether they realised they were probably going to die (χ^2=37.44, df=4, p<0.001). Further analysis suggests that those dying with cancer were more likely to be told than not told that they were going to die or would not get better (n=23, 76.7%) than those dying from other illnesses (n=26, 43.3%) (χ^2 = 8.96, df=1, p<0.01). Those reported to have died from dementia were no more likely to be told (n=6, 42.8%) than those dying from conditions other than cancer (n=20, 43.5%) (χ^2 =0.01, p=0.99). In addition, those who had an illness of more than six months' duration were more likely to be told that they were going to die or would not get better (n=38, 63.3%) (χ^2 =4.09, p<0.05) than those whose illness had been shorter. Those people with ID who were told that they were not going to get better or to die, were more likely to be reported to be have been aware that they were dying (n=27, 71.0%) than those were not told (n=20, 40.0%).

Over half of the respondents thought that doctors (55.2%) and families (51.7%) were the key people in deciding what to tell the person about their illness and prognosis. The main reasons for talking about the possibility of dying were the person's right to know (41.3%), and so that the person could be involved in making treatment and care decisions (30.3%). Few staff (10.1%) said that the person asked. The reasons for *not* talking about the possibility of dying were more diverse, with the person's inability to understand the concept of dying mentioned most frequently (22.7%). Asked whether they thought that the person was given the right amount of information, at the right time, about half of all respondents (55.8%) thought it had been right, whilst around a third (34.1%) were not sure about this.

Communicating with people with ID who were bereaved

Table 3 also includes an overview of the staff-reported characteristics of people with ID who were bereaved. Of 200 staff who described an adult with ID who experienced bereavement within the previous 12 months, 151 staff (75.5%) reported that the deaths resulting in bereavement had been expected, and 49 staff (24.5%) reported that the death had not been expected.

Of the 151 staff reporting that the person with ID had experienced an anticipated death of a relative or loved one during the 12-month period, 49 staff (32.4%) reported no one talked about this with them. Whether or not someone did talk about this with them was not found to be significantly associated with either the person's level of *Communication and understanding* score category (χ^2=5.20, df=3, p=0.157), or their level of *Understanding death* category (χ^2=2.17, df=3, p=0.705).

Where staff said that the person had not been told, the reasons they gave were diverse. The most frequently stated reason was that staff themselves had not realised that the person would die (29.9%) and that staff weren't completely sure about the prognosis, so couldn't give clear information (17.3%); 13.4% of staff said that it was because the person wouldn't be able to understand the concept of dying. Similarly, when staff reported that the person *had* been told they gave a range of reasons, including the person's right to know (25.0%); so that the person could say goodbye (23.5%) and/or spend quality time with their relative/friend (22.1%); because the person asked (21.3%); copes better if they understand what is happening (21.3%); or the family wanted them to be told (21.3%).

Staff training and confidence

With regards to the levels of staff training and confidence, 190 (27.5%) of all staff (n=690) reported that they had received some guidance or training on working with people with ID who are terminally ill or bereaved. Training levels were significantly higher (χ^2=22.04, df=2, p<0.01) for those who had supported a terminally ill person in the past year (60 out of 129 staff, 39.5%). Those who had recently worked with someone who had been bereaved, however, were less likely than other staff to have received training; just 22.0% (44 out of 200 staff); but this was not significant (χ^2=2.97, df=2, p=0.227).

Despite the relatively low levels of training, just over half of staff (367, 53.2%) reported feeling confident about working with people who were terminally ill, and two thirds of staff (437, 63.4%) reported being confident about working with people who experienced bereavement. There was no statistically significant difference in levels of confidence about working with someone with terminal illness or bereavement between staff who had or had not supported a person with terminal illness (χ^2=8.92, df=4, p=0.063), or someone who had been bereaved (χ^2=3.99, df=4, p=0.407), than other staff. The staff who had supported a person who had been bereaved in the past year were not found to be statistically more confident about working with someone with terminal illness either (χ^2=13.81, df=4, p=0.08), compared to other staff, but they were found to be statistically more confident about working with someone who has been bereaved (χ^2=13.29, df=4, p=0.01).

Few staff were in favour of non-disclosure to people with ID (n=9, 1.4%); around a quarter of staff (n=156, 24.5%) thought that people with ID who are terminally ill should definitely be told that they are likely to die. Significantly more staff thought that people in the general population should definitely be told this (n=275, 43.2%) (χ^2 =45.64, p<0.01).

Staff who had been confronted with death, dying or bereavement in the past year were asked what support would be useful. Table 5 gives an overview of their responses.

DISCUSSION

Significant numbers of staff reported that they had worked with someone who had died or had been bereaved over a 12-month period. The topics of death, dying and bereavement are therefore important for ID services and their staff.

Communicating with people with ID who were dying

This study confirms that people with ID who are terminally ill are most likely to be in a situation where they know that they are ill, but are protected from knowing that they are likely to die. In describing the profiles of people with ID who had died or who had a life-limiting condition, staff showed that they faced significant communication challenges. Only one in five of terminally ill people with ID were reported to have good communication skills and understanding, and only one quarter were reported to have good understanding of death. The person with ID's reported communication level was significantly associated with whether or not they were told that they were not going to get any better and their illness was terminal. However, the person's ability to communicate or understand did not affect whether or not they were told what was wrong with them; over half of the terminally ill people with ID were told they had an illness, but it seems that the implications of the illness were not made clear to most of them. This suggests that staff are willing and able to talk about ill health, even if the person might have difficulty understanding it fully, but stop short of talking about death and dying. People with ID were more likely to be told about their prognosis and impending death if they had a cancer diagnosis, which is in line with findings for the general population (K. J. Hunt et al., 2014). This may be due not only to the fact that cancer has a relatively predictable illness trajectory, but also to the professional resources, expertise and support generally available to cancer patients. People with ID who had been ill for longer were also more likely to be told their prognosis, which suggests that time may be a critical factor in deciding whether to help a person with ID understand that they are going to die.

Decisions about whether and how to talk about ill-health and dying may be particularly complex if the person has some, but not full, understanding and communication skills (Irene Tuffrey-Wijne, 2013b). It is important that the people involved in the person's life communicate with each other and, ideally, take the same approach towards truth disclosure and ways to support the person. It is worth noting that staff said that, in the main, it was families and doctors who had a key role in deciding what a person with ID should or should not be told. Previous studies suggest that doctors, in contrast, think that it is care staff who have the key role. An ethnographic study of 13 people with ID who had advanced cancer found that “medical staff did not help families and social care staff in breaking bad news… Most medical staff thought that the person’s closest carer knew best, and left it at that” (I Tuffrey-Wijne, 2010) (p.82). This points towards potentially complex situations where staff need to liaise with a multidisciplinary team, with a need to clarify and understand everyone’s role. Staff also need to work together with families, which requires sensitivity and skill. The staff in this survey recognised the importance of the family’s role in the person’s life. These are likely to be difficult times for families. How families can best be supported and included within residential care and supported living settings needs further investigation.

Communicating with people with ID who were bereaved

For most people with ID who had been bereaved (75.5%) staff reported that the death of the relative or close friend was expected; this means that there was opportunity for people to be informed that their relative or close friend was ill and going die from their illness. However, for almost one-third of these adults, staff reported that no one talked about this with them. Three quarters of bereaved people with ID were reported to have good understanding and communication skills, and over half were reported to have full or reasonable understanding of death, but this made them no more likely to have staff talking to them about the possibility of dying. This suggests that other factors, regardless of ability levels, may influence this. The survey does not provide clear answers about what these factors are.

It seems important, however, that staff *do* talk death with people with ID who are terminally ill or face bereavement. There are indications within the study findings that staff need to be proactive in deciding whether, and how much, to talk about dying with people with ID, and need to take the initiative in doing so. Few people with ID were reported to ask about death. Previous studies have also shown that people with ID may want to talk about their loss, but do not always initiate those conversations. One focus group study, involving 21 people with ID who had lost a friend or relative to cancer, found that they themselves suggested “someone to talk to about my feelings and worries” as the most helpful support strategy. The authors noted that “many participants had not had an opportunity before to talk about their bereavement; their sense of loss was raw, even many years later” (Irene Tuffrey-Wijne et al., 2012) (p.516).

This is clearly a difficult area for staff, and one they need support with. We found high levels of uncertainty about the right amount of information to give to people with ID about their illness and prognosis, so it is somewhat surprising that staff also reported relatively high levels of confidence in dealing with death, dying and bereavement. This may be explained by the fact that the profile of staff who took part in this study, with regards to their age and experience of working in ID services, seemed to constitute an experienced part of the workforce, so they may have had significant life and work experience, including experience of death. It is possible that experience is an important factor that can help staff feel more confident about death-related issues. It may be important, therefore, for service managers to consider not only the training but also the life experience and work experience of teams that are confronted with death and loss. All teams are likely to benefit from the support of experienced colleagues, managers and/or outside professionals, but this is particularly crucial for inexperienced staff.

Limitations and strengths

This is the first UK-wide study to survey the experiences of staff who support people with ID in relation to communicating about death and dying. A major strength of this study is the high response rate from support workers working in services that provide support for people with ID across the whole of the UK. It reflects the illness- and communication-related issues that staff are dealing with, and highlights the areas where they need support. Whilst we cannot say whether the findings are generalisable to people with ID living with families or in non-ID settings, they are probably generalisable to staff working in similar ID services across the UK.

However, some of the findings need to be interpreted with caution. Representativeness was affected by the fact that service providers were selected via personal networks and snowballing. Organisations with a positive culture or top-level managers with a positive attitude towards death-related communication were probably more likely to take part. Despite clear and repeated explanations from the research team that middle managers, who had a gatekeeper role of selecting and passing on the survey link to individual staff, should select participants at random and include service settings where no deaths or bereavements had been experienced in the past year, the middle managers were probably more likely to invite staff who had these experiences. Staff were then probably more likely to participate if they did, indeed, have recent experience of death or bereavement at work.

There is also the issue of ‘double counting’. Our guidance to middle managers was that only one staff member per team or residential setting should complete the questionnaire. However, we found clear indications that in at least one case, more than one questionnaire was returned by different staff members from the same team, concerning the same death. The survey was anonymous, which was a requirement from the university ethics committee that approved the study; this means that we could not screen out instances of double counting. Whilst this does not affect the generalisability of findings related to the experiences and opinions of staff who support people with ID, it does mean that the findings in relation to the profile of people with ID are not generalisable. This study does not give a representative mortality and bereavement profile of people with ID, and the findings should not be interpreted as such.

Conclusion

Globally, death and loss affects many people with ID, requiring both a pre- and a post-mortem response. Supporting the workforce in this aspect of their work is a matter of importance for ID service providers. All providers of ID accommodation should consider carefully how they can best ensure that their staff are able to provide adequate support for people with ID who face death and bereavement. This includes a consideration of what training to provide, and who should receive this training. It is important for all staff who work with people with ID to think about death and dying, how this affects the people they support, how to talk about death and dying, and how best to support people with ID through bereavement. Given the important place of families in people's lives, and the need to work together, it might be worth considering inviting families to training events or discussions around death.

Whilst it is important that all staff know how to communicate about dying with people with ID, service managers may decide that it is not necessary to train all their staff in providing actual, practical end-of-life care, as such situations may not arise for a number of years within a particular ID settings or home. Managers do, however, need to ensure all staff can access adequate support if a person with ID has end-of-life care needs. This could include ad-hoc training, engaging the support of outside agencies (such as palliative care services), and ensuring that there are relevant policies that help staff to know what to do and who they can turn to for information and support. Managers have a particular role to play in building and maintaining good working relationships with families, doctors and outside agencies.

Future research should focus on the development and testing of support strategies for people with ID who face their own death or the death of someone close to them. These could include the development of resources that enable people with ID to talk about dying and to be involved meaningfully in end-of-life decision making. Special thought should be given to developing resources for those supporting people with ID who are dying of conditions other than cancer, including dementia and frailty. Other essential future work includes the development and testing of staff training initiatives; investigations into the perspectives and needs of family carers; and investigations of ways to enhance collaboration between services, families and people with ID.

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Table 1: Routes through the survey: expected death, terminal illness and bereavement

Respondents were asked to select one person with ID as the focus for the survey questions, as follows:
[a] Expected death: If a person had died in the past 12 months, the respondent was asked: "Was this person ill or unwell before s/he died, so that *you knew* beforehand that s/he was probably going to die?" If yes, the respondent completed questions about that person. If more than one person had died an expected death in the past 12 months, the respondent was asked to choose the person who had been ill the longest before s/he died.
[b] Terminally illness: If nobody had died an expected death (either nobody had died during the past 12 months, or any deaths had been sudden/unexpected) but someone was currently terminally ill, the respondent completed questions about the terminally ill person. This was defined as follows: "They have a life-limiting (terminal) illness or condition. You expect that they will probably die from this within the next few years." If more than one person was currently terminally ill, the respondent was asked to select the person who had been ill the longest.
[c] Bereavement: If nobody had died an expected death or was currently terminally ill, but someone had been bereaved, the respondent completed questions about the bereaved person. This was defined as follows: "Their relative, friend or house-mate has died in the past 12 months." If more than one person had been bereaved in the past 12 months, the respondent was asked to select the person who had the most significant relationship with the deceased; or, if unsure about this, the person whose name came first in the alphabet.
[d] None of the above: The respondent was taken straight to the final general questions about general attitudes, opinions and training needs.

Table 2: Numbers of staff who have supported people with ID who have experienced death, terminal illness or bereavement in a 12-month period

Survey question	**Response**	**n (%)**
Has anybody died in the past 12 months? (n=690)	Yes, 1 person Yes, more than 1 person No *Missing*	133 (18.4%) 29 (4.2%) 528 (76.5%) *34 (4.9%)*
Was/were any of these deaths expected by staff? (n=162)	Yes No Not sure *Missing*	111 (68.5%) 42 (25.9%) 8 (4.9%) *1 (0.6%)*
Is anybody terminally ill at the moment? *This means: they have a life-limiting (terminal) illness or condition. You expect that they will probably die from this in the next few years.* (n=690)	Yes No Not sure *Missing*	59 (8.1%) 622 (90.1%) 5 (0.7%) *4 (0.6%)*
Has anyone been bereaved in the past 12 months? *This means: their relative, friend or house-mate has died* (n=690)	Yes, 1 person Yes, more than one person No Not sure *Missing*	156 (22.6%) 147 (21.3%) 367 (53.2%) 15 (2.2%) *5 (0.7%)*

Table 3: Staff-reported profile of people with ID who were dying or bereaved

Profile characteristics		**People with ID who were dying** n=152 (100%)	**People with ID who were bereaved** n=200 (100%)
Sex	Male	77 (50.7%)	113 (56.5%)
	Female	67 (44.1%)	83 (41.5%)
	Missing	*8 (5.3%)*	*4 (2.0%)*
Age	19-49	20 (13.1%)	102 (51.0%)
	50-69	80 (54.6%)	70 (35.0%)
	70+	44 (11.2%)	19 (9.5%)
	Missing	*3 (2.0%)*	*9 (4.5%)*
Underlying conditions	Down syndrome	29 (19.1%)	22 (11.0%)
	Autism	25 (16.4%)	60 (30.0%)
	Dementia	34 (22.4%)	10 (5.0%)
	Diagnosed mental health condition	40 (26.3%)	62 (31.0%)
	Regular behaviours seen as challenging	60 (39.5%)	88 (44.0%)
Terminal illness or condition of which s/he died	Cancer	40 (26.3%)	Not applicable
	Dementia	18 (11.8%)	
	No specific diagnosis *(e.g. old age)*	18 (11.8%)	
	Not sure	15 (9.9%)	
	Other	52 (34.2%)	
	Missing	*9 (5.9%)*	
Who has died?	Relative	Not applicable	142 (71.0%)
	Partner		2 (1.0%)
	Friend		22 (11.0%)
	Housemate		16 (8.0%)
	Other		4 (2.0%)
	Missing		*14 (7.0%)*
Ability to communicate and understand* *Score ranges from 0=unable to communicate or understand, to 15=needs no help/understands fully*	0-3	26 (23.7%)	8 (4.0%)
	4-7	17 (11.2%)	22 (11.0%)
	8-11	43 (28.3%)	61 (30.5%)
	12-15	31 (20.4%)	88 (44.0%)
	Missing	*25 (16.4%)*	*21 (10.5%)*
Understanding the universality and permanence of death**	0	34 (22.4%)	10 (5.0%)
	1	6 (3.9%)	6 (3.0%)
	2	17 (11.2%)	31 (15.5%)

Score ranges from 0=unable to understand, to 4=understands fully	3	11 (7.2%)	26 (13.0%)
	4	38 (25.0%)	87 (43.5%)
	Missing	*46 (36.9%)*	*14 (7.0%)*

*** "Ability to communicate and understand" scores were based on the following five questions:**

How much help does s/he USUALLY need with….

- Deciding what to wear
  0. *Can do this on his/her own*
  1. *Needs a bit of help*
  2. *Needs a lot of help*
  3. *Someone has to decide for him/her*
- Making someone understand what s/he wanted or needed
  0. *Can do this on his/her own*
  1. *Needs a bit of help*
  2. *Needs a lot of help*
  3. *Cannot do this at all – we can only guess what s/he wants or needs*
- Understanding what other people say to him/her
  0. *Understands everything without help*
  1. *Needs a bit of help*
  2. *Needs a lot of help*
  3. *Cannot understand at all what other people say to him/her*
- "You are going on holiday in six months' time."
  0. *S/he would understand accurately how long s/he has to wait for the holiday.*
  1. *S/he would understand that s/he has to wait for the holiday, but wouldn't really understand how long*
  2. *S/he would think that the holiday would happen immediately*
  3. *S/he wouldn't understand it at all*
- "You are going on holiday next week."
  0. *S/he would understand accurately how long s/he has to wait for the holiday.*
  1. *S/he would understand that s/he has to wait for the holiday, but wouldn't really understand how long*
  2. *S/he would think that the holiday would happen immediately*
  3. *S/he wouldn't understand it at all*

**** "Understanding the universality and permanence of death" scores were based on the following two questions:**

Do you think s/he understands that everybody dies?
Do you think s/he understands that people who die can never come back?
For each question:

0. *Yes, s/he understands this completely.*
1. *To some extent, but s/he does not grasp it fully.*
2. *No*

Table 4: Talking about dying with those who are dying

Survey question	**Response**	**n=152 (100%)**
Was s/he ever told about his/her illness, or what was wrong with him/her?	Yes	80 (52.6%)
	No	38 (25.0%)
	Not sure	24 (15.8%)
	Missing	*10 (6.6%)*
Was s/he ever told that s/he was not going to get better?	Yes, and ALSO that s/he would die	28 (18.4%)
	Yes, but NOT that s/he would die	24 (15.8%)
	No	46 (30.3%)
	Not sure	41 (27.0%)
	Missing	*13 (8.6%)*
Do you think s/he ever realised that s/he was probably going to die?	Yes, definitely	177 (11.2%)
	Yes, probably	34 (22.4%)
	Probably not	45 (29.6%)
	No, definitely not	24 (15.8%)
	Not sure	22 (14.5%)
	Missing	*10 (6.6%)*

Table 5: What support would be useful for staff?

Staff who said they would find the following quite/extremely useful (%)

	Staff who have supported a dying person n=152	**Staff who have supported a bereaved person** n=200
Training		
Training on end-of-life care	119 (78.3%)	154 (77.0%)
Training on advance care planning	117 (76.9%)	148 (74.0%)
Training on breaking bad news and communication	115 (75.7%)	155 (77.5%)
Training on bereavement	113 (74.3%)	152 (76.0%)
Talking		
Talking with colleagues, informally	138 (90.8%)	137 (68.5%)
Talking with the whole team *for example, in team meetings*	103 (67.8%)	139 (69.5%)
Talking with my manager, one-to-one	107 (70.4%)	129 (64.5%)
Talking with a professional outside my organisation *e.g. a counsellor, nurse or doctor*	102 (67.1%)	97 (48.5%)
Talking with my family and friends	69 (45.4%)	92 (46.0%)