TITLE

Investigating the factors that affect the communication of death-related bad news to people with intellectual disabilities by staff in residential and supported living services: an interview study

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Abstract

Background: Many people with intellectual disabilities are affected by death, yet conversations about death are often avoided by staff working with them. This study aimed to assess staff training needs and to develop, trial and evaluate a training course on communicating about death and dying.

Method: (1) Semi-structured interviews with 20 staff in residential/supported living services to establish training needs; (2) three one-day courses were attended by 114 staff and evaluated through questionnaires. The course consisted of World Café sessions, presentations and feedback by people with intellectual disabilities, and an expert teaching session.

Results: Staff fear, cultural influences and inexperience with death-related conversations were major communication barriers. Evaluation of the course was overwhelmingly positive.

Conclusions: Intellectual disabilities services must have clear staff training strategies around death, dying and communication. More work is needed to assess the resource implications and impact on practice of different training methods and other support strategies.

Key words

Intellectual disabilities, communication, death and dying, terminal illness, bereavement, staff training

Background

When people have an illness of which they are expected to die within the foreseeable future, it is likely that they are told the bad news, in western societies at least (Seale, 1991). The vast majority of people want this kind of information (Fallowfield, Jenkins, & Beveridge, 2002), which enables them to prepare for impending losses and be involved in care and treatment choices, if they so wish. There are movements towards talking more openly about death and dying in general, regardless of whether people are currently affected by terminal illness or bereavement (Dying Matters, 2015). There is consistent and growing evidence, however, that people with intellectual disabilities are protected from knowing about death and dying. In particular, they are less likely to be told or helped to understand that they themselves are dying or that a loved one is going to die (Bernal & Tuffrey-Wijne, 2008; Brown et al., 2002; Ryan et al., 2011; Tuffrey-Wijne et al., 2013; Tuffrey-Wijne et al., 2010; Wiese et al., 2013; Wiese et al., 2014). Staff in generic healthcare services, including doctors and nurses who would usually discuss a poor prognosis with their patients, tend to leave such conversations to families or care staff when the patient has intellectual disabilities (Tuffrey-Wijne et al., 2010). However, conversations about death are avoided by staff in services for people with intellectual disabilities, even if they believe in principle that their clients should know about dying. Reasons include concerns about the client's capacity to understand, worries about a lack of experience and skill, and a perceived lack of opportune moments for conversations about dying (Ryan et al., 2011; Wiese et al., 2013).

The difficulties care staff have in communicating about death and dying were further highlighted in a randomised controlled trial of two different bereavement interventions for people with intellectual disabilities (Dowling et al., 2006). Traditional specialist volunteer bereavement counsellors were able, with relatively little training, to adapt their skills for use with people with intellectual disabilities, leading to measurably improved outcomes. Conversely, care staff who received training to deliver integrated bereavement support within the client's care setting mostly dropped out of the study.

This issue is highly relevant for intellectual disabilities services, where staff will inevitably have to support people affected by death, dying and bereavement. People with intellectual disabilities are living longer than before (Coppus, 2013; Patja et al., 2000). Communicating about death and dying becomes more relevant as people age and experience more losses in their lives. There is some evidence that people with intellectual disabilities want such communication. One study investigated the support needs of 21 adults with intellectual disabilities who, between them, had experienced the cancer-related deaths or imminent deaths of 36 relatives, partners and friends. Feelings of exclusion among those who had not been told about the illness was a major theme. Participants voted "Someone to talk to about my feelings and worries" as the most helpful support strategy; "A support worker to

be with me" also scored highly (Tuffrey-Wijne et al., 2012). Other studies have also found that people with intellectual disabilities do not want to be excluded from conversations about death and dying, but they want to have explanations in a way they can understand (McLaughlin et al., 2015; Tuffrey-Wijne et al., 2007). It seems necessary, therefore, that support staff engage with people with intellectual disabilities who face terminal illness (their own, or their family's or friend's), and communicate with them in a way that suits their needs.

However, this is an undoubtedly challenging area of practice. Whilst healthcare professionals are routinely taught how to communicate bad news to patients (Baile et al., 2000; Buckman, 1992; Paul et al., 2009), this is not the case for professionals and staff working with people with intellectual disabilities; yet, conversations about death and dying may require particularly sophisticated communication skills when people have intellectual disabilities (Blackman, 2003). It is of concern that staff are not trained or prepared for this.

Staff training

There are questions to be answered about the usefulness of training, and indeed, about the proposed recipients of training. Who is best placed to help people with intellectual disabilities communicate about death and dying, and by implication, who should be trained? There are also questions about the most valuable *content* and the most useful *format* of training for staff in intellectual disabilities services.

Berkhof *et al.* (2011) suggest that it is difficult and time-consuming to change existing communication behaviour of medical professionals, as communication is based on deeply rooted habits and related habitual patterns. They analysed 12 systematic reviews on communication skills training programmes for physicians and found that training programmes were effective if they lasted for at least one day, were learner-centred, and focused on practising skills. The best training strategies included role-play, feedback and small group discussions. There was no evidence for the effectiveness of modelling, written information, or oral presentations alone.

The use of case studies have also been found to be beneficial for intellectual disabilities care staff with regards to learning skills and gaining confidence around supporting people with intellectual disabilities who have been bereaved (Needham, 2016).

Skillbeck (2015) points out that it can be difficult for health and social care students to learn how to engage in discussions to support people who are dying or bereaved. If students do not receive support in this during their education, they are less likely to engage in therapeutic relationships and less likely to be 'conversations ready' (Skilbeck 2015). She found that "death cafés" can complement other types of end of life care education by

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creating space where conversations about death and dying take place. Death Cafés involve groups of strangers gathering to eat cake and discuss death with no objectives, direction or themes; the objective is simply to increase awareness of death with a view to helping people make the most of their lives (Impermanence, 2016). The movement started in 2011 and has spread across the world. Adler et al. (2015) report on Death Café sessions run as part of an inter-professional end-of-life course, involving a hospice and a university. They found that participants were surprised at the ease with which they were able to discuss end of life issues in these settings; sharing personal concerns in a group of strangers was reported to be not only comforting, but also served to normalise the death-related topics.

The World Café method is a more structured way of exploring issues, through discussions in small groups. It involves setting up informal 'café-style' environments with tables and tablecloths, drinks, snacks and coloured pens, and inviting staff to come along to explore issues. Discussions are held in 20-30 minute rounds, with each table focusing on a different theme (The World Cafe, 2016). World Cafés have been used to generate ideas, share knowledge, stimulate innovative thinking and explore action in real-life situations (Burke & Sheldon, 2010).

Initiatives that included active involvement of people with intellectual disabilities in delivering training have been found to have a positive impact on students' confidence, attitudes and knowledge (Atkinson & Williams, 2011; Smith et al., 2016).

It is clear from the literature that staff in intellectual disability services need support around death-related communication. Staff training can be one way of offering such support, but in order to ensure that the content and format of such training meets staff needs, more needs to be understood about the barriers to communication.

Aims

The overall study had two stages, each with a distinct aim. (Stage 1 aimed to understand the context of death related bad news situations within intellectual disabilities services, with a focus on the factors that affect (non-)disclosure of bad news, the barriers to effective communication about death and dying by support staff, and staff views on possible strategies for improvement. Stage 2 aimed to develop, trial and evaluate a training course on communicating death-related bad news that is relevant for staff in intellectual disabilities services. In this paper, we focus primarily on stage 2, but provide brief information about the methods and results of stage 1, sufficient to help readers understand how the stage 1 findings informed the staff training course that was delivered and evaluated in stage 2. The methods and findings of stage 1 are more fully reported elsewhere (Tuffrey-Wijne & Rose 2017).

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Methods

The study was conducted by two researchers (ITW and TR) with support of a statistician (RG). Advice and scrutiny was provided by a Research Advisory Group consisting of two senior service managers, a support worker, a family carer and academic, three people with intellectual disabilities and an intellectual disabilities nurse. In addition, the research team met three times with a Reference Group of seven people with intellectual disabilities at a local intellectual disabilities day support service, who had all volunteered to be part of the group. They provided feedback on the study findings.

Ethical approval for stage 1 was granted by the Faculty Research Ethics Committee of Kingston University & St George's, University of London. Stage 2 was considered to be service development rather than research, and therefore did not require ethical approval.

Stage 1: staff interviews

Semi-structured interviews were held with 20 staff (13 junior care/support workers and 7 managers) working in eight different residential or supported living services for people with intellectual disabilities in London, UK. The interview guide included questions about the participants' experiences with communication around death-related bad news situations. This was followed by these questions: *What would help you if you faced a similar situation again? What kind of training would you find helpful? Is there anything that would be more helpful than an external training event or course?* Data collection took place over 5 months (2015-2016). Data were analysed using framework analysis procedures, which are a useful way of identifying patterns and themes across qualitative data (Gale et al., 2013). More detailed information about the data collection and framework analysis procedures is given in Tuffrey-Wijne & Rose (2017)*.

Stage 2: training course

Three separate one-day training events had been planned to take place at the end of stage 1. We opted for a university venue, which had to be booked before commencement of stage 1, so unfortunately there was little flexibility about the parameters for the course with regards to time and space.

Planning: Much of the discussions within the weekly team meeting, meetings with the Research Advisory Group and Reference Group was centred on the implications of the study findings for training. Training needs were proposed, based on (1) explicit comments and suggestions from interview participants, and (2) the overall stage 1 findings, which led to the distillation of training needs that were less explicit. We also had to decide who the course would be targeted at, and which training needs could be realistically met within a one day

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course. An expert in the training of teams and individual staff within intellectual disabilities
services (AW) helped to plan the course and support the delivery.

As it became clear that a key staff training need was to improve the ability to talk about
death and dying, not only with people with intellectual disabilities but also with each other,
it was decided to take a World Café Method approach for part of the course. It was
anticipated that this would have the dual benefit of helping course delegates to talk about
death and dying, and of 'role modelling' ways in which they could help their teams do the
same*.*

Course development started after 10 interviews and the ideas were fed into the final 10
interviews to assess acceptability and desirability. Interim findings were presented to the
Research Advisory Group as a series of statements, and their feedback was incorporated
into the course development. The findings were presented to the Reference Group of
people with intellectual disabilities in the form of a short fictional case study of "John", a
man with intellectual disabilities who was terminally ill, and his care staff, family and friends.
John's story was supported by pictures and provoked valuable group discussion. This case
study was then used to formulate seven topics for table discussion during the World Café
sessions, including for example:

- Should John be told that he is going to die?
- How important is it to 'keep things positive'?
- One of John's friends has profound intellectual disabilities. Could you help her
  understand that he has died?

The full discussion topics and accompanying pictures are available from the first author on
request. An overview of the development and implementation of the training course is
given in figure 1.

--------------------------------*Figure 1 about here*---------------------------------------

Running the course: The courses were free of charge. A total of 114 people attended,
including 7 of the 20 interview participants. Registration had to close for the second and
third event, as these were over-subscribed. Despite advertising the course widely among a
health and social care services, only one participant (a palliative care educator) did not come
from an intellectual disabilities background or service (see Table 1).

Evaluation: The course was evaluated through (a) an evaluation form, gathering immediate
feedback on each session and on the day overall; and (b) a questionnaire to assess

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immediate and sustained learning; identical questions were asked at the beginning and end
of the day. They were Likert-scale questions assessing self-reported difficulty or worry with
regards to talking about dying, as well as self-reported skill and knowledge of available
resources. 108 completed forms and questionnaires were returned on the course days (95%
response rate). All participants had written their email address on the questionnaire,
consenting to being contacted again with a repeat questionnaire. This was emailed to them
three months later and included one additional question *("Has the training had any
influence on your work during the past 3 months? If yes, how?"*). Two weeks later, the email
was re-sent to non-respondents; 24 follow-up questionnaires were received (23% response
rate). Scores were compared over the three time points using box plots and line charts
linking individual participants' responses. Sign tests were used to assess the statistical
significance of increases or decreases in confidence over time.

--------------------------------**Table 1 about here**--

Results

Summary of findings from stage 1

We begin with a brief account of the stage 1 findings, because these data strongly
influenced the content and methods of the staff training course in stage 2. More details of
the stage 1 findings can be found in the companion paper (Tuffrey-Wijne & Rose 2017). The
following three factors had a particularly strong influence on the way staff communicated
with people with intellectual disabilities about death and dying: fear and distress around
death; life and work experience; and organisational culture. We briefly summarise these
before focusing on staff training needs.

Fear and distress around death

Staff felt frightened and unprepared for dealing with issues of death and dying; this
contributed to avoidance of death-related conversations with clients. They were concerned
that communicating openly about death might cause their clients distress, partly due to
their own lack of skill. There was a tendency among staff to 'keep things positive'.

Life and work experience

The lack of preparation and training for the job of care worker was striking. Staff with
experience of death and dying, either in their own lives or at work, coped better with
supporting people with intellectual disabilities who were facing death and loss. There was a

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lack of guidance for staff in the area of death-related communication; staff communication was influenced by personal beliefs or opinions.

Organisational culture

Analysis of interviews with several staff members from within the same service providers showed that junior staff felt more comfortable to talk about loss, death and dying in settings where managers talked with staff and clients about death, providing positive role modelling.

Training needs

In response to questions about specific training needs, interviewees covered three important areas: *who*, *what* and *how*. Who should be trained? What should training cover? What format should training take?

Who *should be trained?*

There was a strong sense among interviewees that breaking bad news is part of the role of staff working in residential and supported living services, and not simply that of external health or social care professionals. Most felt that this is the domain of managers, not junior staff. It was also recognised that some staff may simply find this kind of communication too difficult.

> "I feel if there is something that is too much for me and at the time I feel I didn't have the right words to say I would get my manager or a senior member who is on duty." *(Participant 3, care worker)*

The question arises whether all staff (including junior staff) should receive training around communication, death and dying, or whether training should focus on staff with specific responsibilities, interest or aptitude. Opinions on this were divided.

> "I think everybody should be trained... when we all do the training then we all can come up with good ideas and better things and we can all share as a group." *(Participant 8, care worker)*

> "I think training should be slightly different [for managers and superiors], because we tend to be their [junior staff's] support. Even though we work together as a team." *(Participant 11, manager)*

Most interviewees thought that training would be useful for them, although several (on both managerial and junior level) questioned whether training in death-related communication could actually make a difference. There was a general sense among participants that no training could prepare them for the realities of supporting clients around death and dying.

What should training cover?

In relating their experiences of supporting terminally ill clients, staff explicitly highlighted their need to have training and support around end of life care – not just communication, but also providing all-round support, including physical support; as well as knowing where to go for help.

The most frequently mentioned communication concern was related to simply not knowing how to break bad news, and in particular, what words to use. Staff worried that 'saying the wrong thing' could be harmful to their clients. This need made sense in the context of strong evidence from the interviews that many staff find it difficult to use direct, straightforward language around death and dying.

> "[When a service user has died, the others] are told, 'They have gone to a better place'. Or something. Not straight away that a person has died. You can't say that." *(Participant 16, care worker)*

There was also a sense that staff teams would benefit from talking more about death and dying.

> "I think [talking about death] will help, especially help the support workers, a lot because it prepares you. (…) Once it's spoken about it makes it a little bit easier. But if nothing is said to anybody or nobody is trained about it and all of a sudden it happens, it hits you like a ton of bricks." *(Participant 18, care worker)*

How should staff be trained?

People differ in their learning styles and preferences, and this was evident in interview responses. Some participants mentioned their preference for training in person, rather than e-learning. There was also a preference for practical, rather than theoretical, input.

> "If you were just to sit there writing things down and taking loads of information, it is very overwhelming." *(Participant 13, care worker)*

A number of participants spoke of an interest in working with case studies or practice examples. Opportunities to share experiences were also seen as useful. Some participants' teams had been given training or information by external professionals, which had been helpful, as it opened up opportunities to talk about death as a team, facilitated by someone who was at ease with the topic.

> "The lady came here from the hospice and gave training about bereavement. It was really interesting as she had a sense of humour. (…) We spoke about

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death. It was good to have death on it. At least we had to speak about death." *(Participant 7, care worker)*

The idea of involving people with intellectual disabilities in training (proposed by the interviewers) was also welcomed.

"I had something like that in my training, and it is good to hear their point of view. (…) The interactions as well, it breaks down the barriers, and you don't get so nervous when you are going to meet service users. So it was good." *(Participant 13, care worker)*

Developing and delivering the training course

The data suggest that intellectual disabilities staff need help in overcoming their fear and anxiety with regards to talking about death and dying, not only with their clients but also with colleagues and other people without intellectual disabilities (see also Tuffrey-Wijne & Rose 2017). Staff also need training and guidance around the impact of their choice of words on people with intellectual disabilities.

Participants expressed a need for general end of life care training. We could hypothesise that improving staff understanding of the physical and emotional processes of death and dying would improve their ability to communicate about death. This, however, was outside the scope of the training days, where the focus was on communication only.

Following team discussions, it was decided that the aims of the course were (1) to increase staff readiness for and confidence in talking about death and dying, not only with people with intellectual disabilities but also with their own peers; and (2) to ensure that staff knew where to find help and support in having bad news conversations with people with intellectual disabilities. It was also hoped that the course would improve staff skills in this area, but that would be more difficult to assess and evaluate.

Involving people with intellectual disabilities: As the interviews had shown that many staff are hesitant about discussing death with people with intellectual disabilities, we anticipated that the input of people with intellectual disabilities as speakers, telling their own death-related bad news stories and giving their opinions on the questions raised in the World Café sessions, could have an important role-modelling function and break down barriers.The Reference Group was asked questions about some of the topics for the training day, using 'John's story' (such as: 'What words should staff use when they tell John's friends that he has died?' 'Should staff always be cheerful and positive when they are with John?'). Three Reference Group members then formed a 'panel' on the training course, sharing their opinions and answering questions from participants. In addition, one of these panel members gave a talk about her own experiences with dying, bereavement and bad news.

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Session on 'how to break bad news': As some study participants had indicated that they wanted to develop skills and know 'how to' break bad news, including what words they could use, an expert session was included where some of the basic principles of guidelines for breaking bad news to people with intellectual disabilities (Tuffey-Wijne, 2016) were explained.

Evaluating the training course

The 'vibes' during the training courses were extremely positive, with high active engagement from the participants. This was reflected in the feedback received through evaluation forms. Participants were asked to rate each session from 1 (poor) to 10 (excellent); mean scores for the sessions ranged from 8.3 to 9.2 (see Table 2).

Participants were asked to write down three words that summed up the training course; 289 words were received. The most frequently mentioned words were "informative" (42x), "interesting" (33x) and "thought provoking" (17x).

Participants were also asked what they found most useful about the course. A total of 109 statements were received, which showed that *Talking about death (World Café)* and *Hearing the perspectives of people with intellectual disabilities* was seen as more useful than being given general information or guidelines on how to break bad news (see Table 3).

-------------------------------*Tables 2 and 3 about here*---

In response to the question how they thought the course would affect their practice (if at all), delegates wrote a total of 95 comments. One of these was "Don't know"; all others were positive. A representative selection is given in Box 1.

-------------------------------*Figure 2 about here*---

Participants' responses to the pre- and post-course questionnaire, designed to evaluate their immediate and sustained learning, are given in Figure 2. Questions 1 and 2 assessed the level of difficulty or worry participants experienced in talking about death and dying; questions 3 and 4 assessed self-perceived skill; and question 5 assessed knowledge of resources. As can be seen, the score immediately after training was higher than the pre-training score on all questions. The scores of 58% of participants (n=108) improved with regards to question 1, and the scores of over 80% of participants improved for questions 2,

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3, 4 and 5. Sign tests show that this shift was significant (p<0.0001) for all questions. The 3-month follow-up scores were not significantly different from the pre-course questionnaire scores, but these follow-up scores are of limited usefulness because of the small and possibly underrepresentative sample (n=24). Feedback comments received 3 months after the course (see Box 2) give a mixed picture. Whilst they mostly conveyed positive effects, there was some dissatisfaction with the relatively low emphasis on expert input and direction around "how-to" communicate bad news.

-------------------------------*Boxes 1 and 2 about here*---

Discussion

Whilst communicating with clients or patients who are affected by death is challenging for all healthcare professionals (Dosser & Nicol, 2014), this may be particularly the case for staff in intellectual disabilities services, for whom death may be an unexpected part of their work and who are not usually trained or prepared for this. Some staff clearly indicated that supporting people who were dying was "too much" for them, and emotionally distressing. We assume that these staff will have difficulty supporting their clients well, or communicate effectively with them about death and dying, as they may be inclined to avoid death conversations that add to their own distress. This study has shown that staff are inhibited by general inexperience of the practicalities of dying and inexperience in talking about dying; but also by fear, and in some, by reluctance to address issues around death. Avoidance of death-related communication also had roots in culture (including organisational culture), which is further explored in the companion paper (Tuffrey-Wijne & Rose 2017).

In the light of the stage 1 study findings, the training course had a strong emphasis on practicing "talking about dying" in general, with a lesser focus on learning specific skills in "breaking bad news". One course participant described this as 'de-sensitisation'. Opening delegates' eyes to different approaches and ideas was achieved through the sharing of case studies and personal experiences, not only those presented by the team but also those shared between delegates.

It appears, from the course evaluation, that the one-day training course achieved its aim of reducing self-reported worry and improving self-reported skill and knowledge around communication of death-related bad news. The strong emphasis on delegates talking together about their experiences, which took up about half of the course, was highly valued and appeared effective, as was the involvement of people with intellectual disabilities. It is

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noteworthy that over half of all participants gave the talk by a woman with intellectual disabilities the highest possible score (10 out of 10), indicating the power and importance of giving people with intellectual disabilities opportunities to tell their own stories as part of staff training. Our findings confirm reports in the literature that there are real benefits in involving service users in training programmes; it can give students insight into the experience of service users (Costello & Horne, 2001) and challenge assumptions (Schneebeli et al., 2010). Research data on involving people with intellectual disabilities in delivering education are limited, but there is some evidence that such involvement can have a deep and positive impact on students (Bollard et al., 2012; Smith et al., 2016).

Measuring the effectiveness of communication training is always a challenge. The extent to which the self-reported improvements were sustained over time is not completely clear, as response rates at 3 month follow-up were too low to draw firm conclusions. Even less clear is the impact of training programmes on practice. Whilst it is reasonably straightforward to assess self-reported confidence and skill, it is more difficult to assess whether staff practice has actually been affected. A review of 245 studies on how medical professionals break bad news to cancer patients, for example, found that less than 2% addressed psychosocial outcomes for patients. Our study used participant self-rating as an outcome measure, including asking for participant feedback on whether their practice had been changed. Other outcome measures, such as behavioural observation or client/family feedback, would have been more rigorous but also much more complex and time consuming. It must be acknowledged that positive ratings at the end of a training day – or even several months after the training – are not necessarily an indication of changed or improved practice.

The study by Dowling et al (2006) is of particular interest here. In their comparison of two bereavement interventions, one group of intellectual disabilities staff and carers received two days of training in order to be able to support the bereaved person with intellectual disabilities in their home and work environment. Staff volunteered for this role; they could ask for supervision from a bereavement counsellor on request and had access to advice from the research team. Despite all this, most (nine out of 11 staff/carer clusters) abandoned the work. The authors reported that these participants found the role requested of them too demanding, although they had declared (at the recruitment stage of the study) that their role included providing emotional support. It seems, therefore, that a change in staff practice around death communication may be particularly hard to achieve, even among staff who are interested in this area and self-select for training.

Who should be trained?

The question whether all staff should be trained in death-related communication, or only some staff, is an important one for services. Is it possible, or even desirable, for staff who are clearly afraid of death and dying to confront those fears in the workplace? Being able to have focused conversations with people with intellectual disabilities about death and dying, and to break bad news sensitively, taking account of the person's wishes, needs and abilities, requires advanced communication skills. It may indeed be the case that people with intellectual disabilities are best served if those who communicate with them on this level are staff who have a particular role; many interviewees indicated that those in senior positions should take this on. Some staff may have a particular aptitude or interest in this area.

Stancliffe et al. (2016) have noted that within the mainstream literature (Neimeyer, et al., 2004), there is evidence that the ability and willingness of staff to talk about death and dying is related to their personal fear of death. Wiese et al. (2015) suggest that self-selection of staff for training programmes might be one way of dealing with this. This seems a sensible suggestion. If it is difficult even for self-selected staff to sustain effective bereavement support for people with intellectual disabilities, as the findings of Dowling et al. (2006) indicate, then we could infer that participating in training on death-related communication may simply be too much to ask of staff who are reluctant to talk about death.

However, we would also argue that the ability to confront issues of death and dying, to not "gloss over" them by changing the subject or "keeping things cheerful", is important for all staff, including the most junior or the most reluctant. A focus group study of people with intellectual disabilities affected by cancer deaths found that they had a tendency to protect their families and carers from their own distress and did not usually ask for support; they feared that they would be dismissed by professionals, and where thus left with significant unmet support needs (Tuffrey-Wijne et al., 2012). It is important, therefore, that staff (including junior staff) do not block such conversations, although it seems appropriate that junior staff ask for help from more experienced or more senior colleagues when conversations are difficult. As we have seen, death, dying and bereavement are increasingly present within intellectual disabilities services, especially as the client population is ageing. These issues are therefore relevant to all staff. We believe that it is important for staff to be aware of their own communication patterns, and of how these might affect their clients.

This may be best addressed through ensuring that staff teams are supported by people who are comfortable and confident in talking about death, as some stage 1 participants indicated. This would provide positive role modelling and support for individual staff and teams. We found that the role of team managers or service managers was important in this respect (Tuffrey-Wijne & Rose 2017). We would suggest, therefore, that attending a training

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course like the one described here might be particularly beneficial for managers, who may be able to use some of the ideas and discussions in their own teams, including the World Café model itself. It would be useful to explore whether training the managers or key members of the team can have an effect on the communication skill of the wider workforce, along "train the trainer" principles (Orfaly et al., 2005). We have produced an on-line guidance document for managers, titled "Helping teams in intellectual disabilities services talk about death and dying" *(www.breakingbadnews.org/tools/).*

One of the challenges for intellectual disabilities services within the UK is that the workforce, and especially junior care staff, is largely untrained; the low levels of training among the stage 1 participants reflected this (Tuffrey-Wijne & Rose 2017). Even if death and dying was included on the curriculum for staff training, this may not be accessed by large parts of the workforce, and therefore these issues may well need to be addressed "on the job". We conclude that it is particularly important for managers to be aware of their crucial role in enabling and supporting their teams to cope with death and dying, including communication.

It was interesting to note that staff from one service, where interview participants seemed to struggle most with distress around death and dying within their care homes and avoided death conversations most strongly, did not attend the free-of-charge training days (despite having expressed interest when interviewed, being invited several times, and the manager reserving 15 places). On the other hand, the two services where communication about death seemed more open sent a number of senior and junior staff to the training days (23 and 13 respectively). This could be an indication that those staff who avoid death communication most strongly, are perhaps less likely to attend external training events of this kind. In the light of our proposition that *all* staff should be "conversation-ready", or at least know how to get the right support for their clients even if they themselves cannot provide it, the question arises how such staff can be prepared or supported. It is not clear whether openness to communication training is a prerequisite for gaining benefits from it, or whether those who are most resistant would in fact benefit most. Can training change staff culture, or does there need to be a culture change before staff can benefit from training? Such questions are crucial, but not easily answered through a single project like this one.

Further research is needed to investigate and assess the practicalities and effectiveness of support measures other than formal training. Codling et al. (2014) assert that paid carers who support people with intellectual disabilities at the end of life need support and training from professionals who are at the forefront of care delivery. One way to address the barriers to communication, therefore, may be to invite external professionals who are skilled in communicating about death and who may be able to offer support to teams, such

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as palliative care or bereavement professionals. An interview study, involving staff from both palliative care services and intellectual disabilities services, found that involving professionals experienced in death and dying gave staff teams confidence in providing support to dying and bereaved clients (McLaughlin et al., 2014). Few participants in stage 1 of the study had received such external support. Junior support workers who took part in this study were clear that they would turn to their managers for help, support and advice (Tuffrey-Wijne & Rose 2017)*.* It seems appropriate, therefore, that service managers in particular know where to find resources and external support, if needed.

Strengths and limitations

The fact that this project involved mostly intellectual disabilities staff from in and around London, which has an extremely diverse workforce, has implications for representativeness. Cultural differences must be taken into account when interpreting the results.

The development of the staff training course was based on the findings of staff interviews, as well as discussions with a range of stakeholders. The extent to which all training needs can be known and articulated by the workforce itself is debatable. In this study, the team decided to focus on practicing the more general skill of enabling staff teams to talk about death and dying, rather than the specific skill of breaking bad news to someone with intellectual disabilities – although specific guidance (for example, "what words to use") was woven into the course. It may have been useful to try out different a format and content for training, and compare feedback.

The difficulty of assessing changes in practice following a training course of this kind has already been discussed, and is perhaps the most significant limitation of this study.

The other main limitation is that this study and the training course were focused on support staff in residential and supported living services for people with intellectual disabilities. It did not address the issues for families or for other types of staff, especially those at the front line of end of life care provision, who also need considerable support in the area of bad news communication with people with intellectual disabilities (Ryan et al., 2011; Tuffrey-Wijne et al., 2008). Their training and support needs, however, are somewhat different from those of intellectual disabilities staff. Palliative care staff, for example, can be expected to be skilled in talking about death, and are unlikely to need the same level of support in this. It does seem justified, therefore, to focus training on specific professional groups. However, the benefits of cross-fertilisation of knowledge and skills (for example, bringing palliative care professionals and/or family carers into training for intellectual disabilities staff, and vice versa) should be further explored.

Conclusions

Given the magnitude of the issue of death and dying within intellectual disabilities services and the importance of adequate communication with clients, it is imperative that the intellectual disabilities workforce receives training in communication, death and dying. The development of comprehensive strategies for training the workforce is a priority, and the resource implications for this must be assessed and addressed. This must include a clear assessment of who should be trained. This study has highlighted the extent to which intellectual disabilities staff struggle with communication around death, and therefore, their urgent need for support. We recommend that future studies focus on describing the elements of training strategies, including the way they were implemented and an assessment of the outcomes.

Our finding that organisational culture (including the support provided by management) affects the way staff communicate with clients about death and dying, has implication for staff training. We believe that one-off training events like this are most likely to be effective if they are supported by a culture of openness within services. The benefits of other support strategies should also be explored; for example, input/support/guidance/de-briefing from palliative care or bereavement professionals for staff teams that face issues around death and dying. Furthermore, it must be borne in mind that 'one size does not fit all', and different training or support strategies may be needed to meet the needs of the entire workforce. This is a highly sensitive and challenging area of practice, but if staff are well supported, they, and the people with intellectual disabilities they work with, will benefit hugely. As one interview participant said, "For me, supporting people who are dying is one of the most powerful experiences I have had in this organisation, and that's something I am really grateful for, that I could be around. It's very much life-changing. So I would encourage everyone, just don't be afraid and go for it."

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BOX 1: "How do you think today will affect your practice (if at all)?"

A representative selection of the 95 responses given by participants in answer to this question:

- "Today has been an eye opener. It has made me aware about not only breaking bad news to people with LD but breaking bad news to anyone."

- "Will feel more confidence to bring up the subject of death in team meetings."

- "It will help me to answer questions from the people I support about death and dying."

- "Nothing can prepare you but the more we talk about it the easier it becomes to talk about it. A bit like desensitisation."

- "Assist me to be more confident and make sure we have these brave conversations in and out of work. Well done team."

- "I'll be going back to my team to discuss the day. I wonder if we need a more co-ordinated approach around this."

- "Will take back knowledge to other colleagues and use information."

- "Providing practical support. Implementing this training experience. Support staff - encouragement and reassurance."

- "Encourage my organisation to talk more about loss and bereavement and change the culture."

BOX 2: "Has the training had any influence on your work during the past 3 months (with your colleagues or your clients)? If yes, how?"

A representative selection of the 12 free-text responses given by participants in answer to this question, 3 months after the course:

➢ I have had felt more able to talk to my colleagues about it and pass on what I learned for the training day, which ultimately, is to be honest! I enjoyed the training day.

➢ I found it easier to talk to service users, not avoiding the subject as I may have done in the past, but instead encouraging them to express their feelings

➢ The training was beneficial and thought-provoking, however in my opinion (…) I felt like the training was very much relying on us to come up with our own ideas for the whole day and did not learn from yourselves, delivering the training, any new information.

➢ Found the training really useful and very reassuring. Feel I have more knowledge and confidence about how to approach this subject and how to access all the tools that are available. The information I learnt has since been presented at a workshop we carried out within our trust – using the materials from the day certainly helped to structure the event

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TABLE 1: Breakdown of course delegates

Delegate job/role	n	
Manager of residential/supported living service	29	
Care/support worker	25	
Intellectual disability professionals	44	
Of which:		
Nurse		*15*
Student nurse		*6*
Psychologist		*6*
Educator/practice development		*5*
Social worker		*4*
Mental health nurse		*4*
Speech and language therapist		*4*
Educator/practice development (palliative care service)	1	
Parent	2	
Other *(incl: activity coordinator, health facilitator, inclusion facilitator, assessment officer, project worker)*	14	
TOTAL	**114**	

Course session	Mean	Median	Range
World Café discussions	8.3	8	4 - 10
Talk by woman with intellectual disabilities	9.2	10	6 - 10
Panel and study findings	8.3	8	1 - 10
Expert session	8.5	9	5 - 10

TABLE 2: Evaluation of the course sessions

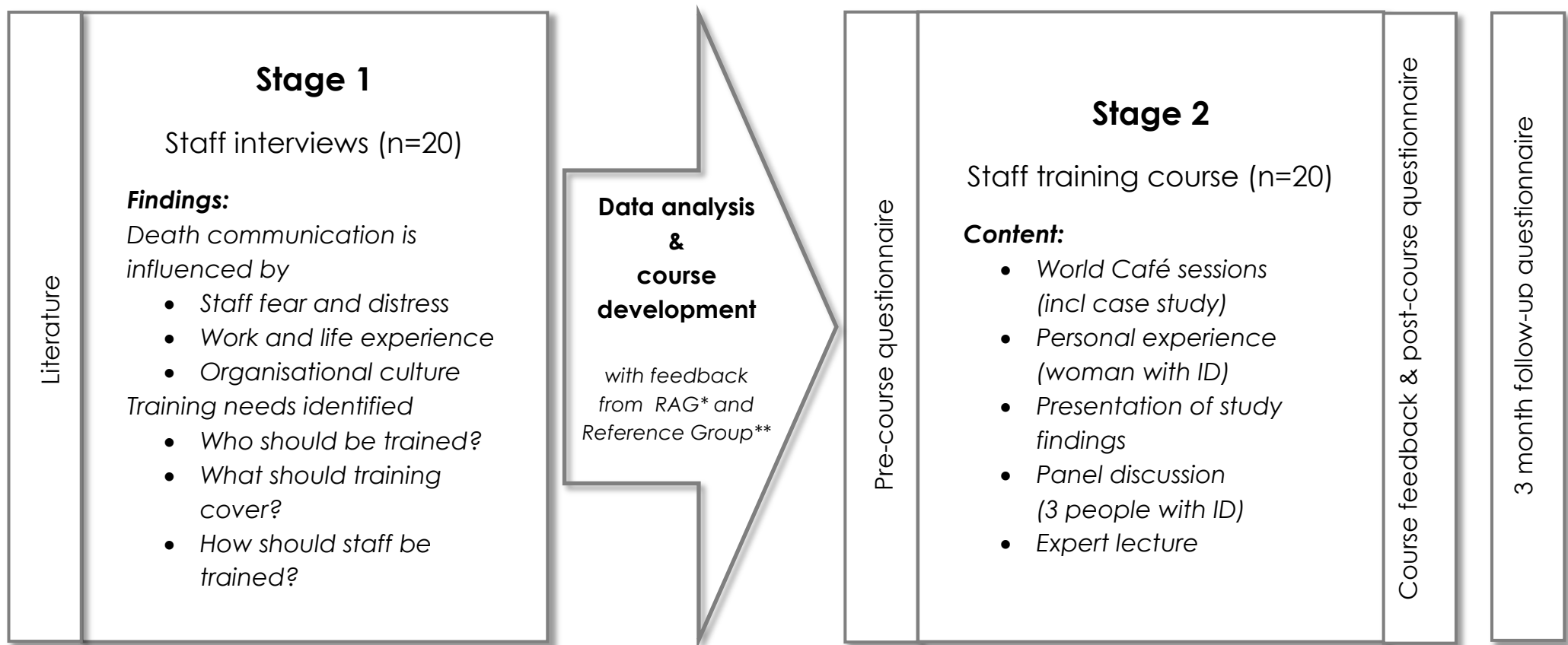Course participants (n=108) rated each session from 1 (poor) to 10 (excellent)

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TABLE 3: "What has been most useful about the course?"

What has been most useful?	Number of statements	Selected participant statements
World Café discussions; Sharing experiences; Listening to other participants	51	"Good to talk with other attendees." "Table discussions." "Death Café." "Life experience shared." "Starting a conversation about the issue." "Hearing opinions from other support workers." "Other people's opinions and experiences and suggestions made."
Listening to people with intellectual disabilities; Panel discussions; Talk by woman with intellectual disabilities	42	"Hearing from *(names of the three presenters/panel members with ID)* about their personal experience." "Hearing from service users." "Having service users who can tell you first hand, how they are feeling." "Amazed at the panel talking about their experiences." "Listening to the panel and their experiences, realisation of how to give bad news and how they feel about it."
Receiving guidelines; Expert teaching session	16	"Techniques and tips about ways to talk about bad news with people." "Exercise about breaking bad news in chunks." "Results of the study." "The discussion about guidelines for how to break bad news."

Course participants' (n=108) statements in response to this question; some gave more than one statement

Figure 1

Development and implementation of training course

Literature

Stage 1

Staff interviews (n=20)

Findings:
Death communication is influenced by
- *Staff fear and distress*
- *Work and life experience*
- *Organisational culture*

Training needs identified
- *Who should be trained?*
- *What should training cover?*
- *How should staff be trained?*

Data analysis & course development

with feedback from RAG* and Reference Group**

Pre-course questionnaire

Stage 2

Staff training course (n=20)

Content:
- *World Café sessions (incl case study)*
- *Personal experience (woman with ID)*
- *Presentation of study findings*
- *Panel discussion (3 people with ID)*
- *Expert lecture*

Course feedback & post-course questionnaire

3 month follow-up questionnaire

ID = Intellectual disabilities

*Research Advisory Group (stakeholders)

**Reference Group (7 people with ID)

## FIGURE 2: Assessment of participants' learning

Q1: In general, how difficult or easy do you find it to talk about death and dying (e.g. with your family and friends)? *Score 1 (very difficult) to 10 (very easy)*

Q2: "You need to talk about death and dying with someone with learning disabilities." How worried does this make you feel? *Score 1 (very worried) to 10 (not at all worried)*

Q3: How skilled do you feel about communicating with people with learning disabilities who experience a bereavement? *Score 1 (not at all skilled) to 10 (very skilled)*

Q4: How skilled do you feel about communicating with people with learning disabilities who have been diagnosed with a terminal illness (from which they will die)? *Score 1 (not at all skilled) to 10 (very skilled)*

Q5: Are you aware of any resources that can support you around communicating bad news to people with learning disabilities? (eg materials, guidance, other professionals/services) *Score 1 (not at all aware) to 10 (very aware)*
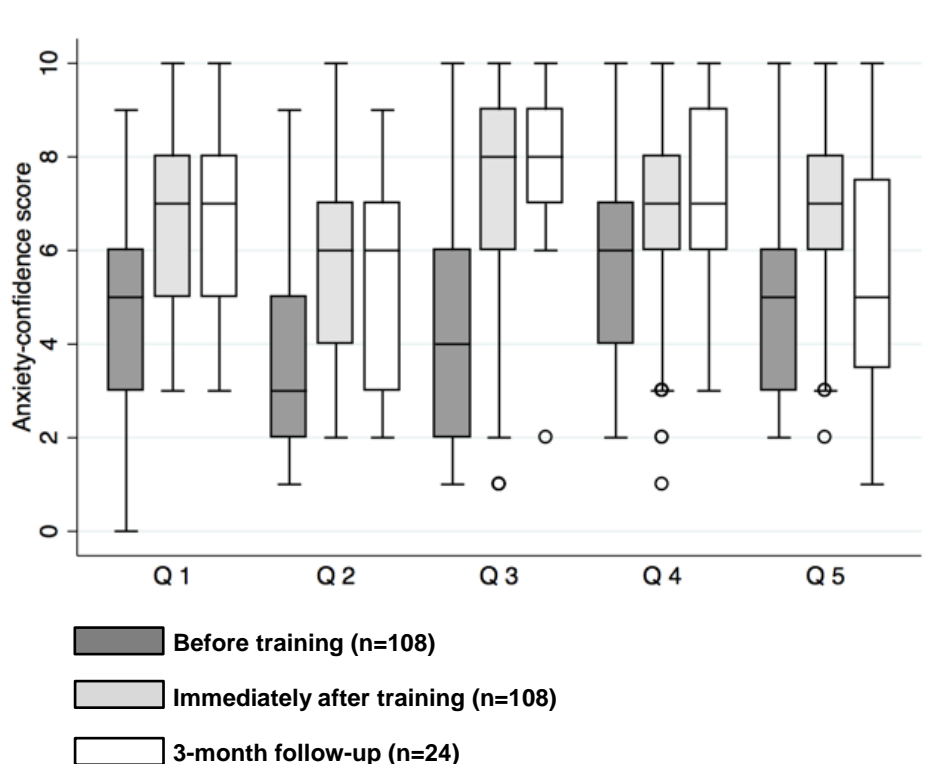
The central rectangles in the box plot span the first quartile to the third quartile (the *interquartile range* or *IQR*) – in other words, half of all answers fall within the rectangle. The line in the rectangle represents the median score. The "whiskers" above and below the box show the locations of the minimum and maximum scores given to that question by respondents.