

**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:* Most staff working in intellectual disability services will be confronted with people with intellectual disabilities who need support around death, dying and bereavement. Previous studies suggest that intellectual disability staff tend to protect clients from knowing about death and avoid communication about death. The aims of this study were to gain further insight into the individual, organisational and contextual factors that affect the communication of death-related bad news to people with intellectual disabilities by intellectual disability staff, and to develop guidelines for services to enable appropriate communication with clients about death and dying.

*Method:* Semi-structured interviews were held with 20 social care staff working in intellectual disability residential or supported living services in London, who had supported a client affected by death-related bad news in the past six months.

*Results:* Staff found supporting people with intellectual disabilities around death and dying extremely difficult and tended to avoid communication about death. The following factors had a particularly strong influence on staff practice around communicating death-related bad news: fear and distress around death; life and work experience; and organisational culture. Staff attitudes to death communication had a stronger influence than their client's level of cognitive or communicative abilities. Managers were important role models.

*Conclusions:* Service managers should ensure that all their staff receive training in death, loss and communication, but also, that staff are enabled to reflect on their practice, through emotional support, supervision and team discussions. Future work should focus on the development and testing of strategies to enable intellectual disability staff to support their clients in the areas of dying, death and bereavement.

## Keywords

Intellectual disabilities, communication, death, palliative care, bereavement, support staff

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## Introduction

Death and dying have become highly relevant topics within intellectual disability services. With increasing longevity of people with intellectual disabilities, more will live for a significant part of their lives outside their family, in residential care settings or supported living settings. Currently, almost half of all adults with intellectual disabilities in the UK who are known to intellectual disability services live in such settings (Finlayson et al. 2010). Their move to residential or supported living services may have been provoked by the death or illness of a family member. With passing time they are likely to be exposed to more deaths among those they know and love; for example parents and other relatives, friends, house-mates and support staff. Ultimately, people with intellectual disabilities will themselves be dying. Increasingly, therefore, staff working in supported living and residential care settings will need to deal with death and dying. There is evidence that support staff are motivated to provide continued care for clients who approach the end of life, but lack skills and confidence in this area, which can lead to considerable emotional stress among staff (Tuffrey-Wijne et al. 2009; Karen Ryan et al. 2011a; Wiese et al. 2012; Todd 2013).

Difficulties around communication have been consistently highlighted as a key challenge in supporting people with intellectual disabilities around death, dying and bereavement (Tuffrey-Wijne & McEnhill 2008). Whilst nowadays, most doctors and nurses are in favour of telling patients that they have a terminal illness (Seale 1991), this does not occur to the same degree for people with intellectual disabilities, who are often still protected from knowing about death (Tuffrey-Wijne et al. 2013). In a review of the literature around intellectual disability and decision making at the end of life, Kirkendall et al. (2016) found that people with intellectual disabilities were often assumed to lack capacity and therefore not informed of a terminal diagnosis. This is of some concern for several reasons. Being shielded from knowledge of their own impending death prevents people with intellectual disabilities from being meaningfully involved in their own advance care planning (Mullick et al. 2013). One of the consequences of this is that decisions are made by third parties, whose values may not necessarily reflect those of the individual, and who may have a different

perspective on the person's quality of life (Kirkendall et al. 2016). Furthermore, knowledge of expected death of a loved one enables people to anticipate the death and thus allow for a period of anticipatory grieving. It has been recognised that a lack of anticipatory grieving before the death is a risk factor for complicated grief afterwards; it can lead to particularly stressful grief episodes even years after the death (Moon 2016).

Three studies are of particular interest with regards to the practice of death communication by staff in residential and supported living services. Wiese et al. (2013) used focus groups and interviews to explore the way in which community living staff in Australia communicated with people with intellectual disabilities about death and dying, and found that whilst the staff unanimously agreed that their clients should know about dying, in practice there was limited engagement about the topic. Study participants were mostly prepared to talk with their client about a family death that had occurred, but none engaged with people with intellectual disabilities who were themselves dying, except if the dying person initiated the conversation. Ryan et al. (2010; 2011b) also conducted focus groups with staff, including 64 staff working in intellectual disability settings. They found that staff were aware that people with intellectual disabilities were often deeply affected by the deaths of peers and needed preparation for such deaths; however, this did not translate into action. There was a lack of staff engagement in helping people with intellectual disabilities understand the facts of death, and support was predominantly provided after the death of a peer, rather than beforehand. These findings echo those of Tuffrey-Wijne et al (2009), who conducted an ethnographic study with 13 people with intellectual disabilities who had cancer and found that only two were helped to understand their diagnosis and prognosis; carers (including support staff) had a strong influence on this.

It seems, therefore, that staff tend to avoid open conversations around death, and that post-death communication (for example, about funerals) is easier for staff than pre-death communication. There is no evidence within the literature that open awareness and open communication before the death happens is detrimental to people with intellectual disabilities, and some evidence that it is in fact helpful (Ryan et al. 2010; Tuffrey-Wijne et al. 2012). Indeed, Ryan et al. (2011b) conclude that the quality of care provided to people with intellectual disabilities at the end of life cannot be guaranteed unless staff engage in appropriate communication with them about end-of-life care issues.

Several studies by Tuffrey-Wijne et al. explored the practice of bad news disclosure further (Tuffrey-Wijne 2012; Tuffrey-Wijne et al. 2013), using interviews and focus groups with a wide range of stakeholder groups including people with intellectual disabilities themselves. This culminated in the development of a new model for breaking bad news to people with intellectual disabilities (Tuffrey-Wijne 2012).

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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These studies have highlighted a number of salient issues related to bad news communication, which were used to develop the interview guide and initial coding framework for data analysis (see “Methods”).

It is of interest that the above studies did identify some services where there was more open communication around death. Whilst these studies have provided insight into the likely barriers to communication, it is not clear which of these barriers are particularly strong, or why some staff and some services manage communication differently. A more detailed insight into these issues will aid understanding of how barriers can be overcome within intellectual disability services and how staff can be effectively supported.

The aims of this study, therefore, were to gain further insight into the individual, organisational and contextual factors that affect the communication of death-related bad news to people with intellectual disabilities by support staff, and to develop guidelines for services to enable appropriate communication with clients about death and dying.

## Methods

### *Sample*

Semi-structured face-to-face interviews were conducted with 20 staff working in eight different intellectual disability residential or supported living services in London, UK. They represented a very wide range of experiences and backgrounds (see table 1).

Inclusion criteria were that participants had, within the past six months, been closely involved in supporting one or more adults with intellectual disabilities who had a death related bad news event. ‘Death related bad news’ was limited to: the anticipated/expected death of a person with intellectual disabilities themselves, or their relative, fellow resident or staff member; or the actual death of the relative, fellow resident or staff member of a person with intellectual disabilities. All interviewees had supported people with intellectual disabilities who had been bereaved; 13 had also supported people with intellectual disabilities who had died in the past six months. In addition, most interviewees spoke about further experiences that were longer ago.

Participants were recruited through advertising the study on social media and intellectual disability internet forums and by emailing a study information flyer to a wide range of stakeholders including local council authorities, community intellectual disability services and charitable organisations. The researchers also attended a meeting of intellectual disability service managers of one London borough, to explain the study and encourage distribution of study information. Purposive sample selection was anticipated in order to ensure representation of a range of roles, backgrounds and bad news experiences; however,

the consecutive potential participants who came forward represented such a mix, and thus were all included in the sample. Saturation of data (when no new themes or insights were found) was reached after 16 interviews, and data collection was stopped after 20 interviews.

### *Materials*

The interview guide (available on request) was developed specifically for this study, with input from a research advisory group which included three people with intellectual disabilities, a family carer, intellectual disability service managers, an intellectual disabilities nurse specialist and a care support worker. It was trialled before the first interview and adapted throughout the study to enable a more in-depth exploration of emerging themes. Whilst the interview questions related to an exploration of real-life situations, the focus was on staff behaviours, views and experiences. Details about the person(s) with intellectual disabilities they spoke about were not systematically gathered. The interview guide covered the extent to which the person with intellectual disabilities was able to understand the bad news, and how (s)he was supported with this; reasons for (non-)disclosure of the bad news; the effects of (non-)disclosure on the interviewee and on the people involved; barriers and enablers with regards to communication; and strategies for improvement, including training.

Interviews were conducted by TR (14) and ITW (6). They were held between December 2015 and April 2016, at the participants' work place, and lasted 46 minutes on average (range 20-73 minutes).

Interviews were audio-recorded and transcribed verbatim, with the exception of one interview where the participant did not want the audio-recording equipment to be used; in this case, notes were taken during the interview, which were subsequently written as field notes. Names and other identifying details were anonymised at the stage of transcription. All data was entered into Nvivo, a computer programme for qualitative analysis (Bazeley & Jackson 2013).

### *Data analysis*

The data were analysed using a Framework Analysis procedure in a series of steps (Ritchie & Lewis 2003; Gale et al., 2013):

- *Familiarisation with the interview*: Two researchers both listened to all audio-recordings and read the transcribed interviews several times.

- *Coding*: A list of initial codes was developed, based on the literature. Two researchers independently read the first few transcripts line by line, applying codes to passages that seemed to fit.
- *Developing and applying an analytical framework*: The researchers then met to compare and discuss their coding. Some codes were not reflected in the data; these were collapsed or deleted. As data collection progressed, one researcher then coded all subsequent transcripts into this analytical framework. The research team held weekly discussions about the emerging findings. Interim findings were presented to the research advisory group and a reference group of six people with intellectual disabilities, for feedback and discussion. The codes were adjusted and refined during this analytical process. For example, the code 'staff attitude towards bad news disclosure' was expanded upon to reflect the influence of staff cultural background, life experience and work experience. The code 'relationship with the individual' was expanded to 'close bonds', to reflect the influence of close, almost family-like relationships that many interviewees talked about and which affected their bad news communication.
- *Charting data into the framework matrix*: The lead researcher then read all interview transcripts again and summarised them, using the codes and emerging themes, and referring to interesting or illustrative quotes. This provided an overview of the data and data analysis whilst retaining the 'feel' and original meaning of the participants. Links were also made between interviewees; for example, differences and similarities in the coding of interviews from participants working within the same service were noted. The summaries were shared within the research team and with the research advisory group.
- *Interpreting the data*: Throughout the process, the two researchers kept memos, noting down any interesting new ideas, links or possible interpretations, with a particular focus on themes that were under-represented in the literature. Relationships between codes and themes were explored. The overall themes were identified.

### *Rigour*

Verbatim transcripts were offered to participants in order to give them an opportunity to add or amend; however, only one participant took up this offer, and no amendments were received. The participant whose interview was not audio-recorded did not want to see the field notes. Trustworthiness of the findings was enhanced by the involvement of the research advisory group and reference group. At the end of the study, the findings were presented to and discussed with over 100 intellectual disability staff (including some of the participants) from a wide range of services, as part of three training events. Feedback showed that the findings had relevance and credibility.

### *Ethical issues*

Ethical approval for the study was granted by the Research Ethics Committee of the Faculty of Health, Social Care and Education (Kingston University & St George's University of London).

It was anticipated that staff working in intellectual disability services may be deeply affected by the deaths of bereavements of the people they support. The study protocol provided strategies for supporting staff, including the instruction to terminate the interview and offer further support (including referral to a bereavement support agency) if the interviewer or interviewee was of the opinion that the interview caused undue distress. Both interviewers were skilled in sensitive communication and experienced in bereavement support. All participants were given our email address and work telephone number in case they wish to talk things through after the interview. In practice, whilst several interviewees did show signs of distress during the interview, all wanted to continue with it.

### **Results**

The following factors had a particularly strong influence on staff practice around communicating death-related bad news: fear and distress around death; life and work experience; and organisational culture.

#### *Fear and distress around death*

When asked about their communication with people with intellectual disabilities who were dying, staff often focused on the entire experience of supporting someone through the dying process, rather than on their communication. Being required to provide end of life care caused huge distress. Staff felt frightened and unprepared. Their avoidance of death-related conversations with clients stemmed in part from a fear of dealing with death in general.

*"It was really too much for me (...) I was very close to him. It was very hard, as I was his carer. His key worker (...) I felt very bad. I couldn't imagine even someone was dying." Participant 16 (care support worker, client died of cancer)*

Communicating bad news was difficult, even avoided, mostly because of worries about how the person would react and how staff would then cope with that reaction.

*"I think really I should have had the guts to tell her. But I just couldn't... I couldn't bring myself to say it (...) I didn't want to see the hurt on her face and the fear. I think she was frightened anyway. I just couldn't bear to see her that way." Participant 6 (manager, client died of cancer)*



One interviewee, who seemed able to communicate openly about death with people with intellectual disabilities, explained how difficult people's distress could be.

I was asked to tell her that [her house mate] had died. And we did it very simply, we just went to his bedroom, there was a bed, there was no [house mate] in it and I just said, "Fred is gone, he is dead." Which wasn't so difficult for me but what was difficult was her reaction, that was just heartbreaking because she was completely in despair... That's the most difficult because, you know, I can't help her with that." *Participant 5 (manager)*

The impact of the interviewees' close relationships with their clients was significant. Several interviewees cried in the interview. They described close bonds, forged through daily and intimate contact, sometimes over many years.

"We were doing handover, and then we just had to stop because there was all of us, tears in our eyes and you can't help it." *Participant 9 (manager)*

Staff found it difficult to be detached from their clients, putting themselves in their shoes and suffering alongside them.

"I am thinking about the service user, what the service user is going through. Maybe putting myself in that situation, imagining that I am going to die. It is heart-breaking... Maybe I am having to go that way one day. It is so hard... I would prefer not to be around to give that news or speak to the service user about it." *Participant 3 (care support worker, client died of cancer)*

Even those who reported to support open communication and early awareness of death appeared to avoid death conversation in practice, by using euphemisms or trying to minimise the starkness of their words.

"They put the coffin in front and they had a picture of her on top. Oh dear Lord, this is a new thing they do now. I said, 'Yeah, that's [your sister] but she's at peace now, nobody's going to hurt her, she's not feeling ill anymore, she's really happy.'" *Participant 15 (manager, client's sister died)*

Whether or not staff attempted to communicate openly with their clients about death and dying did not appear to be affected by the client's cognitive or communicative abilities. Staff who communicated openly about death with people with intellectual disabilities would find a way to do this regardless of the person's level of disability, whilst staff who avoided death communication would do so even if their client had good verbal and cognitive skills.

### *Life and work experience*

Many interviewees talked, unprompted, about personal experiences of loss in their lives. They were clear that this influenced the way in which they approached death and dying at work. Life experience could serve to prepare staff to cope with death at work, but it could also hinder, evoking painful memories.



“The amount of people I have lost in my life, I have gone through a very difficult loss of my sister (...) It doesn’t make it [*coping with clients dying*] easier – well, it does make it easier in a sense of how do I respond outside my body, but it doesn’t make it easier that I will feel less sad about it.” *Participant (manager, client died of cancer)*

Cultural backgrounds also played a part. The cultural make-up of the intellectual disability workforce in London was reflected in the wide range of nationalities among the interviewees (see table 1). One care worker from Africa commented:

“Where I come from, you don’t tell somebody they’re dying. You can’t tell somebody who is sick and dying, ‘Oh you’re going to die’. We just keep saying ‘He’s going to be alright’. Whereas here they will tell you, they will even give you a date!” *Participant 18 (care support worker)*

In terms of work experience, the lack of preparation and training for the job of social care worker was striking. Most interviewees had come from overseas and many had taken the job simply because it was the only one available to them.

“I couldn’t refuse [this job], it was through the Job Centre, so if you refuse it, they stop your money (...) Now for me, this job comes with a lot of responsibility and I wasn’t sure if I was ready for that responsibility or not. For months I didn’t want to be left alone with anyone (...) It’s not just scary for me, you have literally got someone else’s life in your hands.” *Participant 13 (care support worker)*

“In here, care staff didn’t graduate with anything, they’ve got no degree, not a very high education, and they are dealing with death and life which is so deep and profound.” *Participant 17 (manager)*

There was also a strong sense among staff that you cannot really be prepared for supporting people around death and dying, and that they mostly learned from experience. It was particularly hard to be prepared for the emotional impact of supporting people around death.

“It is a difficult area, it makes you think. Even with your personal life. I have done end of life [training] for three days with the hospice. I don’t actually feel that I have come away learning. My experience from what we have done, it didn’t teach me anything. From the personal side of it. You are taught how to spend time with service users and how to support them. But not shown the other side of supporting yourself, your staff members. Because without them you wouldn’t be able to support somebody.” *Participant 11 (manager, several clients had died)*

### *Organisational culture*

Junior staff were very clear that it was not their role to communicate about death with their clients.

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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“We are carers. When this situation happened, the managers and the seniors, they are here. I am very new here. I don’t have the moral authority or the knowledge. My job is to serve people, that’s it.” *Participant 7 (care worker, client died of cancer)*

This same participant, when asked whether she could imagine herself ever talking about death with a terminally ill client who asked if he was dying, said:

“I would say, ‘don’t think like that’, that one day everyone is going to die. Because the most important thing is to give what we can whilst the person is alive. To give juice or chocolate. To give some comfort, that is the most important thing to do. Not to have these discussions with people that are at death stage.” *Participant 7 (care worker, client died of cancer)*

There were several services where both the manager and some of the more junior staff were interviewed. It appeared from these interviews that where managers provided positive role modelling in terms of communication, and talked to their staff about death and dying, junior staff were more likely to talk about death themselves. One support worker, who was fairly new to the role, felt able to cope with supporting a client who had lost a close relative, because of the manager’s support:

“The manager more or less spoke to all of us about his situation and that he has lost [his relative]... With the prompting of the manager concerning the death, and then she said, ‘keep an eye on him’... I would say the manager is there for us, obviously... She will help.” *Participant 10 (care worker)*

Two of the intellectual disability services appeared to have clear staff support structures as well as rituals around death and dying, including opportunities for everyone to see the body, events celebrating the person’s life and preparing for funerals. This gave staff confidence that there was a ‘script’ if someone died within their service; managers would know what to do, how to support and guide them, and how to talk to the surviving clients. There seemed to be an openness about death within these organisations, which was reflected in the way they talked with clients. Clear guidance, role modelling and experience were important in this.

“For me, the most important thing was what [senior manager] taught us. She said, ‘Be as straight as possible. You know, there is no way the news *He is sleeping, he is in heaven...* Just tell, *He is dead, she’s dead, you will not see her again.*’ Because with Michael, if you tell him that Henry is in heaven now, he will ask when he comes back, you know, because he doesn’t understand that to be in heaven means that he is dead.” *Participant 5 (manager)*

This same organisation had sent an entire team for group counselling when a client was dying and operated a kind of ‘buddy system’, where all staff were linked with a senior colleague (who was not part of their management structure) for peer support.

“So there is this culture that if you’re in trouble there is someone that you can talk to... for me this was just kind of part of the support. I never was involved in looking after anyone with

cancer before, I was very new.” *Participant 5 (manager, reflecting on her first experiences of the death of a client, over a decade ago)*

This is in contrast to most other participants. Some found it helpful to talk to their managers, but in general, junior staff did not take up repeated managers’ offers to talk things through if needed, or suggestions of seeking outside support from a bereavement counsellor or palliative care specialist nurse.

“They [*managers*] try to talk to me and things. But I don’t like talking to them. It’s not about management. It’s about my feelings.” *Participant 16 (care worker, several clients died)*

Indeed, some participants seemed to use the research interview as an opportunity to reflect and debrief, which they had not done previously.

## Discussion

Most intellectual disability support staff in this interview study found working with clients who experienced death or loss extremely difficult. It confronted them with issues of mortality – not only in the people they supported, but also in themselves – causing fear and distress. They also worried that they lacked the skills, experience and mandate to communicate with their clients about death. Most staff used strategies to avoid open communication about death, even if they favoured open awareness; for example, through their choice of euphemisms when talking about death. This echoes the findings of Ryan et al (2011b) that staff were concerned that their lack of skill and experience in the area would cause harm if they engaged in open conversation.

The presence of intellectual disability, and people’s perceived inability to understand or cope with bad news, has often been given as a reason for avoiding death communication (Tuffrey-Wijne et al. 2013). It is therefore of particular interest that in this study, staff willingness and ability to engage with death communication was affected more strongly by their own attitudes than by the cognitive and communicative abilities of their clients.

Avoidance strategies used by staff to protect themselves and the people they support may be well-meaning but are not helpful and should be addressed. It is crucial to train all staff in end of life issues, bereavement theory and communication skills (Watters et al. 2012; Tuffrey-Wijne 2013; Codling et al. 2014). However, our findings indicate that education alone is not sufficient; support staff (including, and perhaps especially, the most junior and inexperienced) also need considerable practical and emotional support. Dossier and Nicol (2014) assert that working with the dying and the bereaved requires a certain level of maturity and self-awareness; reflective practice is integral to this. They propose various ways in which essential support can be provided to individual staff and teams, including

clinical supervision (either individually or as a group or team), peer-support and critical analysis of significant events. We found that staff do indeed seem to benefit from support and supervision beyond line management structures, and struggle when it is lacking. The provision of staff support therefore needs to be part of an organisational culture, where there is an expectation on staff that they talk through and reflect on the difficult issues that confront them. Staff should also be enabled to reflect on how their own personal death experiences, views and fears affect their work with people with intellectual disabilities.

There was little evidence within the interviews that team managers received support or external supervision themselves. It seems reasonable to suggest that they might benefit from this, as they too could be deeply affected by death and loss events of clients. Managers play an important role in promoting a culture of openness and sensitive support that is based on the individual needs of each person. It seems important that they talk openly with their teams about death and loss, in order to reduce staff fears and avoidance strategies. A cost effective way of providing staff support might be through inviting an external professional (such as a palliative care nurse or bereavement counsellor) to meet with the team and facilitate discussion and reflection. A key requirement for such facilitators is that they are experienced in talking about death; this is the expertise many intellectual disability services lack and need (Dowling et al. 2006).

### *Strengths and limitations*

This study built on previous work by using themes emerging from the literature as a starting point, which enabled us to focus on the most pertinent issues and enhance insight into previously reported phenomena. Findings from small qualitative studies cannot be generalised. It is important to note that the intellectual disability workforce in London is particularly culturally diverse and may not reflect settings in other geographical locations. Furthermore, the views of families or people with intellectual disabilities themselves have not been addressed in this study. However, the findings can be used by service managers to look at their own settings and reflect on the relevance for their own workforce.

### **Conclusion**

Most staff working in intellectual disability services will be confronted with people with intellectual disabilities who need support around death, dying and bereavement, and thus face difficult conversations that require a sensitive approach. Staff need to be well supported to enable them to manage this difficult area of their work. Service managers should ensure that all their staff receive training in death, loss and communication, but also, that staff are enabled to reflect on their practice, through emotional support, supervision and team discussions. Further research is warranted to investigate the generalisability of

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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these findings. The first author currently leading a UK-wide survey of intellectual disability services to assess the scale of the issues and possible strategies for staff support. Future work should focus on the development and testing of strategies to enable intellectual disability staff to support their clients in the areas of dying, death and bereavement.

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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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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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**Table 1: Participant characteristics**

| <b>PARTICIPANTS</b>                             | <b>n=20</b> |
|---|-------------|
| <b>Gender</b>                                   |             |
| Male  | 3           |
| Female  | 17          |
| <b>Age</b>                                      |             |
| 26-40   | 6           |
| 41-60   | 12          |
| 60+   | 2           |
| <b>Role</b>                                     |             |
| Care worker/support worker                      | 13          |
| Manager/assistant manager                       | 7           |
| <b>Country/area of origin</b>                   |             |
| Eastern Europe                                  | 6           |
| Africa  | 6           |
| UK  | 4           |
| Southern Europe                                 | 1           |
| Rep. Ireland                                    | 1           |
| Caribbean                                       | 1           |
| South America                                   | 1           |
| <b>Previous training</b>                        |             |
| None  | 6           |
| Vocational training<br>(incl: Care; Management) | 7           |
| University graduate                             | 3           |
| Not specified                                   | 4           |