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## ORIGINAL ARTICLE

# Paid carers' understanding and experiences of meaningful involvement in bereavement for people with intellectual disability when a significant other is dying

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## Abstract

**Background:** Wider communication about death and dying for those with intellectual disabilities has been highlighted as being of key importance.

**Objective:** To gain the perspective of paid carers based in residential homes about meaningfully supporting individuals with intellectual disabilities in the bereavement process.

**Methods:** Semi-structured interviews were conducted with paid carers working across two residential homes.

**Results:** Four themes were identified: (a) challenges in having conversations about death and dying; (b) meaningful involvement of residents in the bereavement process; (c) the relationship between paid carers and residents (including the impact of a resident's death on paid carers); and (d) the support needs of paid carers.

**Conclusions:** The recommendations from previous research of meaningfully involving people with intellectual disabilities in the bereavement process have not filtered fully into practice. Paid carers still highlight the need for specialist support and advice to help them discuss and increase involvement in death and dying.

## KEYWORDS

bereavement, death and dying, intellectual disabilities, meaningful involvement, staff support, training

## 1 | INTRODUCTION

The care provided for people with intellectual disabilities when facing death and dying is an area that has received increasing attention in recent years (Tuffrey-Wijne et al., 2016). As adults with intellectual disabilities are living longer they are more likely to experience the death of a person important to them, which includes the loss of family, friends, co-residents with intellectual disabilities, and even the death of a professional carer or support worker. People with intellectual disabilities experience grief and research shows that many individuals have a very similar experience of bereavement to the general

population (Lord et al., 2017; McEvoy et al., 2010). However, this may be more challenging to identify as people with intellectual disabilities may demonstrate their grief in ways that may not be readily recognised by others, such as lethargy, neurotic disorders, irritability, becoming louder or quieter and becoming scared of their own death (MacHale et al., 2009; MacHale & Carey, 2002; McEvoy et al., 2010).

Paid carers, healthcare professionals and relatives are often the only people available to provide bereavement support (Clute, 2010), but they may be unsure of how to communicate and explain death and dying to the individual experiencing grief (Bennett, 2003; Lord et al., 2017). Paid carers have also been found to overestimate the individual's

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understanding of the concepts of death and dying and to underestimate the likelihood of changed behaviours following a death (MacHale et al., 2009). Tuffrey-Wijne and Rose (2017) found that care staff tended to avoid conversations around death and dying and found them very hard to undertake. This was influenced by their own emotions, personal and work experiences and the culture of the organisation. There were concerns of upsetting the people with intellectual disabilities and euphemisms were often used as way of reducing the harshness of the situation. Tuffrey-Wijne and Rose (2017) also found that paid carers limited the involvement of individuals with intellectual disabilities as a way of protecting them from the realities of death. Other studies have confirmed these findings, with issues arising from not informing the person with intellectual disabilities of the nature or treatment of a terminal illness, the circumstances of a death, the role of the undertaker/coroner and/or not offering the chance to attend the funeral or to view the body (McRitchie et al., 2014; Weise et al., 2014). Therefore, individuals with intellectual disabilities are at greater risk than the general population of not being involved with, or not being informed about, a death.

In a similar way to the general population, people with intellectual disabilities who have not been informed of an expected death will have an increased risk of experiencing psychological problems and a more complicated grief (MacHale & Carey, 2002; Moon, 2016). Encouragingly, involvement is increasing with more people with intellectual disabilities being included in funerals than in the past (Tuffrey-Wijne & Rose, 2017). This involvement has been reported to be important, although hard for carers to implement, as individuals with intellectual disabilities may say they continue to love and miss the deceased person (Thorp et al., 2018). However, taking part in bereavement rituals may aid the understanding of the abstract concept of death. This includes using simple and direct language about death and dying as well ensuring the person is involved in the funeral and able to reminisce about the deceased after the event. Furthermore, individuals can feel a sense of pride in being involved in such rituals (Lord et al., 2017; McRitchie et al., 2014; Morgan & McEvoy, 2014). Therefore, supporting people with intellectual disabilities requires a different, more specialised approach compared to the general population.

There is no standard agreed minimum level of training in order to be a carer. Many do work towards a care certificate, which is a set of 15 standards around health, safety, safeguarding and life support (Skills for Care, 2021), although none of these standards include death and dying. In their interviews with residential and paid carers, Tuffrey-Wijne and Rose (2017) noted the poor training and preparation their participants had received in order to take on the role as a social care worker. With regard to bereavement support, only 27.5% of care staff had some guidance or training on working with people with intellectual disabilities who are terminally ill or bereaved (Tuffrey-Wijne et al., 2020). In other studies, staffs have reported having a lack of knowledge, feeling unprepared and unconfident in operational procedures after a death (McEvoy et al., 2010; Morgan & McEvoy, 2014). Furthermore, care agencies are not always aware of the grief experienced by both the residents and the care staff (McEvoy et al., 2010), and therefore they may not appreciate the need for support. Interventions to provide bereavement and grief training and support for paid carers have shown self-reported reduction in worry, self-

reported improvement in skill and increased confidence in communicating about death and dying (Tuffrey-Wijne & Rose, 2017). However, they do not seem to have been implemented well, if at all, into daily practice (Tuffrey-Wijne et al., 2017; Watters et al., 2012).

Given the rise in research in this area, this study aimed to find out how the research so far has filtered down into practice, with the key focus on how paid carers currently understand meaningful involvement in the bereavement process. More specifically, we looked at how this was seen in the specific situation of when a fellow resident had died or was dying.

## 2 | METHODS

### 2.1 | Participants and procedure

Using regional knowledge and networks, residential homes that had experienced a recent bereavement were targeted. Three residential homes were identified as having experienced a bereavement in the last 2 years and agreed for a member of the research team to pass the contact details of the manager to the lead researcher. Only two of these residential homes were willing and able to invite paid carers to take part and the lead researcher arranged a suitable time to come to each site to speak with the paid carers.

### 2.2 | Ethical considerations

University ethics approval was obtained from the School Ethics Committee. All participants were given the opportunity to ask questions and were informed of their right to withdraw at any time, without giving a reason. Participants gave written consent before taking part in the interviews. They were also informed that only the research team would have access to their data and no identifiable information would be reported. As participants were recruited through their manager, no personal information was obtained. Interview data were stored on a University network in a password-protected NVIVO file.

### 2.3 | Design

Qualitative methodology using thematic analysis of semi-structured interviews was employed as a method to identify, organise and analyse the themes found within the data. This method allows similarities and differences within research participants to be identified and unanticipated insights can be highlighted. Furthermore, this approach is useful in small exploratory studies and has been used in similar topic areas to understand the carer perspective (Tuffrey-Wijne & Rose, 2017).

### 2.4 | Materials/measures

A topic guide was developed by the research team, which included a specialist community matron, a health psychologist researcher and a

palliative care academic. This included background information about the carers themselves and the level of support and preparation carers felt was given to residents and to themselves before and after a death. The views of carers on how they were able to meaningfully involve residents throughout the bereavement process were sought, particularly what they considered most important when supporting and preparing them for a death.

## 2.5 | Data analysis

Thematic analysis was used, as outlined by Braun and Clarke (2006) to identify patterns, concepts and themes across the data. Two members of the research team (J.H., A.S.) read and re-read the interview transcripts to gain familiarity, to start looking for patterns and to then independently generate codes on NVIVO12. Differences were compared, discussed and an agreement reached. These codes were combined into themes and subthemes, following discussion with all the authors, aligning with relevant quotes. Revision and refinement of the themes was undertaken until all were assured that the themes were clearly confirmable. A log of activity and notes on the development of the themes was kept. To limit potential bias, the two lead members (J.H. and A.S.) were independent of the topic area and of the clinical services.

## 3 | RESULTS

### 3.1 | Descriptives

Seven paid carers (two males and five females) were in post at the time of a resident's death and agreed to take part, which included support workers, assistant service managers, and a service manager. The length of employment of the paid carers ranged from under 1 to 19 years – with a wide variation of experience from many years of experience to only a few months. All were based in residential homes that cared for individuals with significant intellectual and developmental disabilities, with commensurate challenges to communication.

### 3.2 | Themes

The four main themes and key points within each are outlined in Table 1.

#### 3.2.1 | Conversations about death

This first theme goes beyond communication, looking at how and when paid carers discuss death and dying, and their own level of comfort in discussing this topic. A few participants mentioned the real-life challenges to know the level of understanding when talking about

**TABLE 1** Main themes

| Theme                       | Key points   |
|-----------------------------|--|
| Conversations about death   | <p>Paid carers were unsure how much residents could understand about a fellow resident's death.</p> <p>Paid carers were concerned about upsetting residents.</p>   |
| Meaningful involvement      | <p>Meaningful involvement was seen as a good thing by staff but they were unsure of the appropriate level.</p> <p>Involvement of residents occurred mostly after a death.</p>                              |
| Carer–resident relationship | <p>Close relationships are formed between paid carers and residents.</p> <p>Paid carers experienced grief and upset at the death of a resident.</p>  |
| Staff support               | <p>Little formal support was provided but there was much informal support.</p> <p>Limited utilisation but positive experiences of using external organisations such as local hospices/NHS specialists.</p> |

death to the individuals in their care, as many had limited verbal communication skills. There was also a genuine concern about upsetting individuals in talking about a recent death.

Carer 4: The problem is how much they would understand of it that was the problem. We did have conversations with them but at the end of the day it was difficult to determine whether they've understood what you are saying or not.

Carer 3: But I suppose if it was a service user that was up the other end of the home or whatever that didn't really have much one-to-one time with that person, if it wasn't really going to benefit them, I probably wouldn't discuss that because it could cause behaviours, it could cause certain things, do you know what I mean?

Efforts were made to support the residents, especially if they were having particular struggles, but the emphasis was very much after the death and on the death rituals as a way to help. When death was discussed, it was not referred to directly or at length with people with intellectual disabilities. This is highlighted in the quote from Carer 7, which shows that it was common for paid carers to use euphemisms as a way of reducing the severity of the situation.

Carer 2: Yes. She was helped through... well, cause she was very upset, she was helped right through and things tried to be explained to her, so and then to help her get through it they made, you know, a goodbye card and stuff like this, you know, to go in

the coffin for her and the rest and that helped her get through it.

Carer 7: So, but from the client's point of view, I don't really know how much they understand about death, but then again you look at one point for example, I'll take a specific one in number two [be]cause that's where one of my clients who passed away, and I think that client it's very raw with most of the staff even today to talk about. And I say, 'Oh, [resident 2]'s gone to heaven', you know, '[resident 2]'s gone to heaven, she's not coming home, I'm sorry', you know, and she would just go, 'Oh dear, oh God'.

Despite these efforts to protect residents from the harsh realities of death, it was recognised by one paid carer that this was not necessarily effective, as the residents were aware that something was going on.

Carer 1: Well some of them, they were aware that something's not right and something's going on, so we didn't want to tell them like straight away, 'Oh, that person's died', because that's not nice. But they did know that something's happening.

### 3.2.2 | Meaningful involvement

A person-centred care approach is needed to have meaningful discussions and involvement. Without the full understanding of the impact of grief and loss, paid carers might believe they are taking a 'person-centred' approach when they are not. This can be by over protecting the individual or by taking a generalised approach in which everyone does the same, such as everyone attending the funeral. This is reflected in the two subthemes, which are concerned with how paid carers understood meaningful involvement in the bereavement process and their experiences of involving people with intellectual disabilities.

#### *Staff understanding*

In line with taking a person-centred approach, most paid carers agreed that it was a good idea to involve their residents in the bereavement process as well as the death rituals, with some insightful reflections highlighting the importance of being honest and transparent.

Carer 1: No, I think it's good to involve them as well, because, well, they feel a loss as well. If we're losing somebody, all the energy at home changes and they can feel it as well. So, if they are involved in their goodbyes that's really important as well.

Carer 4: I think it's just to engage them in meaningful activity, so they are engaged in whatever they are

doing, so that they don't lay idle for too long because what I observed is it's when they are idle that ... for example we ... I was talking about the music. The music is playing and you just see somebody, tears coming out. You don't know whether the tears are ... that they are enjoying the music, or they have remembered something.

Carer 5: For me individually the concern is not lie to them. So try to not talk that much, to do not get trapped myself in my words, so just try to in a clear and short sentence, try to explain what happened.

However, some paid carers were unsure if meaningful involvement was possible with barriers around the uncertainty about the individual's understanding, as well as maintaining the privacy of the individual who was dying.

Carer 2: That is a hard one. It would depend on the resident, 'cause some of them aren't capable to process it, some of them are, but some of them aren't interested in that person, don't know much about them. So that is a hard one.

Carer 3: So yes, it's quite hard to get someone involved along with someone's end-of-life stages, I think, because it's not really ... it should be kept quite private.

#### *Resident meaningful involvement*

When asked about their experiences of involving individuals with intellectual disabilities in the bereavement process, the lack of understanding and/or relevance was reiterated.

Carer 3: The other service users either didn't really understand what was going on or didn't have a very, you know, wasn't really relevant to go into detail with them, because... in the daytime didn't really mix...

There was no mention of involving individuals before a death occurred. The carers talked about how they involved people with intellectual disabilities following the death of a fellow resident, which took a person-centred approach, including providing reassurance, making a card, writing a goodbye letter, attending the funeral and planning the wake.

Carer 2: ...Well like I say, it was to make a goodbye card and goodbye letter and just little things like that and it helped her. Helped her get through it.

Carer 4: ...I won't say there was a structured process of doing it. There wasn't. It was more like an informal conversation with them. But all the

funerals, we made sure they were all there... we made sure.

that chat, it was just a half an hour chat, it's not good enough.

### 3.2.3 | Carer-resident relationship

The impact of a resident's death on paid carers is highly pertinent as it may impact on their support of and communication with the residents. It was very clear that the paid carers developed strong relationships with the people with intellectual disabilities and that they worked very hard to provide the best care and end of life care for them. Furthermore, paid carers very commonly experienced grief themselves over the loss of a resident, which they struggled with.

Carer 3: Yes, she had a soft spot for me... out of all of us here at the home she'd have wanted me to have been... I did have a really good relationship with [resident 1], yes.

Carer 4: You end up being connected with them and it becomes very difficult to move yourself away from this thing, somehow you end up involved to the end.

Carer 5: [Staff 1] gave me a lot of support... I remember that she just hugged me because I couldn't keep myself together and I was crying a lot because it's a negative impact, on us...

### 3.2.4 | Staff support

Given the impact of a resident's death, it was pertinent to understand how paid carers were supported. This support was variable. One carer felt that there was managerial support given around the end of life, although this was on request rather than formal or structured support.

Carer 3: We did, we had full support of the management as well. They were telling us if we need any time, talk to them or [if] we not feel that we can support this person this day, they were actually quite involved in their care as well and yes, we could always count on their support as well.

Much of the support that paid carers talked about was informal from colleagues or a short chat from their managers, which sometimes was not enough.

Carer 2: Well, just other members of staff, they've been really supportive...yes, we've got a good network.

Carer 6: They didn't have enough support. Like I said, when [resident 4] passed away we had the manager who came in and had a chat with me, but

Two paid carers did mention external support such as from a local hospice and the district/intellectual disabilities nurses, which was positively received. This does not appear to be something set up specifically but was an available resource.

Carer 5: This time was a bit more hard because I was a bit by myself over the weekend with the staff - by myself with [resident 3]. The NHS gave us especially the district nurse, she gave lots of help, lots of help.

Carer 7: But with [resident one], we did... somebody came, LD [learning disability] team came to chat with us 'cause they realised that we were so... it was very raw, and this nurse came one day and said like, 'Oh, let's just talk about [Carer 7], we're here to support you and everything'.

One striking comment was that more was needed to prevent prolonged grief for both paid carers and individuals under their care.

Carer 6: ...it would be good after the occasion and then people just sit down and talk about it rather than... because basically it seems like they're leaving people to grieve for the rest of their... people may need that support and different people may need different level of support.

## 4 | DISCUSSION

### 4.1 | Conversations about death

Most of the paid carers interviewed recognised that the people with intellectual disabilities were impacted by the death of a fellow resident. However, the level to which it was thought to be an issue varied amongst them, and some did not think it would have an impact at all. Paid carers found it challenging to know how much the individuals understood about death and dying. They were not comfortable having direct conversations, particularly in relation to a fellow resident. Other words were often used to describe the situation, such as 'going to heaven' or 'going up to the sky'. This has been found in other research with staff reporting feeling scared and unprepared to have conversations and deal with death in general (Morgan & McEvoy, 2014). Tuffrey-Wijne et al. (2020) highlighted that there is a high level of skill and confidence needed to communicate about death and dying, but there is no standardised requirement for training. Furthermore, the care

certificate that many paid carers work towards does not contain a standard on this topic.

## 4.2 | Meaningful involvement

The majority of involvement discussed by the paid carers in this study was around the involvement after a death had taken place. There was limited acknowledgement of the need for involvement beforehand and reluctance to divulge information about a fellow resident out of respect for their privacy. This is reflected in the literature with many studies looking at the post-bereavement period with only a few, including Morgan and McEvoy (2014) and Tuffrey-Wijne and Rose (2017), looking into issues relating to an expected death. Other studies have highlighted the importance of the quality of the involvement and that people with intellectual disabilities will vary in the support that they need to cope with grief (Clute, 2010). It was evident that the paid carers had considered some of these elements, such as providing a supportive environment and making memorials, but other aspects, such as visiting funeral homes and offering bereavement counselling, were not mentioned.

## 4.3 | Carer-resident relationship

While it is recognised that paid carers grieve when an individual dies (McEvoy et al., 2010), there is little research around how paid carers may have developed close bonds with residents, which in turn affects the support they provide. Within the current study, the dedication and hard work that was given to the individuals with intellectual disabilities was evident and their well-being was always prioritised. This is reflected in the decisions that were made for the residents, the way that paid carers went above and beyond when caring for a person with intellectual disabilities who was dying and the involvement in the death rituals after a death had occurred. This is pertinent for the key workers as they may be particularly close to the individual dying and undertake the majority of interactions. Moreover, this may have been over many years.

## 4.4 | Staff support

It came through clearly that paid carers felt a lack of formal support around when and how to have conversations about death, bereavement and the bereavement process, and how to manage their own grief. Surprisingly, there was little mention of the specialist intellectual disability teams that provide services to the residents and paid carers at these residential homes. However, the carers who did mention these services were very positive. The lack of knowledge and confidence is found in the literature which stresses the importance of providing support to people with intellectual disabilities to identify and manage their feelings, emotions and reactions to a loss and its aftermath (McEvoy et al., 2010; Morgan & McEvoy, 2014).

Care agencies need to ensure that paid carers are aware of the available support and recognise training and support around death and dying as an area of real importance. Service managers may be key in supporting death-related conversations and embedding training, reflection and support into the working lives of intellectual disability staff (Tuffrey-Wijne & Rose, 2017). The personal attributes of paid carers, rather than their communication skills and cognitive ability, play a fundamental role in enabling openness to the topic. These personal aspects have been shown to lead to conversations about death (Tuffrey-Wijne & Rose, 2017).

## 4.5 | Strengths and limitations

The main limitation of this work was that it was carried out with a small study sample and in a limited geographical area. In addition, only the perspective of paid carers was considered in this study, and it was not possible to get a wider perspective from individuals with intellectual disabilities and their family, which would have been very helpful in understanding these issues. Furthermore, the residential homes that have greater challenges in this area may be less likely to take part in research, and those involved in this study may not be representative of the wider community. However, the findings are consistent with the wider body of research in this area, supporting the development of a greater knowledge base and raising awareness of the topic.

## 4.6 | Implications and future directions

The current research around the importance of meaningful involvement for individuals with intellectual disabilities in the bereavement process does not seem to have been accepted within normal practice. There are some positive steps around after a death has taken place, but very little in advance of an expected death. In addition, little formal support for paid carers is in place. Suggestions for future research would be to develop person-centred end of life policies and practices that are then assessed. Guidelines could then be generated for paid carers to have more meaningful conversations around death and dying. These guidelines would be helpful when a resident dies, providing information as to where to get support for the paid carers themselves and how to support and discuss with other residents. This in turn would promote and increase a better bereavement experience for people with intellectual disabilities, improving their quality of life and reducing related health and behavioural issues.

## 5 | CONCLUSION

In line with research in this area, this study highlights the need for the meaningful involvement of individuals with intellectual disabilities when faced with an expected death, and shows that this is still not happening fully in practice. Specialist services and external organisations are available to provide support and should be better utilised in

residential homes for staff support. The study also highlights the importance of providing appropriate and timely support and training for paid carers, enabling them to develop their skills around, and increase their awareness of, meaningful conversations around death and dying.

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## AUTHOR CONTRIBUTIONS

**Julie Hedayioglu, Sue Marsden and David Oliver:** Contributed to study design and implementation of the study, provided critical feedback and revisions on the manuscript and approved the final version for submission. **Amy Sackree:** Contributed to the implementation of the study. **Julie Hedayioglu and Amy Sackree:** Contributed to the analysis of the dataset.

## CONFLICT OF INTEREST

The authors declare there is no conflict of interest.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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