

Moral distress in carers for people with an intellectual disability who died during the COVID-19 pandemic, a template analysis extending the Barlem and Ramos model of moral distress.

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Abstract

Background

This article aims to understand moral distress in carers of people with an intellectual disability during the COVID-19 pandemic.

Method

Nine staff carers of seven people with an intellectual disability, who had been participants of the IDS-TILDA study in Ireland, who died during the COVID-19 pandemic participated in in-depth, semi-structured telephone interviews. Template analysis was used to analyse the interviews.

Results.

Obstructions in performing their duties left carers feeling powerless and experiencing moral conflict distress, moral constraint distress and moral uncertainty distress. Most managed to connect to the moral dimension in their work through peer support, understanding they fulfilled the wishes of the deceased, and/or thinking about how they or others did the best they could for the person they were caring for.

Conclusions

This research demonstrates that whilst restrictions may have been effective in reducing the spread of COVID-19, they were potentially damaging to carer wellbeing.

Keywords

Moral distress, COVID-19, caring, moral resilience, moral residue, intellectual disability.

1. Introduction

This paper explores the experiences of carers, in Ireland, providing end-of-life care for people with intellectual disabilities in circumstances that necessitated disease prevention over individual psychosocial wellbeing through a model of moral distress. Carers in this instance refers to paid carers who are employed by a disability services provider. The emergence of the COVID-19 pandemic has resulted in many carers providing care in situations with scarce supplies, triaged resources and the needs of the individual being treated as secondary to the prevention of disease spreading (Hossain & Clatty, 2021). Having disease control as the top priority clashes with best practice in end-of-life care which has an emphasis on family involvement, symptom control, multidisciplinary team collaboration and bereavement support for families and other residents, all of which have been largely absent during the COVID-19 pandemic (Lapid et al 2020). The manifestation of being powerless to fulfil the psychosocial values is the experience of moral distress and its subsequent physical and behavioural manifestations.

End of life care

Access to good quality health, including end-of-life care, is considered a human right, and the emergence of the pandemic created one of the greatest challenges to providing high-quality end-of-life care (Lapid et al., 2020). During the pandemic, there are reports that hospitals have rationed scarce resources and have implemented do not resuscitate orders using criteria that have unfairly impacted people with intellectual disabilities (Bagenstos, 2020; Chen & McNamara, 2020; Lintern, 2020).

End-of-life care can be defined as:

“to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages (Izumi et al., 2012).”

Caring for people with an intellectual disability is recognised as a specialist caring role carrying its own qualifications and career pathway. Paid carers offer support in people's own and family homes, and in education and community settings, as well as in out of family home residential settings, and through providing respite services and palliative care (NMB, 2022). Carers of people with an intellectual disability may also care for individual for a more extended period than would be true for other carers and may develop long-term even family-like relationships with those they care for (McCarron, Burke, et al., 2017; Ryan et al., 2011). There have been long-standing concerns about both the readiness of healthcare providers to offer care to people with intellectual disabilities and the quality of care offered and this informed greater concerns about these issues during COVID-19 (McCallion, 2020).

End-of-life care for people with an intellectual disability can be particularly challenging, and difficulties can arise around uncertainty of needs, communication, and pain management (Adam et al., 2020; McCarron et al., 2022; Voss et al., 2019). End-of-life care in this group includes shared decision making, open communications, physical, psychological, bereavement and spiritual support for the person and their carers (Bekkema et al., 2014; McCarron et al., 2022; Moro & McGinley, 2021). End-of-life experiences for people with an ID in Ireland are individualised and people tend to be either live as part of an extended family or within ID residential services and access services dependent on their needs (McCarron, Burke, et al., 2017).

Carers have built up relationships with the people they care for over a long number of years and often have a deep sense of attachment to the person and bereavement when the person dies (McCarron, Burke, et al., 2017).

During the pandemic, carers have experienced high levels of stress, depression, anxiety, work related burnout and feelings of defeat and entrapment (Linehan et al., 2022; McMahan et al., 2020; Sheerin et al., 2022; Willner et al., 2020).

Moral distress

Moral distress describes the adverse psychological reaction experienced by health care workers when faced with having to act in a manner contrary to their ethics, core belief system, or moral code, in care provision (Jameton, 1984; Källemark et al., 2004; Ullrich et al., 2020; Weigel, 2019) or when there is a disconnect between the dictates of professional and personal judgement and the limitations of care imposed by healthcare systems (Sheather & Fidler, 2021) leaving carers powerless to act on of their caring commitments (Walsh, 2018). Moral distress can be caused by current situations or by retrospectively questioning one's earlier decisions (Crane et al., 2013).

Moral distress has been reported for nurses and carers in palliative care, residential childcare, and community-based care (Brazil et al., 2010; McMillan, 2020; Sunderland et al., 2011), there has been no research into moral distress in carers of people with an intellectual disability.

Moral distress in carers can lead to emotional strain, burnout, and poor levels of care (Brazil et al., 2010). Research with carers working in palliative care has found that moral distress occurs in three areas; informal caregivers, challenging clinical situations and service delivery (Brazil et al., 2010).

Barlem and Ramos (2015) have proposed a conceptual model describing how powerlessness is experienced when carers have no chance to recommend, argue for, support or plead on behalf of the person in their care (Walker, 2016), causes an obstruction, or a blockage in the process of moral deliberation. This blockage prevents the satisfactory fulfilment of the deliberation and leading to a loss of ideals and the mortification of professional interests, where carers the suppress their desires, suppressing the verbalisation of internal conflict (Welborn, 2019). The model of moral distress utilised was selected because it gives a complete explanation of the whole cycle of moral distress.

They argue that situations develop that challenge the carer's moral sensitivity causing them to experience feelings of inquietude or restlessness and discomfort, known as moral strangeness. The carer can adjust their moral sensitivity through a process of moral deliberation. However, if there is an obstruction to the deliberation brought about by feelings of powerlessness, the carer enters the

chain of moral distress. The chain of moral distress propels the carer to accept the imposed obstructions to their moral sensitivity, experience his or her moral resistance being reduced and see few possibilities for moral action. Within the chain of moral distress, staff carers become stagnated and experience issues such as the mortification of advocacy, where carers abandon their professional ideals, becoming inexpressive in advocacy.

Welborn (2019) argues that staff carers develop a moral sensitivity to the optimal care they should be providing, and Lutzen and Ewalds-Kvist (2013) agree that any situation where carers feel powerless in advocacy means they are subject to moral distress. The relationship the staff carer has had with the person may suggest a different form of care than what the hospital is proposing/providing, and there may be disruption in carers' ability to advocate when care decision-making and communication effectively transfer to families. Barlem and Ramos (2015) argue there are two paths the staff carer can take. In the first path the carer does not consciously notice the obstruction, they reduce their resistance to the obstruction and stagnate, which leads to adverse behavioural and physical consequences. In the second path the carer identifies the moral distress, and despite the obstruction, they perceive the moral dimension of the changed situation and revert to a situation of moral strangeness.

Moral distress can be further categorised into specific forms: moral-constraint distress, i.e., restricted from the appropriate action; moral-uncertainty distress, i.e., unsure if undertaking the correct action; moral-dilemma distress, i.e., making choices between numerous options; moral-conflict distress, i.e., disagreement about the right action; and moral-tension distress, i.e., feeling unable to share beliefs (Morley et al., 2019). Each of these forms has its own origin and supplies a more nuanced understanding of the reason for the distress. Retrospective moral distress is where on reflection, people feel distressed because of later changes in their moral code or because changing circumstances have brought a renewed and negative focus on previous decisions (Crane et al., 2013).

In response to feelings of distress, staff carers can either share those feelings with colleagues, or they can respect the client and family's wishes (Lutzen & Ewalds-Kvist, 2013). Sharing and respect both allow the addition of meaning to an event, allowing carers to perceive the moral dimension and aid in moral deliberation and moral agency. Carers who do this can escape the chain of moral distress and re-adjust their moral sensitivity. However, there may be some moral residue or leftover feelings of distress if events were deeply troubling to the carer or were very intense (Welborn, 2019).

ID

Whilst there have been reports of powerlessness for staff carers of people with intellectual disabilities during the COVID-19 crisis (Willner et al., 2020) and moderate levels of burnout brought about by excessive and irregular working hours (McMahon et al., 2020; Sheerin et al., 2022), no research has investigated the development of moral distress in those carers. Looking at moral distress as intended here may illuminate further the unforeseen consequences of COVID-19 lockdowns and inform future training to support staff carers who are meeting obstacles in the care of people with an intellectual disability at the end of life. In trying to create a “good death” carers have a moral and ethical framework in place, challenges to this framework are more acute raising the risk of moral-distress (McCarron et al., 2022). This research aims to investigate the experiences of carers of people with an intellectual disability who died during the COVID-19 pandemic through the Barlem and Ramos (2015) conceptual model for moral distress.

2. Methods

2.1 Research Design

This study is nested within the larger Intellectual Disability Supplement to The Irish Longitudinal Study on Aging (IDS-TILDA), and the data is extracted from the end-of-life component. The IDS-TILDA is a longitudinal study researching ageing in Ireland among people with intellectual disabilities

(McCarron, 2011; McCarron, Haigh, et al., 2017; McCarron et al., 2014). The end-of-life component explores the needs of people with intellectual disabilities (and their carers) at their end of life and the care and compassion they received (McCarron, Burke, et al., 2017).

2.2 Participants

Nine carers of the seven persons with an intellectual disability who had been participants of the IDS-TILDA study in Ireland and died during the first year of the COVID-19 pandemic (between January and December 2020) were included in the study. In two cases, there were two interviewees. Two people were included in two interviews as both participants had worked closely with the decedent and it was felt by the respondents that a more detailed picture of the decedents end-of-life could be given from both perspectives.

Table 1 displays the inclusion/exclusion criteria for carers eligible to take part in the end-of-life interviews.

Table 1 about here

2.3 Data Collection

Carers were interviewed in March and April 2021 via telephone by a researcher using a semi-structured interview that is based on the Views of Informal Carers Evaluation of Services Short Form (VOICES-SF) questionnaire. The VOICES-SF questionnaire was developed by the national bereavement study in the UK and was developed to ask carers about the experience of the deceased in the last months of life (Hunt et al., 2019). Following an initial pilot study administration the VOICES-SF was found to inadequately address some person with intellectual disability specific issues and these issues were addressed by adding questions on contacts with family, palliative care, and other residents and end-of-life planning (appendix 1) (McCarron, Burke, et al., 2017). The updated version includes 82 questions, addressing issues including, pain control, experiences across the last months, circumstances surrounding death, support, end-of-life care, post-death/funeral rituals. The questionnaire has been previously described in detail by McCarron, Burke, et al. (2017). The

interviews were audio-recorded and transcribed verbatim. Interviews took between 44 minutes and 94 minutes.

2.4 Data Analysis

Data for the template analysis was extracted from across the transcripts but was typically in sections where carers were describing the diagnosed conditions, the circumstances around the death and the funeral. The Template Analysis was conducted following the guidance of Brooks et al. (2014).

Template analysis is a type of thematic analysis in which an initial framework is specified, the data is initially coded using this framework, and the framework modified as needed based upon the emerging data established themes. The frameworks of moral distress were coded in advance (Barlem & Ramos, 2015; Morley et al., 2019; Morley et al., 2020) with the codes moral sensitivity, advocacy, obstruction due to powerlessness, moral stagnation, reduced resistance and perceiving the moral dimension being coded in advance. All the transcripts were read in advance several times until the researcher was familiar with the data. The transcript was coded to the template and an additional code of moral residue was added. Moral stress was garnered by comparing the definitions of the categories of moral distress to respondents' tone, intonation, and the context of their comments. For consistency purposes all the coding was conducted by a single researcher and was then reviewed and finalised in conjunction with a supervising researcher.

2.5 Ethical Considerations

Full ethical approval was received from the faculty of Health Sciences research ethics committee at Trinity College Dublin. Written informed consent was obtained from each of the carer participants.

3. Findings

3.1 Participant Characteristics

The carers had worked with the deceased for an average of 8.4 years (range 3 years to 17 years).

Eight were female, and one was male. Interviewees ages ranged from 35 to 59 (mean 45.4 years).

Three of the interviewees had been keyworker for the deceased, and all were staff carers in residential care in an intellectual disability service provider.

Four of the seven deceased were female, and three were male. Their ages ranged from fifty to seventy-three (mean = 64 years). Two of the deaths were due to COVID-19, one from cancer, two from pneumonia, one from muscular dystrophy, and one was described as a general decline. Two of the deceased had been ill for over one year, three had been ill between one month and one year, and two had been ill for less than a week.

3.2 Template Analysis

Table 2 indicates that all carers interviewed described moral sensitivities regarding either advocacy or powerlessness and all showed some element of being able to perceive the moral in the situation.

Table 2 about here

3.2.1 Moral sensitivity and moral strangeness

The data show that carers had moral sensitivities about their relationship with those they cared for and the level of care that should be given both at an individual level and a service level. Within these statements' moral strangeness was evident.

"If there was no COVID, we would have been with her a lot of the time and up and down to her and she would have had like, more or less like, nearly 24-hour care from here because that's what we do when anybody goes into hospital, we're with them." (Int1)

3.2.2 Advocacy

Before lockdowns, there was evidence that carers would advocate for the person for whom they were caring.

In this case, the interviewer is describing how they advocated for a resident to die in their usual home rather than be sent to a nursing home.

“We had got a bed, so they had actually been given a bed for him in the local nursing home. And we, everyone decided to step up and just keep him at home because that’s where he wanted to be.”

(Int7)

3.2.3 Obstruction

Obstructions or blockages in the process of moral deliberation were common throughout the transcripts.

In this case when a very ill person was presented to the emergency department hospital doctors directly objected to people receiving treatment considered necessary by the carers:

“A doctor from the general hospital, the first time [name] went down, rang and absolutely ate the head of our director [name] in [town], for sending down a service user in the middle of a pandemic.”

(Int1)

3.2.4 Powerlessness

Once obstructed, there is evidence in the interviews that carers felt powerless.

In this situation, the person was admitted to the hospital where they died alone. Whereas if a test result from a COVID-19 test had been returned they could have died at home:

“Just that that bloody swab wasn’t back. So she could have stayed at home. So she could have died at home, yeah.” (Int5, Int6)

In this case, staff felt stressed that a person with COVID-19 was in the hospital, in isolation, and left to die alone:

“You can’t go in, no-one could see her, no-one could visit her” (Int4)

3.2.5 Mortification of interests

There was evidence that carers were experiencing advocational mortification, where carers no longer advocated.

In this example staff had decided they could not advocate against a medical decision to place a do not resuscitate order on the person they were caring for:

“Now you know again that’s a medical decision, it’s not something that I could even comment on, but you know part of me did feel at the time, gosh, you know.” (Int3)

3.2.6 Reduced Resistance

There was evidence that carers had reduced their resistance to their feelings of powerlessness and were more willing to accept their situation.

In this case, having not advocated against a do not resuscitate order the carer has reduced their resistance to it by psychologically justifying the reasons for the order:

“And there was times I suppose I maybe felt a little bit kind of, just uneasy about it, but at the same time I also understood the reason behind it”. (Int3)

3.2.7 Perceiving the moral dimension

Escaping the chain of moral distress requires carers to perceive the moral dimension, or good, of the situation so they can return to moral strangeness with feelings of inquietude about the situation.

Despite feeling stress over a person being admitted to the hospital and dying alone this carer was able to understand the moral dimension through the acknowledgement from family members of the care they had given the person:

“I actually feel very proud about the care that we all gave her. I’ll change that, and I know that the family are extremely, extremely happy with the care that she received, and they personally sent us letters, thanking and everything.” (Int5)

Despite the availability of formal supports such as staff counselling or employee assistance programmes, there was no evidence of these being utilised by staff carers to help deal with any feelings of distress.

“You know like, employment assistance programme that you can ring, but we did our own little thing to support, yeah.” (Int6)

Most carers would use informal support methods to talk through their feelings and perceive the moral value of their work:

“We would ring each other and “how are you and how are you doing?” (Int8)

3.2.7 Adjusted moral sensitivity

In this example the carer has adjusted their moral sensitivity to take into account the position of the families in the process:

“Yeah, and I suppose one thing I’ve learned from all this is that really once somebody does pass away, I mean the end-of-life care you have, you know, you can have it as beautiful as you like, but at the end of the day its families isn’t it that take over.” (Int3)

3.3 Categories of moral distress

The interviews offered evidence to support three categories: moral constraint distress, moral conflict distress and moral uncertainty distress.

3.3.1 Moral constraint distress

Many carers described how they were constrained from giving the necessary support, especially where the person was hospitalised or would need further support or for themselves on how they would grieve.

In this example the carers were constrained from providing support when the person was hospitalised:

“the biggest thing from the staff group, was that when [name] left we could not support her any further that was huge for us.” (Int1)

3.3.2 Moral conflict distress

Carers felt conflicted about decisions they and others had made during and before COVID that later influenced the lives and deaths of those in their care.

This carer felt conflicted about an earlier decision to move a person to a nursing home despite that move appearing to be the correct one pre-pandemic.

"Well, I definitely would have had guilt. Had she not moved to the nursing home, she would be still alive. That's really the long and short of it, in my opinion" (Int4).

3.3.3 Moral uncertainty distress

For the carers, the COVID pandemic created uncertainty around the decisions made, how those decisions affected a person's death and the value of the carer's own efforts.

In this example the carer is uncertain as to whether the outcome for the person would have been different if they had been hospitalised outside of the COVID-19 pandemic:

"outside of the covid pandemic, would her outcome have been different, now I know eventually the outcome would be the same, but if you get my meaning, she went in at a time when it was, she did have a DNR [do not resuscitate] in place.....but she went in at a very busy time into a hospital system, that was really way over capacity, and I'm not sure, you know did they call it because of that or did they call it because it needed to be called anyway". (Int3)

3.4 Moral Residue

There was also evidence that there was a residue of leftover feelings in four of the interviews

In this instance the carer still believes that the person died because of the restrictions in place at the time and this feeling is still apparent:

"[name] didn't die of COVID. She certainly died as a result of it because she didn't get the full care that she should have gotten, unfortunately, and we all believe that". (Int1)

4. Discussion

This research aimed to understand the experiences of carers of people with an intellectual disability who died during the COVID-19 pandemic through the Barlem and Ramos (2015) conceptual modal of

moral distress. The evidence supports the conceptual model, three of the five categories of moral distress described by (Morley et al., 2019), as well as the concepts of moral residue (Epstein & Hamric, 2009; Welborn, 2019) and retrospective moral distress (Crane et al., 2013). The data highlight how the sub-optimal care caused by service closures and restrictions precipitated a mismatch between carers moral sensitivities and the reality of what could be achieved, leading to powerlessness and moral distress. These findings help to explain some of increased amounts of distress, anxiety and depression experienced by carers and healthcare professionals during the COVID-19 pandemic (da Silva & Neto, 2021; Danet, 2021; Muller et al., 2020; Sheerin et al., 2022)

The ability to recommend, argue for, and/or support the person in their care to ensure the delivery of a “good death” is essential to carers working with people with intellectual disabilities (Ryan et al., 2011). This data shows that during the COVID-19 pandemic, the rules imposed prevented carers advocating for the people they cared for. Powerlessness entered the carers into the chain of moral distress. Once in distress, some carers experienced mortification of advocacy and reduced resistance in the care delivery power struggle.

Three types of moral distress were found in the data; moral constraint distress, moral conflict distress, and moral uncertainty distress. Moral constraint distress emerges when the situation prevents the person from receiving the optimum care (Fourie, 2017). COVID-19 lockdown rules prevented carers support of seriously ill people, and offering natural grieving supports such as visiting in the hours before death and participating in rituals both before and after death. Moral uncertainty similarly arose where the carer was uncertain as to the best interest of the person. Finally, moral conflict distress occurred when carers had become retrospectively conflicted as to whether they had made the right decisions before the pandemic outbreak.

Previous research has argued that the moral dimension can be understood and managed through sharing feelings with colleagues and respecting the wishes of the deceased (Lutzen & Ewalds-Kvist,

2013). There were examples of such management here, and several of the carers realised the moral dimension through remembering the efforts they and others made in prior caring for the deceased.

When carers experience moral distress, there is a threat to professional values, patient care and moral resilience (Bartone, 2006; Daubman et al., 2020; Lutzen & Ewalds-Kvist, 2013; Morley & Horsburgh, 2021; Welborn, 2019). One of the outcomes of moral distress is the mortification of advocacy (Barlem & Ramos, 2015), and there is evidence in the data to support this.

To counteract this, supportive workplaces encourage self-help, and open discussions, to increase resilience (Hines et al., 2021). During the COVID-19 pandemic, supportive workplaces were predictive of lowering levels of distress over time in healthcare workers (Hines et al., 2021; Spilg et al., 2021). The study here did not find that carers accessed formal support such as a staff counselling helpline or internal formal psychological support but instead benefited from informal support from other staff. This preference for informal support has also been reported in other groups of healthcare professionals (Muller et al., 2020) and in unpaid carers (Patel et al., 2021). Work place social support is known to be vital in dealing with death and where people disconnect from social support they are likely to experience psychological distress in the following 12 to 18 months (Barnett et al., 2019; Smith et al., 2020). Evidence of staff still affected by a moral residue (Welborn, 2019) suggests a need to further develop informal staff support networks with key staff perhaps trained in techniques such as reflective debriefing (Morley & Horsburgh, 2021).

4.1 Implications

The study has highlighted that carers ability to care for people with an intellectual disability who were at the end of their life in a manner in keeping with their morals during the COVID-19 epidemic was challenged. This study also demonstrated that in times of high moral distress, staff carers seek support from people they know and trust rather than from helplines and other external sources.

Services need to be aware of the ramifications of moral distress, otherwise experienced carers may leave the profession due to the stress caused by feelings of powerlessness, or the service may suffer due to the stagnation of advocacy. Service providers should also ensure that staff who have worked throughout the pandemic have dealt with their moral distress and that there is no moral residue.

4.2 Limitations

The data presented in this chapter is based on interviews that were not initially intended to investigate moral distress, and none of the participants specifically mentioned such distress at any stage in their interviews. However, there is evidence within the interviews that these carers have been through a distressing time caring for a person who has died during the COVID-19 pandemic. The data is only from staff carers of people who died and did not consider unpaid carers such as family members. Future research should investigate the effects of moral distress on unpaid carers.

Retrospective end-of-life interviews risk being traumatic if conducted too soon after the death but carers' memories also risk being diluted or altered by the passage of time if conducted at too great a distance from the death (Addington-Hall & McPherson, 2001). Past research suggests that carers' responses are most stable between three and nine months after the death (DiBiasio et al., 2015) with the recall of distressing events stabilizing over longer periods of time (Addington-Hall & McPherson, 2001). These viewpoints were considered in the timing of interviews.

Residue of grief from previous deaths may have influenced the current levels of distress felt by the paid carers. However, within the data no examples emerged supporting that the paid carers were carrying over grief from previous deaths. There was evidence that many paid carers were carrying a preconceived idea about their duties and responsibilities around death of the person they cared for.

It was not apparent in the data if the decedents were already considered as close to the end of their life, or if the expectation of death may have influenced how carers perceived the

relationship. However, the data suggest that any distress was caused mostly by perceptions and concerns about how people should be supported when close to death.

4.3 Conclusion

Overall, the data indicate that the COVID-19 pandemic removed power from staff carers to advocate for those with an intellectual disability for whom they have been caring. While COVID-19 may be a “100-year” pandemic, there is learning in these findings beyond the pandemic. When carers are blocked from advocating for those they are caring for, the carer will suffer some form of distress. If carers work in a supportive environment where they receive informal support, they are more likely to discover the moral dimension. Having found the moral dimension within the event, they can recover from their distress and escape the behavioural and physical manifestations of moral distress or the lingering moral residue. However, if carers are not able to find the moral dimension, they may end up trapped in the chain of moral distress. This can lead to the mortification of advocacy, reduced resilience and potentially poorer outcomes for those they are caring for. Management in health and intellectual disability care services should be developing supports to ensure that blockages to advocacy are removed, and supportive structures for the open sharing of problems and ideas by carers are in place. Future research should look at the moral distress of family carers for people with an intellectual disability.

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Table 1: inclusion/exclusion criteria for participants in end-of-life study.

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

Table 2: Steps in the model of moral distress coded for each of the carers' responses.

Interview number and Interviewee	Moral Sensitivity	Advocacy	Powerless	Chain of distress	Perceiving the moral	Moral Conflict distress	Moral Constraint distress	Moral Uncertainty distress	Moral Residue
P1 - Int1	✓	✓	✓	✓	✓		✓	✓	✓
P2 - Int2	✓		✓	✓	✓		✓		
P3 - Int3	✓	✓	✓	✓	✓	✓	✓	✓	✓
P4 - Int4	✓	✓	✓	✓	✓	✓	✓		✓
P5 – Int5 & Int6	✓	✓	✓	✓	✓	✓	✓		✓
P6 – Int7	✓	✓			✓	✓			
P7 & Int8 & Int9	✓	✓	✓	✓	✓	✓	✓		