1 **'Powerlessness' or 'Doing the Right Thing': Moral Distress amongst Nursing Home**

2 **Staff Caring for Residents at the End of Life. An Interpretive Descriptive Study**

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1  **Abstract**

2  **Background:** Caring for dying people can contribute to moral distress experienced by

3  health care professionals. Moral distress can occur when this caring is restricted by

4  organisational processes, resources or the provision of futile care. These factors apply

5  to end of life care in nursing homes but research is lacking.

6  **Aim:** To describe how nursing home staff experience moral distress when caring for

7  residents during and at the end of life.

8  **Methods:** An interpretive descriptive design, using the critical incident technique in

9  semi-structured interviews to collect data from nursing home staff. Data were

10  analysed using a thematic analysis approach.

11  **Setting:** Four Nursing Homes in one large metropolitan area.

12  **Participants:** 16 staff:- 2 nurse-managers, 4 nurses and 10 care assistants

13  **Findings:** Participants described holding 'good dying' values which influenced their

14  practice. The four practice-orientated themes of advocating, caring, communicating

15  and relating with residents were found to influence interactions with residents,

16  relatives, GPs, and colleagues. These led staff to be able to 'do the right thing' or to

17  experience 'powerlessness', which could in turn lead to staff perceiving a 'bad death'

18  for residents.

**Conclusion:** When there are incongruent values concerning care between staff and others involved in the care of residents, staff feel powerless to 'do the right thing' and unable to influence care decisions in order to avoid a 'bad death'. This powerlessness is the nature of their moral distress.

**Key words** Moral Distress, Care homes, End of life care, Nursing Homes.

**What is already known about this subject?**

- Nurses in acute care settings experience moral distress associated with decisions related to end of life care.
- Ethical issues identified in nursing homes are similar to those identified by health care professionals experiencing moral distress in other care settings.
- Futile care contributes to moral distress.

**What this paper adds?**

- Nursing home staff experience moral distress when caring for residents at the end of life especially related to futile care, and caring for those with cognitive impairment.

- Congruence between the 'good dying' values of nursing home staff and others concerned in care enable staff to do 'the right thing' in order to facilitate a 'good death'.
- Incongruent values with others concerned in care creates 'powerlessness' to 'do the right thing' which leads staff to believe that residents experience a 'bad death'.
- Powerlessness and therefore the potential for moral distress is linked to the role held by staff, with health care assistants more likely to be in this position.

**Implications for practice, theory or policy**

- The staff role held within the nursing home influences staff experiences of moral distress. Care assistants are the most powerless to influence care decisions. Acknowledging this difference can inform the support interventions provided.
- The concept of moral distress is evolving but is visible within staff within the nursing home setting, and more work is needed to identify its contributory factors and how to better support staff.

- Staff need to be supported to manage incongruent values to minimise aspects of care which cause powerlessness (such as hospital admission avoidance schemes).

1 **<u>Introduction</u>**

2 Nursing homes in the UK provide 24 hour nursing care within long term care facilities.

3 Residents are often admitted with multiple diagnoses and complex care needs. Nursing

4 home staff provide quality care to meet the physical, mental and psychological needs

5 of the resident with limited and variable outside support (1,2,3). Palliative care

6 research in nursing homes has often focused on interventions to improve the practice

7 of end of life care, rather than exploring how staff cope with the challenges of caring

8 for residents with complex disease trajectories (4).

9

10 End of life care, defined in the UK as being in the last 12 months of life (5), has been

11 identified as the area of care which provokes ethical dilemmas due to poor

12 communication, conflict of opinions, patient suffering and lack of resources (6). These

13 ethical dilemmas have also been identified in nursing homes (7), and by nurses who

14 care for terminally ill patients in other health care settings (8). These ethical issues are

15 very similar to those that contribute to healthcare staff experiencing moral distress

16 (9,10,11,). Jameton (12) proposed that moral distress occurs when a nurse knows the

17 right course of action to take but, due to organisational constraints, is prevented from

18 carrying out the action. Conceptually, moral distress has evolved and more recently

1   been defined as 'a challenge that arises when one has an ethical or moral judgement

2   about care that differs from that of others in charge' (p298) (13).

3

4   Nurses' coping strategies are not always successful and, as a result, morally distressing

5   situations can affect the quality of patient care (14). This is relevant to the nursing

6   home staff population because experiences of moral distress can lead to 'burnout',

7   higher sickness levels and more staff resigning from their positions (15). Addressing

8   moral distress, by the provision of appropriate staff support, has been found to

9   improve staff retention, sickness levels and lead to improvements in the quality of care

10  provision (16). These areas have been acknowledged as problematic within nursing

11  homes (3).

12

13  Prior research on moral distress in care environments involving older people (17) has

14  used quantifiable measures of moral distress (15) to identify contributory factors to

15  the presence of moral distress. A difference between acute and long term geriatric

16  care settings was identified with respect to the causes: futile care caused more moral

17  distress in acute care settings, and cost saving caused greater moral distress in the long

18  term care setting (17). Research in Canada found that the way nurses respond to

19  distress was influenced by the quality of leadership, and that discussions of ethical

1 situations were best facilitated where good leadership existed. (18). Nurses in long

2 term settings experienced an increase in moral distress when they were unable to

3 have ethical debate (17). However little is known about the experience of moral

4 distress within nursing homes. The aim of this study was to understand how nursing

5 home staff experience moral distress when caring for residents coming to the end of

6 life.

7

8 **Methods**

9 An interpretive description research design (19) was adopted for this study. In this

10 approach a practice related goal is identified. The goal in this study was to understand

11 the experience of moral distress when caring for a resident at the end of life. An

12 interpretive descriptive study requires a thorough literature review to provide

13 scaffolding for the study (19) along with the acknowledgement that the researcher

14 brings 'theoretical baggage' to the study, which was reflected on and documented as

15 part of the research process.

16

17 *Setting*

1  The study was undertaken in a large borough in the South East of England which had

2  17 nursing homes, consisting of a mixture of large national companies and small

3  independent homes.

4

5  *Sample*

6  Six homes were randomly selected (3 from large national companies and 3 from small

7  independent homes to capture differing organisational cultures) and the managers

8  were contacted. Managers from four nursing homes agreed for the staff to take part

9  and for the researcher to visit the home to provide additional information on the study

10  to the staff.

11

12  **Participants**

13  Participants (nursing home staff) were invited to participate and those interested

14  contacted the researcher expressing an interest in being interviewed (see Table 1 for

15  demographic characteristics).

16

17  *Data collection*

18  Interviews started with a reminder of the aim of the research, and the focus was on

19  examining situations where the participants had cared for residents at the end of life,

1    where they had achieved the care outcomes or where they had been unable to

2    achieve them due to circumstances beyond their control.

3    The critical incident technique was used to collect data within a semi-structured

4    interview format. The Critical incident technique allows defined incidents to be the

5    focus of the interview (20) in this study these were identified as episodes of care

6    involving residents whom they had known and cared for who had died. Concentrating

7    on these incidents was helpful in that the focus of the interview was defined prior to it

8    taking place, which allowed staff to think about their own incident or incidents they

9    had found positive or challenging identifying the most relevant incidents to answer the

10   research question. Nursing home staff are constrained by time as the work

11   environment is demanding with many shortages of staff focusing on specific incidents

12   utilised the time available to obtain appropriate data. After each interview reflective

13   notes were made and broad ideas and themes were noted, these informed

14   subsequent interviews and enabled probing of issues which were repeated by

15   participants informing more in depth analysis.

16

17   *Analysis*

18   Interviews were transcribed using a denaturalized approach (21) and checked against

19   the original recordings. Twelker (2003) recommends that no less than 50 incidents be

1    collected within a study using critical incident technique. In practice the precise

2    number of required incidents can only be known after preliminary analysis takes place

3    to ascertain the quality of the data. Fifty incidents was the minimum number of

4    incidents adopted to achieve in this study after preliminary analysis of the data, 63

5    'incidents' were identified. No new issues were raised by participants in the last two

6    interviews; this reflects a position of data saturation (23).

7

8    Braun and Clarke's (24) analytical process for thematic analysis was used to analyse the

9    data. The six step process entails: familiarisation with the data, generating initial

10    codes, searching for themes, reviewing themes, defining and naming themes and

11    report writing. Analysis and coding were carried out by AY and verified by KF and SB.

12

13    *Rigour*

14    Rigour was ensured following the recommendations made by Caeilli et al. (25) about

15    locating the position of the research, ensuring congruence with the methods, providing

16    a clear audit trail of where the codes and sub codes developed, in order to ensure that

17    the findings were plausible within this interpretive descriptive study (19, 23). Moral

18    distress is the lens through which the data have been analysed; drawing on definitions

19    from Varcoe et al. (26) and Peter (13).

1

2  *Ethical considerations*

3  Ethical approval was granted by Lancaster University Ethics Committee. Participants

4  were provided with the information on the study prior to the interview including a

5  copy of the consent form which was revisited at the interview prior to signing.

6  Participants could withdraw from the study up to two weeks following the interview.

7  Confidentiality and anonymity were maintained by allocating numbers rather than

8  initials to participants and all data was kept in accordance with the data protection act.

9  The researcher was cognisant of the nature of the research and its potential to cause

10  distress and a protocol was available to follow if required. The researcher had a duty of

11  care for residents and participants were aware of the obligation for any dangerous or

12  unsafe practice to be reported.

13  **Findings**

14  **Table 1 demographic detail of participants.**

| No. | NH | Age/ sex | Role | Length of time in current role or NH | Qualifications | Ethnicity |
|-----|----|----------|------|------|----------------|-----------|
| 1 | 1 | 50 (M) | Deputy manager | 1 year | BSc Nursing | Black Caribbean |
| 2 | 2 | 48(F) | Manager | 5 years | RGN | White British |
| 3 | 3 | 50(F) | Senior HCA | 28 years | NVQ 2, 3 Team leadership 2 | English |
| 4 | 3 | 64(F) | HCA | 22 years | None | English |

| No. | NH | Age/ sex | Role | Length of time in current role or NH | Qualifications | Ethnicity |
|---|---|---|---|---|---|---|
| 5 | 3 | 19(F) | HCA | 1 ½ years | Health and social care level 3 | British Bangladeshi |
| 6 | 3 | 32(F) | HCA | 3 ½ years | NVQ level 5 | Philippine |
| 7 | 3 | 60(F) | HCA | 16 years | NVQ 2 | Philippine British |
| 8 | 3 | 49(F) | RGN | 8 years | RGN (Diploma) | Caribbean |
| 9 | 3 | 35(F) | Deputy manager | 15 years | BSc Nursing | Philippine |
| 10 | 2 | 47(F) | HCA | 30 years | NVQ 3 | White British |
| 11 | 2 | 24(F) | HCA | 2 years | None | White British |
| 12 | 4 | 30(F) | HCA | 9 years | None | Czech |
| 13 | 4 | 49(F) | HCA | 2 years | NVQ 2/undertaking NVQ 3 | British |
| 14 | 4 | 63(F) | RGN | 7 years | Dip Nursing | African |
| 15 | 4 | 58 (F) | Manager | 4 months | MSc Health and Social Care | Chinese |
| 16 | 4 | 50(F) | HCA | 4 years | NVQ 2 doing NVQ 3 | English |

1  M (Male) F (Female) ,HCA (Health Care Assistant), RGN (Registered General Nurse), NH(nursing home),
2  Bsc (Bachelor of Science), NVQ(National Vocational Qualification) Dip (Diploma) Msc (Master of Science)
3
4  Sixteen participants from four nursing homes consented to participate. The majority

5  were care assistants (n=10), along with two nurse managers and four nurses. Most

6  were women (n=15). Participants ranged in age from 19-64 years, with between 1 and

7  30 years of experience of working in care homes. Eight (50%) of the participants were

8  born in countries outside of the UK.

9

10  The data analysis identified that there were positive and negative elements of practice

11  which contributed to the staff experience of end of life care. These were present in the

1    four practice orientated themes of advocating, caring, communicating and relating

2    (Table 2). Positive practice experience could lead to a 'good death' and a negative

3    experience to a 'bad death.

4

5    **Table 2 Practice elements and participant quotes**

| Practice elements | Factors associated with end of life care | Participant Quotes |
|---|---|---|
| Advocating | Achieving residents and relatives end of life wishes and choices | 'She kept on about wanting to eat tomatoes. She couldn't, so we were wetting her lips, we pureed up some tinned tomatoes then strained them so we could use on the mouth swabs. We rubbed the tomato drink round so she could get the taste of tomatoes. Little things like that, the family were so pleased because they said she had been asking all night for tomatoes'. (MAN1) |
|  | Fear of consequences | 'I knew he would die and we didn't want to send him but if we didn't send him then there would be a problem on our side'. (RGN2) |
| Caring | Good care for the dying | 'End of life care in the nursing home is more peaceful and better. We got good care and good nursing homes they make you feel comfortable and decent, respect and everything. Not like at hospital you know, its lack of complete care. So when you go to hospital you are not expecting to die in hospital as you expect to get better. But to come to a home is always at the back of your mind 'this is the end of my life I won't go out again'. We do give complete care and I think we have decent deaths in nursing homes. (RGN 4) |
|  | The lingering death | 'We had a woman recently and she wasn't eating for months and the only thing we could do was push fluids, you can't force as that would be abuse. It is distressing because you just want them to drink but you can't force them, you know that if they don't drink that could be it'. (HCA3) |
|  | Managing symptoms | 'You know it's not like now where there is more when the patient is end of life, and then you got all the things in place like pain killers, too much secretions you got the hyoscine and all that. But it wasn't like that then where I've worked before'. (RGN2) |
|  | Care after death | 'The nurse was called in to confirm, and then I got really upset and she said 'come on now pull yourself together' type of thing and I was like I'm not meaning to do this it's like it's just a reaction'. You don't know how you're going to react at the time so anyway I pulled myself together'. (HCA9) |

| Practice elements | Factors associated with end of life care | Participant Quotes |
|---|---|---|
| Communicating | Communicating with residents and their relatives | 'There was some limited English. I sat her down and we spoke in Chinese and I could totally understand what she was saying, you know she wanted to be able to feed him to give him something. That was the dilemma. That was my dilemma. Do I respect the Chinese values and cultures and or this business about; 'let's give end of life care in a dignified way?' (MAN2) |
| | Communicating with internal and external colleagues | 'Sometimes, well here it's a good environment because you work with the doctor and the doctor is you know, you can communicate with your doctor and you can communicate with the pharmacist'. (RGN2) |
| Relating | Inside the nursing home Residents /Colleagues | 'I think in a nursing home like we are all like one big family, that's how I feel any way. They are an extended part of my family they could be my Nan, my aunt'. (HCA6) |
| | Outside of the nursing home Relatives/GPs Hospital/hospice | 'When we sent him back the next day the hospital accident and emergency department called up asking; 'Why did you send this man to hospital?' I said 'well he's unwell and there was nothing we can do for him he was not taking anything orally so we couldn't give him any medication.' They said 'but he is for end of life care.' I said 'well we weren't aware of that because you didn't send anything with him to say that he is palliative care.' He was not supposed to go back to hospital should anything happen to him so how would we know if they hadn't sent any paperwork.' (RGN2 |

1

2 **Advocating** on behalf of residents and their relatives, enabled staff to fulfil end of life

3 wishes and to ensure everyone was kept informed of the situation in order to facilitate

4 them to 'do the right thing'.

5 For some, fear of losing their job or having a complaint made against them led staff to

6 fear the consequences of advocating for their resident.

7 **Caring** for the dying caused distress to the staff in nursing homes due to the dying

8 trajectory being unpredictable in nature. Residents with cognitive impairment

9 challenged the care that staff could give when the end stage of an illness was

10 protracted.

1

2    Caring for residents at the end of life also gave them a sense of satisfaction that the

3    care they provided was the best a resident could have received. Caring for residents

4    includes the management of symptoms, coping with gradual deterioration, good care

5    provision and care after death.

6

7    **Communicating** well with all concerned in the end of life care of a resident was seen to

8    contribute to a 'good death'. However, poor communication was believed to have a

9    negative contribution which could result in a 'bad death', and therefore lead to staff

10   distress. Communicating with those internally and external to the nursing home was

11   visible across all practice elements and seen as fundamental for the staff to achieve

12   their value of 'good dying'.

13   Communication difficulties were reported as being common between hospital and

14   nursing homes and out of hour GP services, as staff were often told to send the

15   resident to hospital which may have meant going against the resident's wishes.

16

17   **Relating** to residents and all those involved in end of life care in nursing homes

18   contributed to the positive or negative staff experience of end of life care; with poor

19   relationships contributing to distress.

1

In analysing the data on these practice-oriented themes it was identified that the staff

in this study held 'good dying' values (see Box 1) which influenced their practice.

**Box 1 Participants good dying values**

| | |
|---|---|
| *Residents do not die alone* | *Relationships are important* |
| *Residents are symptom free* | *Residents and family are prepared* |
| *Residents receive good care* | *Residents die in the nursing home* |
| *Family are present* | *Knowing residents and their wishes* |
| *Paperwork to be in good order* | *Residents are happy and comfortable* |

5

When the staff values were congruent with others involved in the care of residents,

this could influence the practice of end of life care and staff believed that the resident

had a 'good death' as they were able to 'do the right thing' (Figure 1). When there

were incongruent values with others involved in care the practice of end of life care

could lead staff to experience moral distress due to being powerless to 'do the right

thing' and to influence care decisions which could result in a 'bad death'. In contrast,

when there were incongruent values with residents this did not lead to moral distress

for nursing home staff as meeting the resident's values was seen as meeting the 'good

dying' value of *knowing the resident and their wishes.* As such it was considered to be

1 'doing the right thing'. Whilst not leading to moral distress it could cause emotional
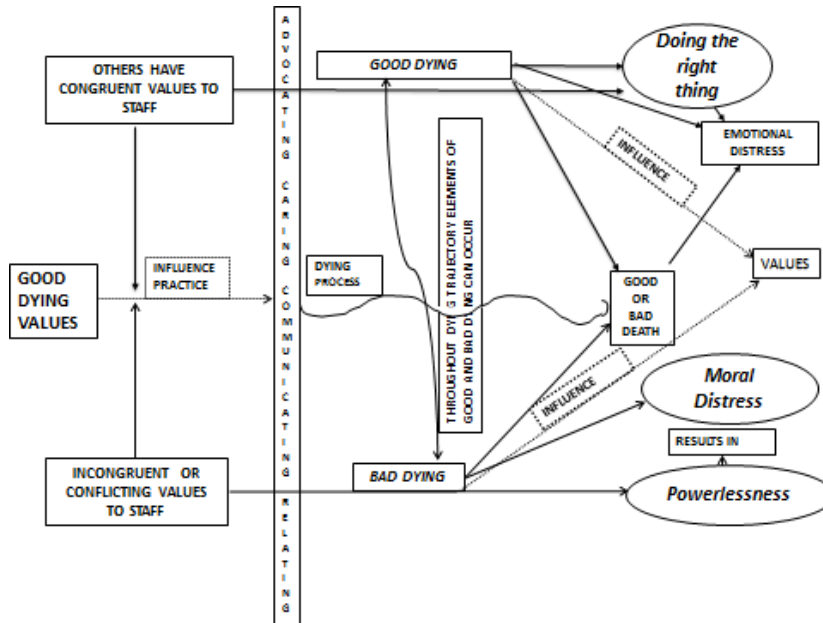
2 distress for staff (Figure 1).

3

4 **Figure 1.** The relationship of values, practice and doing the right thing and

5 powerlessness.

6



7

8

9

10 **Powerlessness**

1    This study found that staff found the decisions made by relatives, GPs, colleagues, or

2    staff from outside the nursing home were more interventional than palliative in

3    nature. Staff saw them as futile, causing more suffering for the resident. These

4    decisions made the staff feel 'powerless' and the 'powerlessness' they experienced

5    was found to be the nature of their moral distress. The ability to comprehensively fulfil

6    the practice of end of life care, and achieve the good dying values depended on the

7    staff role within the home and how confident they were to challenge the decisions of

8    'others'. Healthcare assistants felt 'powerless' to influence decisions as they were

9    excluded from care decisions. Nurses felt 'powerless' to challenge relatives or GPs, and

10   managers felt 'powerless' to influence the hospital to discharge residents in a timely

11   manner.

12

13   The fear that nurses experienced when caring for residents at the end of life was also

14   found to contribute to their experience of moral distress. Fear of the consequences of

15   making a mistake or a wrong decision overrode the participant's need to maintain the

16   'good dying' values, even when they knew the result would cause more distress to the

17   resident or family. The managers, as more experienced nurses, were not fearful of the

18   decisions they made and were more able to advocate on a resident's behalf. Whereas

1    the nurses were more likely to conform to the wishes of others than cause conflict,

2    which they believed would get them into trouble.

3

4    **Discussion**

5    The 'good dying' values of staff influence the way that they provide end of life care in

6    practice. 'Good dying' values linked to the practice-oriented themes of advocating,

7    caring, communicating and relating to enable the participants to do what they

8    considered to be 'the right thing', (27, 28, 29, 30, 31) to facilitate a 'good death' (32).

9    This study found that the moral distress that staff experienced was when they felt

10    'powerless to do the right thing' to facilitate 'good dying' when caring for residents at

11    the end of life. Peter's definition (13) on moral distress links to this powerlessness

12    when those in charge make different care decisions or when there are unequal

13    hierarchies (9). In this study for health care assistants the nurse was in charge, for

14    nurses the relatives were in charge and for managers the hospitals were in charge.

15

16    The link between values, practice and moral distress are reflected in a proposed new

17    definition of moral distress for nursing homes related to end of life care.

18          *'Moral distress in nursing home staff is characterised by the powerlessness that*

19          *staff experience when there is dissonance between their 'good dying' values,*

1     *and those of relatives, GPs and colleagues. This can contribute to staff being*

2     *unable to influence end of life decisions made on behalf of their residents,*

3     *during the complex living and dying trajectory their residents experience'.*

4

5 Johnstone and Hutchinson (33) argue that for moral distress to exist nurses must first

6 be able to critically reflect on why they believe something to be right before they are

7 able to be distressed for not being able to do it. Staff in this study were able to

8 articulate what they believed was the 'right thing to do' when a resident was coming

9 to the end of life, and this linked with their 'good dying' values.

10

11 This study identified that staff experience moral distress when dying residents are not

12 able to receive the care that staff think they should, in order to facilitate what staff

13 believe to be a 'good death'. Valuing a 'good death' is subjective and may not be the

14 same for everyone, which emphasises the importance of communicating with

15 residents about their wishes. It is equally important to acknowledge that the values of

16 staff, residents, relatives, and other health professionals can all influence care

17 provision at the end of life, and understanding the different values held by individuals

18 could reduce moral distress. Utilising a collaborative and palliative care approach to

19 care involving all parties (34,35) in care decisions and plans for care, could improve the

end of life care for residents in nursing homes and reduce the experience of moral distress at the end of life, which concurs with Seymour and Horne's (36) palliative care research. Working together and valuing the opinions and suggestions of those who are involved could help address the unequal hierarchies and reduce the powerlessness that staff experience within this environment.

Training on end of life care, and ethical issues in practice have been identified in previous studies as having the potential to reduce, or protect against, moral distress in practice (10,18,37,38). Education and training were not identified in this study as a contributory factor in the staff experience of moral distress, although several participants had acknowledged that training had enhanced their communication skills and their ability to recognise symptoms.

Conceptual ideas do not remain static, they are built upon and added to through research and new knowledge making them more adaptable (39). Moral distress is a complex and evolving concept which has been found to arise from the situations nursing home staff experience when caring for a resident at the end of life.

This study was limited due to only using one geographical area and a small number of participants. Using the critical incident technique may have constrained the data as the focus was very specifically on residents who had died in the nursing home and personal, cultural and religious values were not explored. Other care situations related to the residents which may contribute to moral distress were not explored within the constraints of this study. There was only one male participant which means a gendered account is presented, albeit one that largely reflects the gender balance in the nursing home workforce (40).

**Conclusion**

This study found that nursing home staff experience moral distress when they feel powerless to 'to do the right thing' and to influence the care decisions about residents at the end of life in order to achieve a good death. Recognising moral distress in this environment can improve the provision of adequate support for staff to continue to carry out their roles and possibly improve care outcomes. Further work is needed to examine interventions which can support staff in a way which incorporates an exploration of their personal values and the values of others so that the practice of end of life care can reduce the experience of moral distress.

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22

*Declaration of conflicting interests*

The authors declare that there is no conflict of interest.

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