

How healthcare providers' own death anxiety influences their communication with patients in end-of-life care: a thematic analysis

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Abstract

Healthcare providers' own death anxiety can influence end-of-life communication. We interviewed nine palliative care health providers about their experiences of providing end-of-life care. Participants also completed the Revised Death Anxiety Scale. A thematic analysis of the interview transcripts identified one theme labelled 'avoidant coping' and another labelled 'death anxiety awareness', which are presented in the context of the participants' own Revised Death Anxiety Scale scores. The findings show that avoidant death anxiety coping can compromise end-of-life communication, but that greater awareness of death anxiety can help overcome avoidant coping. The findings can inform potential improvements in healthcare practice and training.

Keywords: death anxiety, end-of-life care, palliative care, patient-practitioner communication, thematic analysis

Introduction

People's attitudes to death and their fear and avoidance of issues related to death are major barriers in the development of global palliative care (World Health Organisation, 2014, 2018). In the UK, deaths are expected to increase by 50,000 per year by 2023 (Public Health England, 2018), and healthcare providers should give repeated opportunities for discussion so that patients can express their wishes, preferences and beliefs about dying (National Institute for Health and Care Excellence, 2017). Honest discussion between healthcare providers and dying patients is also one of the aims of the UK government's commitment for end-of-life care (Department of Health and NHS England, 2016).

However, patient-provider communication in end-of-life care remains poor in the UK (Davidson & Gentry, 2013). Patient-focused interventions to improve end-of-life communication often have limited impact (Doorenbos et al., 2016; Song et al., 2010), so it is important to enable healthcare providers to improve communication with patients towards the ends of their lives and remove any barriers to better end-of-life care.

'Death anxiety' refers to fear and anxiety related to anticipation and awareness of death, dying and nonexistence, including cognitive, emotional and motivational components that vary according to development and experience (Lehto & Stein, 2009). Patients' death anxiety can be an obstacle to end-of-life communication (Brown et al., 2014), but having a professional role that involves exposure to death and end-of-life decision-making can increase healthcare providers' own death anxiety (Peters et al., 2013).

Greater death anxiety among providers is associated with reduced confidence in discussing end-of-life care with patients and families (Braun et al., 2010), making healthcare providers more likely to avoid end-of-life conversations with patients (Braun et al., 2010; Eggerman & Dustin, 1986), which can lead to delayed end-of-life planning (Reid et al., 2015).

One study showed that nurses with greater death anxiety were less comfortable communicating with patients and families about death (Deffner & Bell, 2005). Another showed that nurses, physicians and social workers' death anxiety were associated with advance directive communication practices; participants with greater fear of death were less likely to collaborate with other health care professionals about patients' advance directive needs, and those with greater acceptance of death were more likely to initiate advance directive communication with patients (Black, 2007).

Studies also showed that nurses and care workers with greater fear of death had less positive attitudes to caring for dying patients and their families (Matsui & Braun, 2010; Rooda et al., 1999). One review suggested that nurses could develop "protective coping mechanisms by distancing themselves from death or practicing death avoidance behaviors" (Peters et al., 2013, p. 20).

Education about death and dying can reduce healthcare providers' own death anxiety (Peters et al., 2013) and training in end-of-life communication can increase their skills and confidence (Dossier & Kennedy, 2014). However, qualitative evidence about healthcare providers' experiences of death anxiety is needed to inform improvements in training about end-of-life communication and decision making (Neimeyer, 2015a). The present study therefore explored ways that healthcare providers' own death anxiety influenced their communication with patients in end-of-life care. The aim was to identify ways that end-of-life care and communication could be improved by removing barriers related to providers' own death anxiety.

Materials and methods

Design

The study was a qualitative thematic analysis of data from semi-structured interviews with healthcare providers working in end-of-life care. The study focused on providers aged between 20 and 59 years because of evidence that death anxiety is higher among people aged under 20 years and lower among people aged over 59 years (Thorson & Powell, 2000; Tomer et al., 2000).

Recruitment and participants

The inclusion criteria were working as a healthcare professional in a UK hospital role that involved conversations with patients about end-of-life care and being aged between 20 and 59 years. Participants were asked to clarify their role and whether this involved them having end-of-life discussions with patients and families both in email communication prior to the interview, and as the first question of the interview, to ensure participants met the inclusion criteria.

Participants were recruited using convenience and snowball sampling (recruitment began at hospitals where the authors had contacts, and participants were encouraged to share the invitation to participate with their colleagues and acquaintances). An invitation to participate, directing

potential participants to contact the researchers about the study, was distributed by email within three UK hospital departments and on relevant social media sites. The study initially aimed to recruit between eight and 20 participants.

Procedure

The study protocol was approved by the university Psychology Research Ethics Committee (Reference 7PS993-AB-1718-AUT-3-JE). Written consent was obtained after participants had read a standardised Participant Information Sheet. Prior to interview, participants completed the Revised Death Anxiety Scale (R-DAS), a 25-item questionnaire with 5-point Likert-type response scales from 'Strongly Agree' to 'Strongly disagree'. Scores range from 0 to 100; higher scores indicate greater death anxiety. The R-DAS has good reliability and is age-sensitive, convenient to administer and effective for making comparisons between and within groups (Niemeyer, 2015).

After completing the R-DAS, participants were interviewed either face-to-face or by telephone by EC. Participants were first asked to clarify that their current professional role involved conversations with patients about end-of-life care, and then asked to describe their personal thoughts and feelings about death and dying, and their experiences of having end-of-life care conversations. The core questions that everyone was asked were:

- Can you tell me about your current role and the setting you work in?
- What do you personally understand by the terms 'death' and 'dying'?
- Can you tell me about your own personal thoughts and feelings about death and dying?
- Can you tell me about your experiences of talking to patients and their loved ones about death and dying?
- Do you ever choose to delegate conversations about death and dying with patients and their loved ones? If so, can you tell me more about this?
- Do you ever notice that you avoid having conversations about death and dying with patients and their loved ones? If so, can you tell me more about this?
- What do you feel are the main barriers to good quality end-of-life communication where you work?

Further questions were asked as appropriate, for example to explore participants' experiences. The interviews were audio-recorded and transcribed verbatim. Pseudonyms were used to protect participants' anonymity.

Analytic approach

Participants' own death anxiety scores were used to provide information about the context of the study and relevant participant characteristics, consistent with recommended standards for reporting qualitative research, which include providing "a detailed profile of the sample" (Twining et al., 2017, p. A5). The interviews were analysed using thematic analysis, a systematic qualitative method allowing detailed description of themes within data and interpretation of the wider topic (Boyatzis, 1998; Braun & Clarke, 2006).

The analysis began with repeated readings of the transcripts to achieve familiarity with the content. Recurring emergent themes were noted and used to create a thematic map, enabling the data to be organised into meaningful themes, which were then reviewed to ensure accurate representation of the data. The thematic analysis was completed before any reference was made to participants' R-DAS scores, which were used after the analysis to put participants' descriptions of their experiences in the context of their own measured death anxiety and to identify consistencies and inconsistencies between participants' R-DAS scores and their descriptions of their experiences.

Results

There were 15 potential participants who responded to the invitation to participate, of whom six did not respond to follow-up emails and nine took part in the study. There were six female and three male participants, aged from 26 to 58 years (mean age 36.6 years). All nine participants worked in different hospitals, and all nine worked in hospital-based roles involving end-of-life conversations. Seven participants were interviewed by telephone and two were interviewed face-to-face; there were no obvious differences between telephone and face-to-face interviews in terms of length or quality. Table 1 shows participant characteristics. R-DAS scores ranged from 34 (Brian, a 29-year-old doctor), to 70 (Charlotte, a 26-year-old healthcare assistant). As in previous research, we classified R-DAS scores of 39 or less as 'low', 40 to 48 as 'moderate', and 49 or higher as 'high' (Thorson & Powell, 2015).

Table 1. Participant information

Pseudonym (age)	Interview	Ethnicity ¹	Role	Experience summary	R-DAS Score
Brian (29)	Face-to-face	White British	Doctor - SHO	11 years: 6 years medical school, 2 years foundation training, 1 year locum in A & E, 3 years A & E speciality training	34 - Low
Joseph (32)	Telephone	Mixed: White Asian	Doctor - Registrar	10 years: 4 years medical school, 2 years foundation doctor, 3 years junior surgical trainee, 1 year surgical registrar	42 - Moderate
Lily (27)	Telephone	White British	Occupational Therapist	6.5 years: 1 year health & social care, 3 years OT training, 2.5 years acute medicine	59 - High
Amanda (43)	Telephone	White Scottish	Nurse	13 years: 3 years nursing training, 4 years respiratory/GI, 6 years haematology including 5 months palliative care project	47 - Moderate
Adam (33)	Telephone	White British	Doctor – Registrar	7 years qualified: 5 working specifically in critical/intensive care	42 - Moderate
Alison (33)	Telephone	White Irish	Trainee nurse	8 years: 5 as HCA and 3 years nursing training	68 - High
Helen (58)	Telephone	White British	Social Worker	35 years: 5 years support work adult LD, 30 years social worker in short term/acute care	41 - Moderate
Charlotte (26)	Face-to-face	White British	Healthcare Assistant	4 years: healthcare assistant	70 - High
Diane (49)	Telephone	White British	Nurse	16 years: 3 years nursing training, 3.5 years learning disabilities, 4.5 years district nursing, 5 years oncology	52 - High

Note:

1. As self-reported by participants

There were three medical doctors (Brian, Joseph, and Adam) with one low and two moderate R-DAS scores; two nurses and a trainee nurse (Amanda, Alison and Diane) with one moderate and two high R-DAS scores; and an Occupational Therapist, a Social Worker and a Healthcare Assistant (Lily, Helen and Charlotte) with one moderate and two high R-DAS scores. All the male participants were doctors and all the female participants were non-medics. The mean R-DAS score was 50.56 (SD 12.65). The male/medic participants had lower R-DAS scores than the

female/non-medical participants [male/medic mean=39.33 (SD 4.62); female/non-medical mean=56.17 (SD 11.58); $t(7)=2.358$, $p=0.05$].

The thematic analysis identified two themes labelled 'avoidant coping' and 'death anxiety awareness'. All the participants were represented in both themes.

Avoidant coping

This theme showed how healthcare providers' ways of coping with death anxiety can act as barriers to better end-of-life care. Six participants (Joseph, Lily, Diane, Adam, Brian and Amanda) described occasions when they avoided or delegated conversations with patients about death. Joseph, a doctor, and Lily, an occupational therapist, both explained their avoidance in terms of their professional roles:

Joseph (R-DAS 42) - I tend to use silence and just let them get to the next stage because eventually they'll probably start asking a few more questions ... it's more about information delivery ... it's more familiar ground than hearing somebody upset and talking about how they'll never see their loved ones again ... as clinicians we tend not to get involved in that side of things

Lily (R-DAS 59) - I still feel like a lot of [whether I avoid the conversation] comes down to whether the doctors have discussed it fully with the patient ... especially when you're planning the patients end-of-life, they want to hear it from the doctor. They don't want to hear it from [an occupational therapist]

Diane, a nurse, described delaying discussing advance care planning as long as possible, based on a doctor's assessment of the patients' prognosis:

Diane (R-DAS 52) – we don't tend to discuss their wishes with them until the doctor has actually said this person doesn't have long left ... before that you're thinking well obviously we hope this won't be needed as they will be able to go home

Diane's apparently reactive approach could sacrifice the potential benefits of earlier advance care planning, which enables more time for discussion, multi-disciplinary team involvement, or referral to palliative care (Eskins et al., 2017). Diane's approach may reflect lack of training, for only one participant (Amanda) reported receiving any training in completing an Advance Decision to Refuse Treatment (ADRT), and only one of the doctors (Joseph) reported ever seeing ADRT documentation.

Adam and Brian, both doctors, described how they avoid end-of-life conversations because of concerns about being wrong about a patient's prognosis, which they apparently saw as conflicting with doing their jobs well:

Adam (R-DAS 42) - It's very difficult to say to a patient definitively yes this person is dying they're not going to survive we need to stop. I think those patients who you thought were gonna do badly and did well almost haunt you when you're trying to have conversations with other patients

Brian (R-DAS 34) - on a personal level, putting your foot in it by saying something that is not true...that's my fear. And avoiding that at all costs I think is kind of one of the driving forces of wanting to do it well

Several participants described distancing themselves from dying patients by making contrasts or highlighting differences between themselves and patient. Joseph, a doctor, distanced himself by highlighting his professional role in the 'machinery' of healthcare:

Joseph (R-DAS 42) - I'm part of the machine that is healthcare delivery, so I have to think about it like a process as it were rather than getting too close to it, otherwise I feel that it would affect my ability to help patients anyway

Amanda, a nurse, contrasted her own unemotional approach to death and dying with the emotional nature of the subject and likely emotional reaction of a patient:

Amanda (R-DAS 47) - I don't tend to get emotional, even when we're talking about a really emotional subject [...] letting [the patient] know that ... if [they] get upset that isn't going to cause me to cry

Brian, a doctor, and Charlotte, a health care assistant, who had the lowest and highest R-DAS scores of the sample, both distanced themselves from issues of death and dying by referring to their relatively young age and good health:

Brian (R-DAS 34) - I don't think I worry about dying. I think probably because I still imagine my death to come in tens of years' time

Charlotte (R-DAS 70) – It's not something I really think about I guess because I'm young and quite healthy

Death anxiety awareness

This theme showed how participants' awareness of their own death anxiety affected their work in positive ways. Charlotte, a healthcare assistant and Alison, a trainee nurse, who had the highest and second highest R-DAS scores in the sample, described how their awareness of their own death anxiety increased their motivation to engage positively with patients who are close to death:

Charlotte (R-DAS 70) – I think about [death] a lot yeah, how can you not in this job? ... I do worry about it ... I would want to know what's happening and how long I've got and have chance to plan things how I wanted them, so it makes me think it's important I do that for my patients

Alison (R-DAS 68) - sometimes I think how can I do this job because I get so anxious about my own death but I think maybe that's what makes me do it, go above and beyond ... so I learnt about how to deal with [my death anxiety] and my own coping mechanisms ... my anxiety probably appears to be quite high but then for me that isn't, that bit makes me probably work even harder because it's not a barrier for me because I always think I'd rather say, speak out loud and get it wrong than not speak out and then something not be done properly

These insights suggest that death anxiety awareness can influence whether an individual with high death anxiety avoids engaging in end of life discussions or makes a conscious effort to have these conversations despite their anxiety.

Brian, a doctor with the lowest R-DAS score in the sample, also described how his awareness of personal mortality led to greater willingness to put himself forward for conversations with patients:

Brian (R-DAS 34) – especially when I see patients a similar age to me, I'm very aware [that that could be me], it prompts me ... to do my best for the patient and talk to them about

what they want to happen...I often put myself forward to have those conversations, because I hate it being done badly

By contrast, Diane reported that her own death anxiety was something she made a deliberate effort *not* to consider, believing that was in the patient's interest, giving an example of an avoidant strategy that was not moderated by awareness of death anxiety:

Diane (R-DAS 52) – I have never thought about whether I'm anxious about dying...I see patients that are obviously anxious but never think that I am too, I feel like they rely on me to not be scared so it isn't something I would want to think about when I am working when I need to be strong for [patients]

Discussion

The findings provide insights into the strategies used by healthcare providers to avoid difficult end-of-life conversations, which included rationalising their avoidance in terms of professional roles or protocols and distancing themselves psychologically from their patients. They also showed how avoidant coping can be overcome by using awareness of death anxiety to increase willingness to engage in difficult end-of-life conversations.

The two themes were closely linked because awareness of death anxiety influenced participants' behaviours in ways that reduced avoidance of end-of-life communication. All nine participants were represented in both of the themes and although male participants (who were all medics) tended to have lower R-DAS scores than female participants (who were all non-medics), there were no clear patterns of differences between them in their interview data. However, participants did not always describe completely consistent views. For example, Charlotte described her own death as 'not something I really think about' when considering her own age and health, but also said 'I think about [death] a lot' when considering her job. This highlights the complexity of thoughts and feelings about death for end-of-life care providers, and the ways that providers' thoughts and feelings about death are not fixed but reflect the context in which they are being considered.

The distancing described by Joseph, Amanda, Brian and Charlotte as part of the avoidant coping theme is consistent with personal construct theory, whereby people contrast their own situation with others in order to distance themselves from threatening events like death. For example, they might see an event as 'predictable, painless and natural' in themselves but 'random, catastrophic or unnatural' in others (Kelly, 1955). Distancing can be a way of coping with death anxiety (Kelly, 1955; Neimeyer, 2015b), and the present study provides some concrete examples of the form that distancing can take among end-of-life care providers.

Previous questionnaire research showed that death avoidance mediated the influence of fear of death on nurses' attitudes to caring (Braun et al., 2010), but the present qualitative findings show *how* this can happen, and also how awareness of personal death anxiety can potentially moderate the influence of death anxiety on care behaviours.

Participants' R-DAS scores helped to put participants' experiences in context, but they also helped to show that participants' experiences and behaviours were not a simple or direct reflection of their level of death anxiety. Participants with different R-DAS scores described avoiding end-of-life conversations in different ways, and participants with high R-DAS scores like Charlotte and Alison described conscious efforts to overcome avoiding discussing death with patients. Once they were able to identify and reflect on their own death anxieties, they felt more able to take active steps to overcome this.

The use of awareness to overcome avoidant coping is perhaps an example of self-efficacy in end-of-life care, similar in some ways to the finding that higher self-efficacy for matters surrounding end-of-life decisions were associated with engagement in a specific aspect of end-of-life planning – signing an organ donation form (Robbins et al., 1991).

The awareness described by participants in the present study is also similar to the concept of ‘death competency,’ which includes a range of human skills and capabilities as well as beliefs and attitudes about those capabilities (Robbins, 1994). The present findings could help to expand and refine the concept of death competency to include the type of awareness that participants described. They also show how the competencies required for working with death and dying combine professional skills and behaviours with awareness of personal attitudes, making them different from many other professional competencies.

The findings have several potential implications for practice. Firstly, they show the value of supporting and encouraging end-of-life healthcare providers to identify and manage their levels of death anxiety, both for their own wellbeing and for the benefit of patients receiving their care. This could happen informally, for example through ‘death cafes’, which are meetings where people discuss death and dying in an informal and supportive setting, loosely structured by a facilitator (<https://deathcafe.com>). Engaging in discussion about death can itself promote increased awareness of an individual’s own attitudes to death and promote reduction of death anxiety (Durlak 2015; Warren, 2014).

Increased awareness of death anxiety might also be achieved using techniques from social/cognitive learning theories that are based on the concept of self-efficacy (Bandura, 1977). Death anxiety is a form of phobia (thanatophobia), so it should be possible to reduce it by observing and modelling less death-anxious behaviours (Bandura, 1968). Healthcare providers who cope with death anxiety by avoiding end-of-life conversations might shadow and observe colleagues who had achieved more awareness of the impact of their own death anxiety and have overcome the impulse to avoid end-of-life communication.

The results could also inform training for end-of-life care providers, which could include greater explicit focus on awareness of personal death anxiety and end-of-life self-efficacy, and the use of awareness-based techniques to overcome avoidant death anxiety coping. As a patient’s condition progresses to palliative or end-of-life care, it may also be useful to clarify for care providers the stages at which they can most effectively become involved in end-of-life communication. Also, team-work and communication between health professionals was rarely mentioned in a positive way by participants in the present study, so future work might also focus on helping and supporting care providers in raising the end-of-life communication issues in the teams they are part of.

Limitations of the study include the relatively small sample size and the fact that participants all self-referred to take part, so we cannot be sure how representative the participants in the present study were of end-of-life health care professionals more widely. For example, it is possible that professionals with less death anxiety would be more likely to be willing to take part in research like this. However, the fact that so few of the present sample reported receiving any training in completing Advance Decision to Refuse Treatment (ADRT) documentation, or even seeing ADRT documents, suggests that the Advance Decision process should feature more clearly in staff training. As a technique for increasing awareness of death anxiety as well as familiarising providers with processes and documentation, it may even be worthwhile to ask end-of-life providers to complete their own Advance Decision documentation as part of training for providing end-of-life care.

More research is needed in this area to understand better how death anxiety can affect the roles and communication of health care professionals. Future research might focus on participants

with more specific professional roles in order to obtain further insights into links between personal death anxiety and professional behaviour. It may also be useful to develop brief quantitative measures of death anxiety awareness, which could be included as pre-intervention and outcome measures in evaluations of training or skills interventions for end-of-life healthcare providers. They could also be used to test the hypothesis suggested by the present findings, that awareness can moderate the impact of death anxiety on caregiving and communication behaviours.

To conclude, these qualitative findings gave insights into the form that avoidant coping with death anxiety can take, which included rationalizing avoidance in terms of professional roles and processes and psychological distancing from patients. They also showed the important role that awareness of personal death anxiety played in overcoming avoidance and increasing engagement in end-of-life communication. Both those insights can inform the development of improved practice and training.

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Declaration of Interest Statement

The authors declare that they have no known competing financial or other interests that could have appeared to influence the work reported in this paper.

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