# The experiences, coping mechanisms, and impact of death and dying on palliative medicine specialists

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#### **ABSTRACT**

Objectives: Research on the experiences, coping mechanisms, and impact of death and dying on the lives of palliative medicine specialists is limited. Most research focuses on the multidisciplinary team or on nurses who work with the dying. Fewer studies consider medical professionals trained in palliative medicine. This study aimed to explore the experiences, coping mechanisms, and impact of death and dying on palliative medicine specialists when dealing with their patients at the end of life.

*Methods:* A qualitative research approach guided the study, one-on-one interview data were analyzed thematically. A purposeful sampling technique was employed for participant recruitment. Seven palliative medicine specialists practicing in one city participated in openended, in-depth interviews.

Results: The analysis of participants' accounts identified three distinct themes. These were Being with the dying, Being affected by death, and dying and Adjusting to the impact of death and dying.

Significance of results: This study further contributes to the understanding of the impact of death and dying on professionals who care for dying patients and their families. Despite the stressors and the potential for burnout and compassion fatigue, these participants employed strategies that enhanced meaning-making and emphasized the rewards of their work. However, the consequences of work stressors cannot be underestimated in the practice of palliative care.

**KEYWORDS:** Palliative medicine physicians, psychological adjustment, life experiences, end of life care.

#### INTRODUCTION

Palliative care aims to prevent and alleviate suffering and provide support to people with life-limiting illnesses, and their families. Multidisciplinary care is paramount, focusing beyond physical symptoms, to include psychological, social, and spiritual concerns (Clark, 2007).

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Professionals practicing in palliative care guide the patients' dying process by organizing individualized plans for patient care (Berger et al., 2000); communicating effectively with patients, families, and colleagues (Fallowfield, Jenkins & Beveridge, 2002); facilitating meaning-making (Currier, Holland & Neimeyer, 2008); having discussions that promote adjustment to an unpromising prognosis but which could lead to a more complete end-of-life experience for the patient and the family (Kaldjian et al., 2008); improving symptom control; and focusing on patients' needs deriving from physical, social, emotional, and spiritual domains (Rokach, 2005).

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Working with dying people can be challenging. Some identified stressors are frequent exposure to death, lack of time, workload demands, difficulties in communication, ineffective coping mechanisms, and a potential sense of helplessness coming from emotional responses including grief, depression, and guilt (Kearney et al., 2009); as well as role blurring, working with uncertainty, and being aware of the medical impossibility of offering a cure (Rokach, 2005).

Burnout, compassion fatigue, and vicarious post-traumatic stress can occur in palliative care workers (Kearney et al., 2009; Rokach, 2005; Vachon, 2011); nevertheless, palliative care has the potential for professional rewards, e.g., to experience high job satisfaction, compassion satisfaction, and vicarious post-traumatic growth from contact with dying patients (Boston & Mount, 2006; Kearney et al., 2009; Lindqvist et al., 2012; Sinclair, 2011; Slocum-Gori et al., 2011; Swetz et al., 2009; Vachon, 2011; Webster & Kristjanson, 2002; Yedidia, 2007).

Research on the impact of dealing with death and dying on palliative care staff is limited (Casarett et al., 2011). Most research focuses on the multidisciplinary team (Boston & Mount, 2006; Lindqvist et al., 2012; Sinclair, 2011; Slocum-Gori et al., 2011; Webster & Kristjanson, 2002; Yedidia, 2007) or on nurses who work with the dying (Dunwoodie & Auret, 2007); fewer studies consider physicians (Dunwoodie & Auret, 2007; Swetz et al., 2009), or compare the differences between health professionals within the multidisciplinary team (Casarett et al., 2011). Little is known about how palliative medicine specialists incorporate their work experiences into their daily lives.

This study explores the experiences of a sample of palliative medicine specialists when dealing with death and dying, the impact of death, and their coping mechanisms.

#### METHODOLOGY

A qualitative research approach was used. Interview data were analyzed thematically (Braun & Clarke, 2006). The University of Adelaide Human Research Ethics Committee (H-033-2010) provided ethical approval.

### **Interviews**

The first author (SCZ), a female psychologist with professional and research experience in the palliative care setting, conducted individual, open-ended, semi-structured, in-depth interviews in participants' consulting rooms between May and September 2010. The interviews focused on participants' experiences

with death and dying, coping mechanisms, and perceived preparation to deal with death and dying. Interviews were tape-recorded and transcribed verbatim by the interviewer. Interviews lasted between 30 and 74 minutes (mean 56 minutes).

Measures to ensure methodological rigor and trustworthiness included: de-identification of transcripts to preserve confidentiality and anonymity; checking of themes by two other researchers (ACH and GBC); and, the opportunity for participant validation of the transcripts (three participants approved their transcripts, two made minor editions, two did not respond). An audit trail was maintained throughout the research process.

# **Participants**

A purposeful sampling technique was employed. Variation in relation to age, gender, and years of practice was sought.

Eight palliative medicine physicians practicing in one city were approached by GBC and invited to participate. All accepted, but only seven were interviewed due to data saturation: five men and two women.

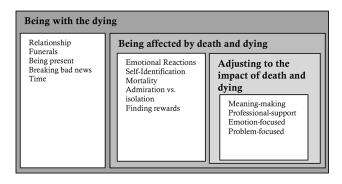
Participants' years in medical practice ranged from eight years to over three decades (Mean = 28 years). Four were working on a part-time basis, and five practiced and observed religious beliefs in a mainstream religion. Six participants held a specialist palliative medicine qualification from the Royal Australasian College of Physicians, and one was an advanced trainee. They all practiced in specialist palliative care services, with a dedicated inpatient unit/hospice, a consultation liaison into tertiary and other hospitals in the region and a community outreach program. Their practice was predominantly characterized by a direct clinical focus with varying degrees of administrative load and teaching of junior staff.

# **Data Analysis**

Transcripts were imported to an NVivo 8 (QSR\_International, 2008) database and analyzed thematically. One transcript was randomly selected and all authors verified coding agreement. Following data familiarization, coding and interpretation of all other transcripts was undertaken individually by SCZ. Emerging themes were discussed and agreed upon by all authors. Final themes and subthemes were identified through patterns in the data. Data analysis was iterative.

# **RESULTS**

Three over-arching themes were identified in participants' accounts of their experiences with their



**Fig. 1.** Overarching themes and subthemes of palliative medicine specialists' experiences and coping mechanisms when dealing with death and dying.

patients' death and dying within the palliative care setting: (1) Being with the dying, (2) Being affected by death and dying, and (3) Adjusting to the impact of death and dying (Fig. 1).

# Being with the Dying

The shared experience of palliative medicine specialists with patients and patients' families at the end of life included: (1) relationship, (2) being present, (3) attending funerals, (4) breaking bad news, and (5) time (See Table 1).

# Relationship

Participants described their level of personal and emotional connection with patients as varying according to the length of the relationship and their level of personal involvement in each case, with a tendency to develop intense connections. The intensity of this closeness was a recurring theme. Blurred boundaries were accepted so long as participants were aware of their level of involvement with

patients and could assess and renegotiate boundaries. This relationship style was preferred in order to have a more valuable doctor-patient encounter, to help patients achieve a good death, and as a meaning-making strategy for the doctor. Sharing of the participant's emotions was seen as crucial for patients and families to feel empathy, sympathy, and the shared humanity of the doctor.

# Being Present

Being present occurred in a variety of ways. Care usually transitioned from having less contact, to more constant care, particularly if palliative care started at an early stage of the illness. Caring for dying patients in different settings allowed participants to establish a meaningful relationship with patients, as well as to be able to have a "picture of them as whole people" (Participant 4). Their availability in different settings was seen as beneficial for patient care, family support, and for the specialists to feel more comfortable with the care of the patient. At the moment of death, it was unusual for participants to be with the patient. Being a palliative care specialist was considered as an opportunity to know patients and to be present in a way that no other medical specialty or health profession could. Being present changed according to the seniority, the role of the palliative medicine specialist and the evolution of palliative medicine as a specialty. As consultants, particularly in teaching hospitals, the role came with a diversification, where less direct, "hands on," patient contact occurred to give space to junior doctors and residents; however, these were recognized as invaluable teaching opportunities. When they desired more patient contact, participants negotiated their level of involvement.

**Table 1.** Illustrative quotations for 'Being with the Dying'

Subtheme	Quotation
Relationship	"you still need to have those human feelings, and if you don't have those, if you are cold and hard and lacking that empathy and compassion and sense of secrecy, you probably are not a good doctor to be working in this area." (Palliative Medicine Specialist 2)
Funerals	"I think it gives time to reflect on the person's life and to acknowledge your own feelings and to sort of step away from the pressure of work, to reflect on the person's life and your own response. ()" (Palliative Medicine Specialist 7)
Being present	"as hard as that was, it was also having the opportunity to see her in all the different places, that most clinicians are sort of stuck in one bit, so they are either in the hospital or they are GPs seeing patients at home, whereas that is the lovely thing about palliative care, it is having that opportunity of seeing people in lots of different venues so you have a picture of them as whole people." (Palliative Medicine Specialist 4)
Time	"Because of the nature of the work that we do, you get an awful lot more time with patients, so I can go and sit and talk to a patient for an hour and nobody is timing me, and saying "you've got ten others" and it might be that I've got 10 other patients, but if I think that an hour of my time is worthwhile then no one is going to question it." (Palliative Medicine Specialist 4)

# Attending Funerals

Participants' contact with the dying and their families did not always cease with the death of the patient. The majority of participants discussed their preference for attending some funerals for a variety of reasons. Funerals showed the family that their contact with the health system did not stop with their relative's death and attendance was seen as an opportunity for bereavement follow-up. Additionally, funerals were useful for participants to gain a different perspective of the deceased. Thus, funerals provided a closure of the relationship. Furthermore, funerals were a controlled opportunity to reflect on participants' own responses to death and dying. Funeral attendance occurred on a case-by-case basis, particularly with those families where there was a close relationship or when they had been invited to attend. One participant reported attending "not often, but not infrequently," with an estimated average of one funeral per month. Another participant described the atypical experience of attending three funerals during a specific week. Of those participants who viewed funeral attendance as an appropriate part of their role, most did not attend due to time pressure. Some participants presented professional boundaries as a reason to be reluctant to funeral attendance, but they all still believed it could on occasions be beneficial for the family.

# Breaking Bad News

Breaking bad news was a constant task in which participants engaged. In some circumstances, participants had a perception of being the first health professional the patient encountered who clearly described the diagnosis and the prognosis of the illness. Despite finding the task a difficult aspect of their role, they acknowledged that they had many skills, not only due to their training in communication, but because of their approach to death and dying.

#### Time

Participants described having more time to see patients, in contrast with other medical professionals; this was seen as an opportunity to focus on aspects beyond the illness. Those participants who had an administrative workload in addition to patient care had less time for patient care, and identified this as a drawback of their role.

# Being Affected By Death and Dying (Positively and Negatively)

Participants' reactions and the consequences, positive and negative, of exposure to patients' death and dying included: (1) emotional reactions, (2) identifying with patients, (3) being reminded of their mortality, (4) receiving admiration — at risk of isolation, and (5) finding rewards (See Table 2).

#### Emotional Reactions

Participants' reactions to the death of their patients were characterized by feelings of sadness, relief, and less often by guilt. Participants mentioned crying or "tearing up." Crying was not seen with a negative connotation, even in the presence of the patient or a relative of the patient. Participants described experiencing grief at a professional level and differentiated it from heartfelt personal losses. Emotional

**Table 2.** Illustrative quotations for 'Affected by Death and Dying'

Subtheme	Quotation
Emotional reactions	"I think also comfortable in showing our emotions, I mean, I have been doing medicine for a long time now, sort of over 30 years and when someone dies, I don't cry, as a routine, but things are very emotional, and I think it is () it brings tears to your eyes, and it is emotional and I think we need to recognize that" (Palliative Medicine Specialist 7)
Self-identification	"She'd made me feel vulnerable, because of the fact that she had children the same age, and I could see myself, I wasn't that much older than her then, and I could see myself in her shoes and identified with her in a way that, you know, I don't so much with an 85 year old who I'd still see as much older than me, although the gap is closing." (Palliative Medicine Specialist 5)
Reminder of own mortality	"I am intensely aware of the gift of being alive, I assume nothing about life, that doesn't make me careless, I am like everyone else, I make my plans. But underneath it, there is this absolutely constant reminder that I am mortal and so I guess I review my life more than I otherwise would if I hadn't been exposed to this work." (Palliative Medicine Specialist 5)
Finding rewards	"So, professionally it is terrific, and I am thankful just to be able to come into work, a work I really like with a really great group of people and making a difference, I think, and I think in palliative care it is never too late to make a difference, and I think that's a wonderful part" (Palliative Medicine Specialist 7)

reactions were short-lived; generally while being present and a few moments after encounters with patients or relatives. Funerals, memorials held in their workplace, and structured meetings were opportunities to revisit emotional reactions. On other occasions, participants were reminded of specific patients when treating patients with similar characteristics. Being aware of the reasons why patients came to mind eased their reactions. The cumulative effect of dealing with many deaths over a short period of time, of caring for a series of patients with very intense or close relationships, or deaths where goals for treatment were not achieved (e.g., poor symptom control), were deemed to be particularly difficult.

# Identifying with Patients

Participants highlighted situations in which patients' circumstances were a reminder of their own. Treating people similar to themselves or to their family members was confronting. Participants said that they employed increased awareness and recognition of their emotions to manage these situations.

# Being Reminded of their Mortality

Working in a setting where all their patients were ultimately going to die was a constant reminder of mortality.

## Receiving Admiration — at Risk of Isolation

By supporting patients and families at the end-oflife, participants dealt with sensitive issues for medicine and society as a whole. Participants reported being admired for working in palliative care and were constantly complimented by patients and friends. Despite being admired, participants admitted being careful in their conversations with friends and family, to abstain from being considered as being too immersed in death and dying and existential issues, for example when socializing.

## Finding Rewards

Participants described their work as rewarding, a career where the "rewards outweigh the cost" of dealing with death and dving. Rewards included: making a difference for patients and families at the end-oflife, being able to offer symptom control, having a privileged access to the patient's life and honoring the medical encounter beyond the physical nature of the illness, and addressing psychosocial and spiritual aspects of the patient at a time when family, friends, and other health professionals do not know how to act. Helping a patient achieve a peaceful death was another rewarding aspect of their practice. A peaceful death was generally evidenced when: (1) futile interventions had been stopped, (2) symptoms were controlled, (3) participants were able to provide support in a psychosocial sense, (4) patients had time to adjust to the prognosis, and/or (5) patients were able to live their last days according to their own wishes.

# Adjusting to the Impact of Death and Dying

Participants down-played the negative impact of dealing with death and dying by reframing their experiences in a way that highlighted positive meaning, both for their patients and themselves. Participants adjusted to their work in a variety of ways, including: (1) meaning-making, (2) professional support, (3) emotion-focused coping, and (4) problem-focused coping (See Table 3).

**Table 3.** Illustrative quotations for 'Adjusting to the Impact of Death and Dying'

Subtheme	Quotation
Meaning-making	"My understanding of death is that it is a beginning, not an end, it is not the worst thing that happens to human beings, I recite the creed and my view of it has changed over the years, but I do believe that our existence on this earth is not finite, that the spiritual part of who we are as a living entity is a reality that is not lost ()" (Palliative Medicine Specialist 3)
Professional-support	"People trust each other enough to kind of say they've been struggling. (account of a time when the doctor was facing a difficult time). So I was able to say to my colleagues "I'm sorry, I am actually not going to be of much use for a while". () we've kind of done that for each other when they have been struggling." (Palliative Medicine Specialist 5)
Emotion-focused	"I don't delineate my boundaries in terms of "this is work and I leave it at the door" those boundaries are quite blurred, but they are not blurred in a context of me thinking that all my patients are my friends. I am pretty comfortable with where those boundaries sit ()".  (Palliative Medicine Specialist 4)
Problem-focused	"I believe very strongly that we should be healthy in these challenging situations, that we should have activities that are restorative for ourselves." (Palliative Medicine Specialist 3)

# Meaning-Making

Meaning was sought in terms of biological explanations of illness progression, such as making reference to life expectancy statistics after a life-limiting diagnosis, as well as accepting death as part of life. Religious and spiritual interpretations were comforting for those with religious beliefs, with death as a transition to an afterlife. Participants with religious beliefs, who worked with atheist or agnostic palliative medicine specialists, stated an inability to understand how those colleagues could deal with their work. However, those who did not subscribe to religiosity felt comforted knowing that patients had had a good life and would live through the memories of their relatives. Participants made meaning of their patients' life-stage, referring in particular to how deaths in older patients were less dissonant. Furthermore, participants' meaning-making processes accentuated the legacy of a patient's death for their own lives, where personal growth and living their lives without regrets were crucial.

# Professional Support

Participants experienced satisfaction with their ability to share the emotional impact of their job with their colleagues or other members of the multidisciplinary team. Besides the formal systems in place for them to vent their reactions, such as debriefing, monthly review meetings, and workplace memorials to remember patients, participants described a strong support system within their practices. In addition, they highlighted forming strong bonds with some colleagues and confiding in them. Relying on others was not seen as a weakness but fundamental to work stability.

## Emotion-Focused Coping

When dealing with the emotional impact of their work, participants expressed a preference for establishing close relationships while keeping boundaries. Most participants were comfortable with not having strict boundaries, but awareness of their involvement was fundamental to control their responses. Self-protection was in the background of their relationships and was important so as to not compromise patient care, nor their own psychological well-being. Their awareness was instrumental for decision-making practices, such as when to talk to colleagues or when to seek help. Among the participants who held religious beliefs, praying was a coping mechanism.

# Problem-Focused Coping

Participants' awareness of the importance of their psychological well-being made them advocates of strategies aimed at reducing the negative impact of their work. Managing their workload and striving for work-life balance was fundamental, and arrangements were made to achieve it. Having a variety of activities, such as time for research, sharing afterhours commitments, and taking time off, were implemented as needed. For some participants having a part-time load further contributed to their selfcare.

## **DISCUSSION**

This study explored the experiences, coping mechanisms and impact of death, and dying on palliative medicine specialists. The analysis of participants' accounts allowed for the identification of three distinct themes; Being with the dying, Being affected by death and dying, and strategies for Adjusting to the impact of death and dying.

Overall, participants' experiences were characterized by feeling comfortable performing the tasks inherent to their role as palliative medicine specialists. These tasks were aligned with the principles and philosophy of palliative care emphasizing an interdisciplinary coordination of care, control of psychological and physical symptoms, and conceptualizing the patient and the family as the unit of care. Working in palliative care, despite making participants feel emotionally vulnerable, brought satisfaction and they experienced personal growth from their contact with the dying. These results share similarities with findings from other studies (Casarett et al., 2011; Penderell & Brazil, 2010; Sinclair, 2011; Swetz et al., 2009).

The participants in this study employed strategies that can be associated with burnout prevention and the experience of compassion satisfaction (Kearney et al., 2009; Maslach & Leiter, 2008; Maslach, Schaufeli & Leiter, 2001; Slocum-Gori et al., 2011; Vachon, 2011). A satisfying workload, having varied work-related activities, being able to share the workload at stressful times, and having a sense of community were fundamental for participants. Swetz et al. (2009) reported that palliative care physicians used professional relationships for burnout prevention and preferred to talk to colleagues over family and friends. Relying on colleagues may offer a shared understanding that enables effective coping and may explain why participants did not mention their family as significant sources of support. Moreover, having a sense of community may foster sharing of emotional and personal reactions to patients, which has been found to promote satisfaction in palliative care (Yedidia, 2007). These findings raise concern for practitioners in rural and remote areas, or those working outside caring teams who may be isolated from a community of care. An alternative for these practitioners might be linkage with specialist palliative services, which can assist with support, guidance and professional discussions (Palliative Care Australia, 2003).

Participants believed that displaying and sharing their emotions with patients and families was beneficial for the doctor-patient encounter. Physicians who share their own vulnerability have been found to have a constructive interaction with patients, develop an exceptional ability to understand the patient, and build trusting relationships (Malterud, Fredriksen & Gjerde, 2009; Malterud & Hollnagel, 2005) provided that emotions are displayed in the service of the patient and/or the family (Malterud et al., 2009). Related to the experience of sharing emotions and honoring the relationship with patients and families was attendance at funerals. Despite the paucity of research, available literature suggests that similar benefits can be derived from funeral attendance (Arroll & Falloon, 2007, Serwint, Rutherford & Hutton, 2006). However, further research into palliative medicine specialists' behavior and attitudes in relation to funeral attendance is required.

Participants had a tendency to find rewards and employed meaning-making strategies in order to cope with the daily impact of their contact with dying patients and their families. Having a transcendent perspective has been found to prevent burnout (Swetz et al., 2009). Furthermore, participants accentuated the value of self-awareness in their day-to-day practice, which has been found to be paramount to clinicians' self-care (Kearney et al., 2009). Self-awareness is an approach of self-knowledge and dual-awareness that allows clinicians to focus on the needs of the patient and the setting of practice, while being conscious of their own internal experiences in relation to their encounters with patients (Kearney et al., 2009).

The consequences of certain work stressors cannot be underestimated. Despite the overall positive experience of caring for the dying, this was possible when participants found meaning, had good sources of support, and engaged in self-awareness. Participants emphasized their vulnerability when dealing with the cumulative effect of caring for many patients, when having difficult days, when seeing patients with whom they had a close relationship, or when caring for those who shared similar characteristics with themselves. Ultimately, the rewards outweighed the cost of dealing with death and dying. However, not all physicians may be able to find rewards in their work with dying patients. Despite the lack of research in the area, clinical or professional supervision may enhance physicians' coping mechanisms when dealing with patients at the end of life (Firth, 2011).

Additional challenges were related to dealing with aspects beyond the death of the patient, such as organizational demands, and having difficulties with colleagues' approaches. For example, with regards to finding meaning through religious and spiritual interpretations, differences in religious beliefs may isolate participants with no religious affiliation from those who find meaning in death through their belief in an afterlife. Furthermore, despite "spirituality emerging as a concept void of religion" (Sinclair, Pereira & Raffin, 2006) and the secularization of the hospice movement (Clark, 2001), the historical relationship between spirituality, religiosity, and palliative care, may deter prospective palliative care specialists who hold no religious beliefs, from entering palliative care training. However, participants who held no religious beliefs were able to find meaning in the death of their patients. Medical professionals' religious beliefs may also impact on decision making in patient care (Seale, 2010).

This study has several limitations. Participants practiced in the same city. Cultural and location differences could be explored quantitatively in future research. Only palliative care specialists currently working were interviewed. The inclusion of physicians who have left palliative medicine would be valuable to better understand where coping failed, or where the work was deemed unrewarding. Furthermore, triangulating the research by interviewing patients, families, and/or nurses may show a different perspective of palliative medicine specialists' experiences with death and dying. Interestingly, this group of participants was fairly homogeneous in their coping methods, perceptions, and experiences with death and dying. These results may reflect the mainstream philosophy of care within palliative medicine, rather than the individual impact of dealing with death and dying; participants may have refrained from discussing particular personal difficulties due to social desirability bias, given the typical portrayal of the positive adjustment to dealing with death and dying, which may have become an expectation from their perspective.

This study further contributes to the understanding of the impact of death and dying on professionals who care for dying patients and their families. Despite the stressors and the potential for burnout and compassion fatigue, these participants employed strategies that enhanced meaning-making and emphasised the rewards of their job. The findings of this study can be used to guide future research that benefits patient care, physician's wellbeing, education, and the practice of medicine.

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