The Empty-Handed Doctor

Responding to the suffering of patients approaching the end of life

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ABSTRACT

The relief of suffering is at the heart of palliative care practice. Yet there has been little exploration of how palliative care doctors, working in different countries and cultures, recognise and respond to their patients' suffering. This research sought to develop a deeper understanding of suffering in the palliative care context, as witnessed by doctors in India and Australia. Through narrative interviews, 18 doctors spoke of how they recognised suffering, and what it meant to them to respond to suffering. The narratives chosen for analysis spoke to the dialogical encounter in which doctors sought to connect with their patients in common humanity, to recognise the particular nature of suffering and to meet in an intersubjective, relational space.

The concept of intersubjectivity provided a lens for analysis of these narratives. Here, 'intersubjective' is used to describe the interhuman experience in which the subjectivities of 'I' and 'Thou', described in Martin Buber's dialogical ontology, are brought to the encounter. I use the term 'dialogical encounter' to describe the meaningful connection between doctor and patient, as experienced by the doctor, where there is a sense of recognition of the 'other' and possible emergence of the 'in-between' realm (Buber, 1970).

A key finding is that the relief of suffering in palliative care involves dialogical encounter between doctor and patient. In this in-between realm of interhuman encounter, suffering is transformed or relieved through the recognition and confirmation of the person who is suffering. Rather than being unidirectional, dialogical encounter is mutual, with the doctor also receiving from the patient, within the normative limits of the therapeutic relationship. The cultural differences apparent in suffering between India and Australia were unified in the experience of dialogical encounter by doctors in both countries.

This thesis reinforces the primacy of the doctor–patient relationship in the relief of suffering and encourages renewed attention to preserving the conditions for the flourishing of this relationship in modern medical practice.

Key words: narrative, palliative care, suffering, physician-patient relationship, encounter, intersubjective

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'Once we dreamt that we were strangers.
We wake up to find that we were dear to each other.'

Stray Birds, Rabindranath Tagore, 1916

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GLOSSARY

Glossary Term	Glossary Definition
Between *das Zwischenmenschliche*	Buber's (1992) concept of interhuman relating, when two people turn towards each other and communicate with each other in a 'sphere which is common to them but which reaches out beyond the special sphere of each' (p. 39).
Dialogical encounter	Meaningful connection between doctor and patient, as experienced by the doctor, where there is a sense of recognition of the 'other' and possible emergence of the 'between' realm (Buber, 1970).
Healing	A relational process of movement towards renewed experience of integrity (Mount & Kearney, 2003). Healing is evidenced by emergence of a sense of newness—new coping ability, new sense of meaning, new outlook on life, improved self-esteem, new experience of personal growth (Egnew, 2005; Guenther, 2011; Morse, 2000; Tedeschi & Calhoun, 1995).
Healing through meeting	Therapy which is centred upon the relation between persons (therapist/clinician and patient) (Friedman, 2002); where 'restoring the atrophied personal centre' (p. 14) is the focus of the therapeutic encounter, and the otherness of the other person is preserved (Friedman, 1995).
Intersubjective	The interchange of thoughts and feelings, both conscious and unconscious, between two persons or 'subjects' (Cooper-White, 2014). First used by phenomenologist, Edmund Husserl (1859–1938), it describes the relational dimension of human existence.
Intersubjective field	This thesis uses Stolorow and Atwood's (1996) definition of this phenomenon, as 'the larger relational system or field in which psychological phenomena crystallize and in which experience is continually and mutually shaped' (p.181).
Intersubjective meeting	Genuine, meaningful dialogue between two people (Dahlberg, 1996).

Intersubjectivity theory	Studies the interhuman space, the reciprocal influence of selves interacting in that space, and the conscious and unconscious experience of that influence (Bradfield, 2012).
Meeting	Turning towards the 'other' in I-Thou, dialogical encounter (Brown, 2015).
Mismeeting *Vergegnung*	Turning away from the 'other'; associated with I-It monological experience (Brown, 2015).
Mutuality	Being present to each other and coming to new knowing of the 'other'.
Object	The 'It' of Buber's I-It word pair.
Subject	The 'I' of Buber's I-Thou word pair.
Subjectivity	'The perception or experience of reality from within one's own perspective (both conscious and unconscious) and necessarily limited by the boundary or horizon of one's own worldview' (Cooper-White, 2014).
Suffering	'The state of severe distress associated with events that threaten the intactness of person' (Cassell, 2004, p. 32).

Chapter 1: INTRODUCTION

1.1 THE RESEARCH IN CONTEXT

Serious health-related suffering (SHS) is the principle indication for palliative care (IAHPC, 2018). SHS encompasses the physical, social, spiritual and emotional domains of suffering associated with severe illness (Knaul et al., 2018;(Radbruch et al., 2020, p. 15). The 2020 consensus derived definition of palliative care states that it is the active, holistic care of patients, their families and caregivers, and includes the prevention, early identification, comprehensive assessment and management of suffering and distress arising from each and any of these domains of suffering (Radbruch et al, 2020). An Essential Package of palliative care and pain relief is recommended as a minimal response of any health care system to SHS (Knaul et al., 2018). This renewed emphasis on serious suffering as the indication for palliative care broadens the remit of this specialty and avoids narrowing its scope to particular prognostic or diagnostic criteria. The inclusion of psychosocial suffering within this term is an important acknowledgement of the multidimensional nature of suffering in health care, extending beyond physical domains to include psychological, social and spiritual care also.

Eric Cassell's classic work on suffering in the health care context provides the definition of suffering used in this study. His conceptualization of suffering as an affliction of person, encompassing all dimensions of 'this complex social and psychological phenomenon' which is person, resulting in a sense of disintegration (1982, p. 639), emphasizes the highly particular and whole-person nature of suffering for each individual. The recent adoption of the terminology of SHS as the basis for palliative care engagement emphasises the need to address not just disease and physical affliction, but to explicitly expand the health care response to address the subjective experience of person.

Despite this emerging emphasis on SHS, there is a lack of research on how suffering is understood by health professionals, and how they perceive their efforts to relieve suffering. This is well illustrated by a systematic literature review of the evidence on the conceptualization, assessment and relief of suffering in patients with cancer. This review included terms such as 'anguish', 'distress', 'pain', and also existential /spiritual issues when these were associated with such terms. The review identified only 126 articles in the period 1992 and 2012 (Cancer Australia, 2011). This study will address this lack of research, focusing on medical health practitioners, as exploration of their experiences are particularly absent in the existing literature.

Furthermore, the existing literature emanates predominantly from high income countries. Yet the global density of SHS is found in low and middle-income countries (LMIC) as measured by reports on the quality of dying (Economist Intelligence Unit, 2015), access to opioids for pain relief and access to palliative care globally (Human Rights Watch, 2015; International Narcotics Control Board (INCB), 2015; Pastrana et al., 2010). Therefore, there is a pressing need to further understand and represent the response to suffering in LMIC. This study seeks to address this gap in the literature by adopting a cross-cultural dimension.

Specifically, the study explores the experiences of doctors working in two settings, Australia and India. The choice of these two countries was multilayered. Australia and India represent two ends of the global spectrum of the quality of dyingEconomist Intelligence Unit (2015). They also represent a high income and a low – middle income country respectively. How these differences impact on the experiences of doctors working in palliative care is not well understood. Practically, as a clinician- researcher who has worked in both countries for many years, access to doctors in these countries was more feasible than approaching less familiar cultural settings and practitioners. My choice of narrative method was facilitated by this previous knowledge of both settings and relationship with doctors in both settings.

In summary, this study aims to explore doctors' experiences of working with palliative care patients, to develop further understanding of how they recognise suffering and

how they seek to respond and relieve it. The research is undertaken cross-culturally, in Australia and India, to explore commonalities and differences in experiences with suffering and to add to the cultural representation in palliative care literature. There is a need to address this gap in the literature.

SUFFERING AND THE MEDICAL PRACTITIONER

Suffering is an 'inevitable companion' for physicians, and not only for those working in palliative care (Lickiss, 2012) and yet their experiences of working to relieve suffering, are poorly studied (Breaden, Hegarty, Swetenham, & Grbich, 2012; Byock, 1996). Doctors and medical students report a lack of confidence in their ability to both relieve suffering and deal with their reactions to patients' suffering (Back, Rushton, Kaszniak, & Halifax, 2015; Egnew, Lewis, Schaad, Karuppiah, & Mitchell, 2014; Meier, Back, & Morrison, 2001). They find it difficult to be with suffering (Cole & Carlin, 2009; Vegni, Mauri, & Moja, 2005). Cassell (1999) suggests that their desire for certainty and objectivity causes doctors' discomfort with examining suffering, and explains why medicine sometimes lacks the capacity to recognise suffering. Doctors and other healthcare providers may contribute to suffering (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004; Berglund, Westin, Svanström, & Johansson Sundler, 2012).

While what suffering means is rarely discussed in medical training, increasing attention has been directed to enhancing health carers' empathic responses to suffering (Buckman, Tulsky, & Rodin, 2011; Stepien & Baernstein, 2006). This is driven in part by recognition of patients' dissatisfaction with the care and communication of health providers (Stewart, 1995). Empathic interviewing is known to reduce patients' psychological distress (Roter, 2000) and enhance the wellbeing of doctors (Shanafelt et al., 2005). This suggests a mutual doctor–patient relationship in the relief of suffering. M. Kearney, Weininger, Vachon, Harrison and Mount (2009) recommend doctors form connections with patients to 'survive' and care for themselves, especially when working in palliative care. This confirms the mutuality of the doctor–patient relationship.

However, efforts to enhance the empathic, person-centred nature of medicine are undermined by organisational and clinical demands on frontline practitioners, which leave little time for relationship building, continuity of care or self-care (Mercer, Hasegawa, Reilly, & Bikker, 2002; Nyström, Dahlberg, & Carlsson, 2003). Role

modelling that prioritise organisational efficiencies may promote distancing and depersonalisation behaviours over empathic responses (Balboni et al., 2015; Hafferty, 1998; Hafferty & Castellani, 2010) and self-care (Philip, 2004).

In India, palliative care doctors are leading the call for change in the practice of medicine and for training in communication skills, empathic practice and person-centred care (Nayak et al., 2005; Rajagopal, 2011; Rajagopal, Vallath, Mathews, Rajashree, & Watson, 2015). This raises the question of how to sustain such a sensitised workforce, in the face of high unmet need (Dharkar, 2018). There is significant tension between what is desired and what is possible (Giannitrapani et al., 2019), especially considering the lack of organisational and professional support (Patel, Deo, & Bhatnagar, 2019; Sadhu, Salins, & Kamath, 2010).

In Australia, palliative care providers experience different challenges, including how to remain true to the founding values of this speciality (Mount & Kearney, 2003; Saunders, 2000) while expanding access and scope of practice. Additionally, with euthanasia and physician-assisted suicide increasingly normalised as a means of 'dealing with' pain and suffering at the end of life, and now legalised in Victoria (Victoria State Government, 2017), the understanding of what modern doctors think about the relief of suffering has gained new importance.

1.2 THE PERSON OF THE RESEARCHER

Providing this personal context is intended to foster transparent engagement with readers of this thesis.

I came to this exploration as a doctor with 25 years' experience working in palliative care in Australia and a long-standing interest in Indian palliative care. I have been involved in teaching, research and quality improvement activities in India, and have collaborated with Pallium India in a mentoring project, Project Hamrahi, since 2010. I held a position on the council of the Indian Association for Palliative Care for four years until 2020.

I also bring a personal lived experience of a life-threatening illness and share a narrative of an intersubjective encounter (an encounter between me and another which was mutually experienced at depth, as subject to subject) and healing

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experience during that illness as important contextual background for my study. It was truly unexpected, unscripted, and perhaps unrecognised as significant by the health providers involved.

MY INTERSUBJECTIVE ENCOUNTER

I began my PhD in 2011, had conducted my research interviews by mid-2015 and was immersed in the analysis of these interviews when, at the end of January 2017, I was diagnosed with early-stage breast cancer. The diagnosis was made on mammogram, initiated due to nonspecific symptoms in my left axilla. Early workup involved a left breast lump biopsy, three days after the mammogram.

I had not met any of the biopsy team before. After changing into the white surgical gown, I entered the biopsy room in the diagnostic imaging department. It had the appearance of a standard clinical procedure room, cluttered with an ultrasound imaging machine and chair, operating-theatre-style table, trolleys with biopsy equipment and dressings, sharps containers, oxygen and other fittings on the walls. The young radiographer greeted me kindly and instructed me to lie on the table. He continued to quietly focus on entering the settings on his machine. The next team member to greet me was the nurse. We chatted about her recent move to this hospital, the reasons for changing workplace and her enjoyment of the new job. Throughout she remained focused on ensuring all was in order for the procedure. I felt in safe hands. The third team member was the doctor—the radiologist who would conduct the biopsy. She softly introduced herself, checked my notes and took my consent for the biopsy. After a brief check of the ultrasound images, she explained her concern that the lymph nodes in my left axilla looked abnormal and recommended that a biopsy be taken of one of these nodes. She gave me time to assimilate this significant news and gently touched my shoulder, saying, 'It is always worse somehow, when it is one of our own'. My tears surfaced, supported by the safety I felt with this trinity of professionals. Quietly, they went about their tasks, professionally, respectfully, with no fuss, no hurry. The room lights were dimmed, for the benefit of the images, further adding to the sense of intimacy and privacy between us. Little was said.

I have come to see this experience as the deepest encounter of my 7 months of treatment and to think of it as healing. During my illness and treatment, I reflected on this often. What transformed this routine, clinical procedure into a healing encounter

for me? Were the team aware of the impact they had on me? What was their experience of the encounter? Would they realise that they were part of a healing encounter?

Perhaps the answer to the first question lies in the team's recognition of me as a person, and the gentle acknowledgement that being 'one of us' (a doctor) brings a particular dimension to being a patient. Did my presence as a patient in their midst cause the professional persona to shudder, revealing that we are all mortally wounded, suffering bodies (Frank, 1995; M. Kearney, 1996)?   Did that common ground of shared profession bring the mutuality of the doctor–patient relationship more distinctly to the fore? Thorne et al. (2005) emphasise the importance of feeling 'known' or recognised. Was it just my shared profession with this team that enabled the depth of recognition in this encounter, or is it possible in any doctor–patient encounter?

The setting of this encounter was also striking. It occurred in a procedural setting, during a routine biopsy, in which the focus was not on healing but on conducting a diagnostic procedure competently. It was not a one-on-one encounter; it involved four people and considerable machinery. There was an imbalance of power, with me clothed only in a nondescript hospital gown and lying on a table, while the others wielded complex equipment, and invaded my body with a large needle. Yet this was all secondary to the intersubjective, dialogical encounter (a meaningful connection in which there is a sense of recognition and welcome of the 'other'), largely unspoken, but deeply moving and validating for me.

Occurring as it did, halfway through the conduct of this study, following my review of the literature and development of a conceptual understanding of the dialogical encounter, I interpreted this experience through the intersubjective, dialogical lens. This personal experience resonated with the theoretical, and helped me to more deeply recognise the centrality of dialogical encounter, of being 'seen', in responding to and relieving the suffering of fear, loss and isolation. I experienced the healing depth of encounter, encouraging me to explore the nature of this in this study.

1.3 RESEARCH DESIGN

Isak Dinesen is quoted as saying that 'all sorrows may be borne if you may put them into a story or tell a story about them' (Ricoeur, 2003, p. 322). This beautifully

encapsulates the power of narrative to bring meaning and facilitate the capacity to endure. In keeping with this insight, narrative enquiry within the qualitative social sciences research paradigm was used for this study. Exploring doctors' experiences of encounters with suffering patients required an approach that would allow depth and breadth of enquiry, and resist objectification and imposed constructs. Narrative methods allow a focus on the content and delivery of story, and on the co-construction of narrative, the dialogical collaborative nature of storytelling. This resonated with the subject matter, and is proposed as an ethical way to engage in cultural studies (Stumm, 2014). Inviting doctors to recount narratives of encounters with suffering offered a dialogical opportunity between participants and researcher to enter mutually into these encounters, from a shared experience of palliative medicine practice, to enquire into the practices and perceptions operating within doctors' experiences. The selfhood and subjectivity of doctors in relation to exposures to suffering warrants greater examination, given the centrality of the dialogical encounter in this domain of medical practice. This study illuminates this dialogical, intersubjective aspect of the relief of suffering by doctors.

I conducted 18 narrative interviews, in-person and through videoconferencing, in India and Australia, between October 2014 and August 2015. I adopted a narrative analytical approach to the examination of these interviews, using both a dialogical narrative analysis approach and Gee's linguistic approach to unpack the dialogical, performative quality of the narratives, what they were doing in the world, and how they affected me as interviewer and dialogical partner.

The aim of the study was to explore doctors' experiences of working with patients at the end of life, in order to develop further understanding of how they recognise suffering and how they seek to respond and relieve it.

The key objectives were:

- to explore how doctors recognise and respond to patients' suffering at the end of life
- to explore cultural commonalities and differences in the experiences of doctors caring for patients who are suffering at the end of life

- to consider how dialogical encounter is experienced by doctors caring for patients at the end of life
- to explore how doctors' sense of self, both personal and therapeutic, is developed and sustained
- to develop a repository of illustrative narratives for future reflection and discussion.

Building on understandings put forward by researchers from diverse disciplines on the therapeutic relationship, insights are offered into the nature of dialogical encounters between doctors and patients who are suffering, and the importance of the intersubjective, therapeutic relationship in the relief of suffering.

1.4 THESIS STRUCTURE

This thesis is presented in eight chapters.

Chapter 1: Introduction has introduced the context of the thesis and its personal and academic rationale.

Chapter 2: Background explores the background to the study, focusing on what doctors understand about how to relieve suffering and the relationship to healing; the study's Australian and Indian palliative care setting; and the impact on doctors of working with suffering patients.

Chapter 3: Literature Review presents the literature review undertaken in 2015 and updated in 2019, in response to the question: 'What is the experience of doctors who are exposed to the suffering of dying patients?' The scope of the review is presented, and the key themes to emerge are discussed. Notably, most studies examining this question were published in the twenty-first century.

Chapter 4: Conceptual Framework offers the framework that informed the analysis and interpretation of the findings from the participant interviews. This framework was based on Martin Buber's relational ontology and the writings of other relational scholars. Buber's notion of becoming self through relationship, applied to the medical relationship, and the healing that may result through meeting—that is, encounter—are proposed as the key conceptual insights.

Chapter 5: Methods details the methodological approaches adopted for this study. The qualitative paradigm is discussed, and the choice of narrative methods is rationalised. The methods are then described, along with an explanation of how the narrative analysis was conducted using both dialogical narrative analysis and Gee's linguistic analysis.

Chapter 6: Findings presents the insights gained through the participants' narratives. The dialogical analysis is presented, focusing on dialogical encounter, and the narratives are organised around this focus. The subjectivity or personhood of the doctor within this encounter is evident. Narratives of dialogical encounter include those of healing, recognition and the limits of realising dialogical encounter. Buber's concepts of 'inclusion' and the 'between'—both core elements of dialogical encounter—are demonstrated through the participants' narratives.

Chapter 7: Discussion distils the perceptions and insights presented in Chapter 6, drawing on previous understandings of the healing relationship in palliative care. The need for greater awareness of and attention to the mutuality operating within the doctor–patient relationship is emphasised, as a means of sustaining doctors in their practice and empowering patients' sense of self in the face of physical decline and impending death.

Chapter 8: Conclusion concludes the study, outlining the new awareness and perceptions that emerged during the research. The potential contributions of this study—that is, the importance of dialogical encounter and recognising mutuality within dialogical encounter—are presented. The limitations of the study are discussed, and areas for further research are identified. A brief autobiographical reflection on the study marks the end of this thesis.

Chapter 2: BACKGROUND

While the nature of health-related suffering and its relief in palliative care practice has received some attention in the literature, there remains a lack of exploration of these areas and of palliative care doctors' experiences of patient suffering. This is an oversight. This review will present existing literature on the impact on doctors of witnessing suffering, the recognition and relief of health-related suffering, discuss cultural aspects of health-related suffering and conclude with background to palliative care in Australia and India.

2.1 EFFECT ON DOCTORS OF WITNESSING SUFFERING

Despite being under-studied, most researchers agree that professional caregivers who frequently witness suffering are subject to risks such as vicarious trauma, burnout, compassion fatigue and moral distress (Vachon, 2012 a). Clinicians report being deeply affected by the pain of those for whom they care (Breaden et al., 2012; Candib, 2002; Frank, 1995; Hegarty, Breaden, Swetenham, & Grbich, 2010). Moreover, K. White, Wilkes, Cooper and Barbato (2004) described unrelieved patient suffering as having an 'enormous' impact on palliative care nurses. Unrelieved patient suffering also leads to distress and loss of cohesion in interdisciplinary palliative care teams (Swetenham, Hegarty, Breaden, & Grbich, 2011).

Witnessing difficult events can have prolonged effects on care providers' professional and personal lives (Ullström, Sachs, Hansson, Øvretveit, & Brommels, 2014). However, even seemingly mundane events (e.g., delays in transferring patients from emergency departments due to lack of beds, unnecessary investigations and confusing communication from different doctors) may cause distress for healthcare providers dedicated to providing the best possible patient experience (Beng et al., 2013 a). Further, staff suffering may be heightened when working with certain patient groups, such as adult cancer patients with young children (Turner et al., 2007).

Others have pointed to the potential for personal growth and transformation through encounters with suffering (Egnew, 2009; Ellis et al., 2015; Geller, 2006; M. Kearney, 2000; Taubman–Ben-Ari & Weintroub, 2008). Victor Frankl's (2004) experience in Auschwitz led him to propose that it is suffering without meaning that leads to

disintegration, not suffering itself, calling the process of discovering meaning in life 'transcendence' (Best, Aldridge, Butow, Olver, & Webster, 2015).

There is little research on the professional and personal impact on palliative care doctors of witnessing suffering, or the development of the capacity to witness such suffering. Conversely, there is substantial literature on physician burnout and its prevalence, the factors contributing to burnout and, importantly, the organisation factors aggravating burnout (Peters et al., 2012; Shannon, 2013; Gama, Barbosa, & Vieira, 2014; Shanafelt, Dyrbye, & West, 2017; Shanafelt, Hasan, & Dyrbye, 2015; Windover et al., 2017; Shanafelt, Swensen, Woody, Levin, & Lillie, 2018). There is also a growing literature on physician wellbeing, with research attempting to identify the protective factors against burnout, how to maximise physician satisfaction and resilience, and how organisational processes might facilitate staff wellbeing (Suchman, 2006; Krasner et al., 2009; Shanafelt & Dyrbye, 2012; Outram & Kelly, 2014; Steckler, Rawlins, Williamson, & Suchman, 2015; Dyrbye & Shanafelt, 2016; Linzer, Sinsky, Poplau, Brown, & Williams, 2017; Noseworthy et al., 2017; Shanafelt & Noseworthy, 2017; Shanafelt et al., 2018;Frankel, Tilden, & Suchman, 2019; Tawfik, Profit, Webber, & Shanafelt, 2019).There is a link between vicarious traumatic exposure and burnout (Showalter, 2010; Ullström et al., 2014).

2.2 WHAT IS KNOWN ABOUT HEALTH-RELATED SUFFERING AND ITS RELIEF

The paucity of research on health-related suffering is an important gap given the centrality of the relief of suffering to palliative care (George & Craig, 2009; IAHPC, 2018; Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008).

Studies tend to focus on individual domains of this experience, such as spiritual distress, existential distress and physical pain (Best, Butow, & Olver, 2014; Boston, Bruce, & Schreiber, 2011; Okon, 2005; Vincensi, 2019). 'Distress' has emerged as an alternative term for 'suffering', leading to the development and global implementation of the Distress Thermometer (Baken & Woolley, 2011; Carlson, Waller, Groff, & Biultz, 2012; Grassi et al., 2011; Wang et al., 2011). However, suffering has a different quality to distress. Etymologically, 'to suffer' is to bear under (Concise Oxford Dictionary, 1999), in contradistinction to 'distress' (to stretch apart) or 'depression' (to be crushed). 'Suffering' includes a sense of carrying forward, of enduring.

Cassell (1982), a pioneer in the study of suffering in healthcare, identified that in addition to relieving patient suffering, medicine also contributes to patient suffering, largely through a decreased capacity to address the subjective experience of the person with illness. His work shows that suffering may arise from a loss of integrity or coherence in any or all of the spiritual, physical, psychological, emotional and social dimensions of person. Saunders (1964) coined the term 'total pain', to encapsulate these multiple dimensions of suffering, an insight praised by Gunaratnam (2012) for recognising the "assembling of heterogeneous phenomena within the domains of pain' (p. 109).

These definitions of suffering differ markedly from the general community's understanding of suffering at the end of life as equating to an experience of intractable physical pain only, and waiting to die (K. Schwartz & Lutfiyya, 2012).

The relational dimension of person, as seen in Lickiss' (2012) 'web of relationships model', is also critical to understanding suffering. She suggests that by using Antonovsky's (1979) 'sense of coherence' when working with people who are suffering, clinicians can better understand the relationships damaged during the suffering experience and explore restorative avenues. Cherny, Coyle, & Foley (1994) emphasise the importance of the interrelationship between doctor, patient and family in the suffering of patients with advanced cancer. The view of these authors is that the suffering of each is interwoven such that perceived distress of any one of these may increase the distress of the others.

The frequent loss of roles and relationships accompanying serious illness make the social and cultural domains of person important in health-related suffering (Priya, 2012). Social suffering involves the loss of social credibility and place due to illness and may be exacerbated when medicine cannot explain the suffering (Kirby, Broom, Sibbritt, Refshauge, & Adams, 2015). Personal sense of self may be threatened and deconstructed by the experience of illness; yet can be reconstructed in positive therapeutic interactions (Priya, 2012). Incorporating a reconstructive understanding of clinical care adds potency to the therapeutic relationship (Friedman, 2009; Kearsley, 2009; Kleinman, 1988).

Arman et al. (2004) agree with Cassell (1982) that healthcare providers can aggravate suffering. In their study, breast cancer patients reported increased suffering due to lack of a caring relationship with their healthcare provider, who failed to treat them as a whole person or recognise the dimension of disintegration within the suffering experience. Unnecessary suffering arising from caregiving also emerged from a narrative study with patients in Sweden. Patients described being mistreated or not listened to; struggling for their healthcare needs and autonomy and feeling judged as a difficult patient; and feeling powerless and objectified (Berglund et al., 2012). Beng, Guan, Lim and Chin (2013, b) also identified patient suffering arising from their interactions with healthcare providers. These experiences highlight the importance of the patient–caregiver relationship in both relieving and causing suffering.

How Physicians Recognise Suffering

There are surprisingly few studies on how suffering is recognised by clinicians. This suggests that what is meant by 'suffering' is assumed to be understood. Given the subjective nature of suffering and the intersubjectivity of the therapeutic relationship, this shared perception is unlikely. Indeed, differences arise between team members in the assessment of patients' symptoms and experiences. Efforts to standardise assessments using tools such as the Edmonton Symptom Assessment Scale and patient-reported outcome measures (Patel et al., 2019; Simon, 2012) still rely on the subjective reports of patients, families and staff, which may not be uniformly measured or interpreted (Daveson et al., 2012). The limitations to using the reports of family or carers are recognised (Nekolaichuk, Maguire, Suarez-Almazor, Rogers, & Bruera, 1999). Little research has been done on the factors influencing these subjective reports.

Understanding how clinicians assess suffering has heightened relevance in the current medical climate, in which the judgement of intolerable suffering is a prerequisite for euthanasia and physician-assisted suicide in many jurisdictions. Lesho, Udvari-Nagy, László, Saullo, & Rink (2006) found that physicians' estimates of the intensity of suffering did not correlate with patients' reports. Two Dutch studies addressing how doctors recognise and empathise with intractable suffering when assessing a patient who had requested euthanasia (van Tol, Rietjens, & van der Heide, 2010; 2012) found marked variation in doctors' judgement of intractable suffering in the functional and

existential domains. They also found doctors considered suffering from an 'imagine self' or 'imagine other' perspective. Given the adaptation to physical decline that often occurs during a progressive illness experience, there are limitations to forming a judgement of intractable suffering from the position of good health.

The interconnection between recognition of suffering, the impact on clinicians and clinical decision-making has not been sufficiently explored. Seymour, Janssens and Broeckaert (2007) note the complex interplay between recognising intractable suffering and clinical decision-making in doctors working in palliative care in the United Kingdom (UK). However, more studies are required to explore this interconnection.

How Suffering is Relieved

The literature is again relatively sparse on the relief of suffering. Medical students recognise the inadequacy of their medical training on relieving suffering and how to deal with its effect on them (Egnew et al., 2014; Outram & Kelly, 2014). In Australia, there are calls to introduce learning about suffering and healing into medical curricula (Bridge & Bennett, 2014). Cancer Australia (2011) conducted a review of the literature, to both define suffering and identify the evidence for effective therapeutic approaches. They found that meaning-centred, hope-centred and stress-reduction interventions appeared effective, while psycho-educational and spiritual interventions were less supported by the current literature.

Looking at the relief of suffering more clinically, Lickiss (2012) recommends ameliorating the 'definable "cause" of suffering, or trigger which is precipitating the sense of being "about to go to pieces"' (p. 255), while also enhancing the individual's coherence, reconnecting them to their sense of self, in their new state of living with illness. Restoring coherence through psychotherapy (Vachon, 2012 b) and fostering healing connections and meaning (Mount, Boston, & Cohen, 2007) have been recommended for the relief of total suffering witnessed in end-of-life care. Similarly, women suffering from chronic back pain (Kirby et al., 2015) and children in pain (Carter, 2004) report needing affective connection with their healthcare provider.

Relationship-centred care advocates identify the connectional dimension of the doctor–patient bond as facilitating healing and relieving suffering (Suchman & Matthews, 1988; Tresolini & Pew-Fetzer Task Force, 1994). The nursing response to

suffering emphasises care and relationship (Fredriksson, 1999; Ozolins, Hörberg, & Dahlberg, 2015). Morse (2000) identifies two phases in the response to suffering—the enduring and emotional behavioural states of response—with the choice between them relying on tacit knowledge (Carlsson, Drew, Dahlberg, & Lützen, 2002). Other authors have identified the need to articulate a medical ethic of care, to improve doctors' capacity to address suffering and sustain themselves in their practice of medicine (Martinsen, 2011b; MacLeod, 2001). The archetype of the wounded healer (Jung, 1985) has been invoked to describe how clinicians could heal patients through a shared vulnerability and understanding of suffering (Benziman, Kannai, & Ahmad, 2012; Corso, 2012; Daneault, 2008; S. Jackson, 2001; M. Kearney & Weininger, 2011; Nouwen, 1972).

The patient perspective is lacking, but Langegard and Ahlberg's (2009) study in patients with incurable cancer found they also identified relational elements in the relief of suffering, such as connection, self-control, affirmation and acceptance. The late author Anatole Broyard (1992), writing about being a patient, asks his clinician to use his imagination to see the patient, to recognise what is personal about his illness. 'Since technology deprives me of the intimacy of my illness, makes it not mine but something that belongs to science, I wish my doctor could somehow repersonalize it for me' (p. 47).

Effective relief of suffering leads to healing, the transformation of suffering, which is distinct from curing. Healing is 'a relational process involving movement towards an experience of integrity and wholeness, which may be facilitated by a caregiver's interventions but is dependent on an innate potential within the patient' (Mount & Kearney, 2003, p. 657). Healing is present in the experience of personal growth, improved self-esteem, new coping ability, new sense of meaning, wholeness, deeper spirituality or change in life outlook, and greater appreciation of life (Egnew, 2005; Guenther, 2011; Morse, 2000; Tedeschi & Calhoun, 1996).

In mutual, trusting relationships, there is potential for growth and healing. In such relationships, doctors may disclose their vulnerability to reduce the suffering of patients' engendered by isolation (Candib, 2001). Disclosing vulnerability also demonstrates their understanding of the patient's experience (Candib, 1987). Doctors need to take care to avoid self-disclosure which is self-seeking (Candib, 1987) and to

maintain self-awareness and self-care (Barnard, 2016) to sustain healthy therapeutic relationships.

In modern times, euthanasia and physician-assisted suicide are promoted by some as a response to suffering. This remains highly controversial and is not universally accepted as within the realms of medical or health care (de Lima et al., 2017; Leiva et al., 2018; Sprung et al., 2018). These approaches are not discussed in this study as my philosophical stance comes from palliative care, which explicitly excludes euthanasia and physician-assisted suicide (Australian and New Zealand Society of Palliative Medicine [ANZSPM], 2017; World Health Organisation, 2019).

2.3 CROSS-CULTURAL STUDIES AND SUFFERING

There is an increasingly relevant need to improve the understanding of cultural issues at the end of life and specifically, of cross-cultural dimensions of pain and suffering (Gysels et al., 2012). Cross-cultural studies may sensitize 'to more qualities and registers' (Gunaratnam, 2012, p.118) of suffering. They provide a vehicle for learning to be 'affected by differences' (Latour 2004: 210 in (Gunaratnam, 2012), by revealing the experiences of another. Examining the experience of suffering across cultures offers rich opportunity to 'make visible differences of interests, access, power, needs, desires, and philosophical perspectives' (Biehl, Good, & Kleinman, 2007, p. 8).

Culture is a complex concept rather than a fixed entity, described as dynamic, constantly evolving and emerging phenomenon, from intersubjective or relational interactions (Biehl et al., 2007). It shapes the environment as well as those who inhabit it. It is in the realm of the indefinable, beyond grasp: "not a variable; culture is relational, it is elsewhere, it is in passage, it is where meaning is woven and renewed often through gaps and silences, and forces beyond the conscious control of individuals, and yet the space where individual and institutional social responsibility and ethical struggle take place (Fischer 2003:7, cited in Biehl et al., 2007, p.7).

This responsive, relational understanding of culture is in marked contradistinction to stereotypical and superficial explanations of cultural variations across populations. For example, the cultural practices and rituals in death and bereavement of a Hindu family are modified by many factors, such as the country of death, their caste, denomination

and sect, practical social influences such as diaspora and travel time, financial circumstances, and the depth of connection to traditional practices (Murray-Parkes, Laungani, & Young, 1997).

The experience of suffering itself, is universal, but is profoundly mediated by culture (Broom, Kenny, Bowden, Muppavaram, & Chittem, 2018; Davies, 2011; Priya, 2012). Culture impacts on how an individual perceives, responds to and makes meaning of, their suffering, how they express suffering, as well as the source and stimulus for their suffering (Helman, 1994). For example, for cancer patients in India, social suffering is shaped by cultural ontologies, which cast cancer as unknowable and 'variably deserved', resulting in cancer diagnosis being surrounded by fear, silence and shame (Broom et al., 2018, p. 56). Moreover, most Western countries, including Australia, are multicultural and the practice of palliative care requires greater perception of different world views (Kirby et al., 2018). Recognising differences leads to greater capacity for perception as described by Latour 2004: 211 in Gunuratnam (2012, p.119): 'The more you articulate controversies, the wider the world becomes'.

Kleinman (1981) identified three sectors of health care, the popular (lay) sector, the folk (healers of a sacred or secular tradition outside of Western medicine) sector and the professional (Western or allopathic medicine) sector, all of which interconnect and relate to each other. Each sector has its own way of defining the nature of ill-health, as well as the nature of a patient and healer and the relationship between the two. The folk sector is large in non-Western countries such as India. Here, this sector has gained prominence in recent years culminating in the establishment of AYUSH, the Indian Ministry of Ayurveda, Yoga & Naturopathy, Unani, Siddha, Sowa Rigpa and Homoeopathy (AYUSH, 2020) in 2014. Tensions and synergies exist between the allopathic and folk sectors, impacting on patients' behaviours and presentations, and their expectations of each sector. Each sector or system seeks to transform suffering through its own set of symbols and narratives (Seale, 1998). The degree of success is in large part determined by the intersubjective cohesion achieved between the patient and healer's frameworks and the capacity for 'empathic witnessing' (Kleinman, 1988,p.154) of the healer.

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Therefore, exploring the cultural nuances and variations which impact on doctors' perception of suffering by studying this in two very different countries, offers potential to better understand how to respond to individual suffering within the context of particular cultural settings, what is common in the doctors' responses across diverse cultural settings, how the respective cultures of the doctors and patients intersect (both the role cultures of patient and professional and the social cultures), and how doctors and patient navigate cultural differences in their mutual efforts to relieve suffering.

2.4 PALLIATIVE CARE IN AUSTRALIA AND INDIA IN THE TWENTY-FIRST CENTURY

SIMILARITIES

Despite significant differences in the stage of development and provision of palliative care in Australia and India (Gómez-Batiste & Connor, 2017; Mitchell, 2011; Rajagopal, 2015; Wright, Wood, Lynch, & Clark, 2008), the education of palliative care doctors in both countries is strongly UK-influenced (Kiss-Lane et al., 2018; Wee & Hughes, 2007).

This shared educational foundation brings many conceptual similarities in the delivery of palliative care between the countries, including organising services to facilitate continuity of care for all patients; a team approach to care delivery, incorporating medical, nursing, allied health and pastoral care expertise; patient- and family-centredness; and a strong emphasis on compassionate communication.

DIFFERENCES

Differences between the countries are attributable to resource inequities and the scale of patient and family need. Challenges to the provision of palliative care in India include:

- a lack of awareness of what palliative care can provide
- geographical constraints
- stigma associated with cancer and dying, including the shame experienced by family members and late presentation for care
- lack of education
- pursuit of aggressive therapies

- palliative care services' resource constraints (Giannitrapani et al., 2019).

While similar challenges may be reported in higher-income countries, the enormity of the gap between what is currently available and what is needed is powerfully illustrated by the 10,000-fold difference in opioid availability between India and Australia for 2014–2016 (see Figure 1). In 2010–2013, India had an estimated opioid deficit of 99.3% (International Narcotics Control Board [INCB], 2018).
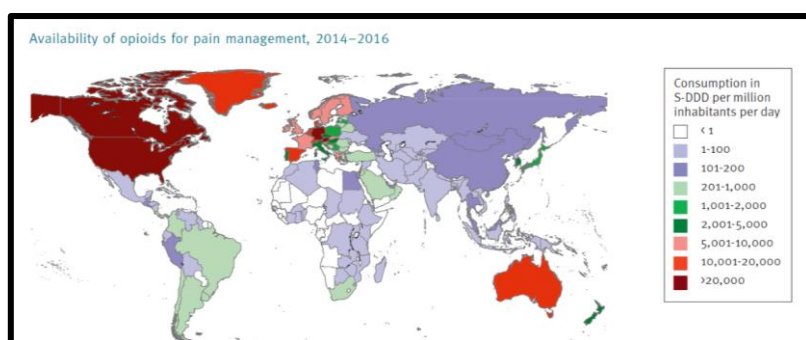
Figure 1: Availability of Opioids for Consumption for Pain Management (2014–2016) (INCB, 2018)

Beyond issues of opioid availability, India scored 67th of 80 countries in the 2015 *Quality of Dying* study, compared to Australia's ranking at second place (Economist Intelligence Unit, 2015). However, compared to the 2010 iteration of this study, India had made progress (Economist Intelligence Unit, 2010) due to increased government support, implementation of a national palliative care policy (in 2012), revision of the *Narcotic and Psychotropic Substances Act* (in 2014) and the emergence of national training programmes. In contrast, Australia is one of only 20 (8.5%) countries to have integrated palliative care into healthcare to an advanced level, and one of only six in the Asia Pacific region, all of whom enjoy higher income levels (Spruyt, 2018). As a high-income country with a universal health system, largely affordable healthcare, government investment in palliative care and widespread access to services, Australia contrasts strikingly with India.

Differences might then be anticipated in the approach to the relief of suffering by palliative care providers in these countries. However, to my knowledge, no studies

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have compared the nature of health-related suffering between Australia and India, or between high-income and low- to low-middle-income settings. In particular, there has been little exploration of the relative impact of the physical, spiritual, psychological and existential aspects of suffering.

Moreover, despite the enormous unmet need for palliative care services in India and globally (Human Rights Watch, 2009, 2015), and the renewed emphasis on relieving serious health-related suffering, surprisingly few studies have examined the concept of health-related suffering in resource-poor settings. Similarly, little is known about how practitioners in those settings address this suffering in the absence of such basic resources as essential medicines, systems of social support and active government policies facilitating service provision. In recognition of this gap, Indian palliative care pioneer Rajagopal (2011) advocated for the role of narratives to help raise awareness of the 'needless suffering' globally and build a 'tool of advocacy' through published narratives of patients' suffering and its relief.

2.5 CONCLUSION

This chapter identifies that palliative care practitioners chronically exposed to suffering are at risk of burnout and other harms and need to adopt self-care practices to restore and sustain meaningful practice. Personal self-care by doctors must be supported by organisational structures and practices that take seriously the wellbeing of staff, to avoid reciprocally negative impacts on patient care.

There are marked inequities of access to palliative care globally. Examining medical responses to the universal experience of human suffering in this cross-cultural study, exploring the commonalities and differences in practices, may improve the understanding of cultural dimensions of palliative care. In view of the sparse international literature on how doctors recognise and respond to suffering, an exploratory qualitative inquiry is an appropriate beginning to understand the complex interplay between the recognition of suffering, clinicians' responses and intersubjective experience.

Chapter 3: LITERATURE REVIEW— EXISTING UNDERSTANDING OF THE EXPERIENCE OF DOCTORS WHO WORK WITH SUFFERING

This chapter presents a interpretive narrative synthesis of the literature reporting on the experience of doctors who care for suffering patients at the end of their lives. A systematic search was undertaken to retrieve the relevant literature, which was then assessed for eligibility and quality (Paterson, 2012).

3.1 METHODOLOGY

The methodology followed for this literature review was a narrative synthesis of data (Aveyard, Payne, & Preston, 2016) identified by a systematic search. This methodology was chosen because it is suited to a review of qualitative literature, from which the main findings emerged from a search on the phenomenon of interest, namely doctors' experiences.

The search terms were limited according to topic refinement (Moher, Stevens, & Garritty, 2014) namely the focus on the nature of the interaction between doctors and patients rather than the impacts of the experience of working with suffering patients. In terms of impacts, many issues were identified in the literature, such as burnout, moral distress, compassion fatigue, exhaustion, as well as positive impacts such as enhanced sense of purpose, personal growth and wellbeing. These terms were excluded as search terms because they were not the focus of the study and also the literature pertaining to these terms is very large such that inclusion in the search strategy would risk obsuring the more sparse literature specifically focussed on the topic. Articles which focused on these issues rather than the interactions between doctors and patients, still emerged from the search conducted, and were excluded.

Other limitations of this search include the exclusion of grey literature; single reviewer only; and handsearching limited to reference lists of included papers and two internet search engines only. Therefore, while following a systematic process, this literature review was not consistent with a comprehensive systematic review. Another limitation

of the search was that it includes empirical articles published in the English language only and limits the search time period from the start of 1960 to August 2019, corresponding to the period of the modern palliative care movement. However, in a preliminary scoping search, only one article was identified prior to 1960.

The narrative synthesis used thematic analysis techniques to develop an overarching conceptual understanding of the selected literature (Paterson, 2012). This approach is consistent with the interpretive epistemological paradigm of this study (Cherry, Perkins, Dickson, & Boland, 2014; Paterson, 2012) .

The review question was: What is the experience of doctors who are exposed to the suffering of patients at the end of life?

End of life was understood as the later stages of a terminal illness and was searched for under the MESH term of 'terminal' in this study. 'Terminal care'/'end of life care' however, is not the same as 'palliative care'. 'Palliative care' was used to identify practitioners more likely to be caring for patients at the end of life. As the scope of palliative care practice evolved over the period of this search, with an increasing focus on earlier integration of palliative care into illness trajectory, this search revealed research exploring suffering at an earlier stage of illness, beyond the actively dying phase. Since the aim of the study was to explore practitioners' experiences with relieving suffering of patients, articles involving palliative care doctors were included, even if including experiences with suffering in a wider group of patients than those who were in the final stages of a terminal illness.

The aim of the study was to explore how doctors' recognise and respond to suffering of their patients. The term, 'experience' was used in the review question, to capture the literature that relates to the impact of this dimension of practice.

3.2 METHOD

SEARCHING THE LITERATURE

The search was conducted in November 2015 and updated in August 2019. Four electronic databases were searched: Ovid EMBASE, Ovid Medline, Ovid PsycINFO and EBSCOHost CINAHL.

In all databases, the search strategies used a combination of subject headings and various text words (found in titles and abstracts) to identify the literature. Subject headings used in Ovid Medline included: 'Physicians' or 'Students, medical' and 'Attitude of health Personnel' and 'Palliative care' OR 'Terminal care'. Text words used included: 'suffering', 'experience' or 'impact'. All word variations were searched. Searches in CINAHL, PsycINFO and Embase followed a similar format with variations according to each database's subject thesaurus. Dying' was included by one database (PsycINFO) as a MESH term; for other databases, this term was searched for under 'terminal'.

Table 1 presents the key search terms and inclusion and exclusion criteria listed according to PICo (**P**opulation, phenomenon of **I**nterest, **Co**ntext), a specific mnemonic for reviewing qualitative literature (Joanna Briggs Institute, 2014) and recommended by Boland, Cherry and Dickson (2014) as a more inclusive, framework in which the phenomena of interest may be a condition (experience) or an intervention. Other frameworks such as SPICE include intervention and comparison, terms which are more prescriptive in nature and may be less suited to the literature on doctors' experiences.

The Medline search strategy is shown in Table 2. For the complete search strategies for each database, see Appendix 1. Handsearching of reference lists of included papers and the use of internet search engines, PubMed and Google Scholar, identified an additional 15 articles. Only empirical articles were included.

Table 1: PICo Search terms, and Inclusion and Exclusion Criteria

PICo	MESH and Text Search Terms Used	Inclusion	Exclusion
Population	*Doctors* Detailed as: 'physicians, students, medical, interns'	• Studies in which qualified or trainee doctors were enrolled • Humans	• Studies in which non-medical health professionals only were enrolled • Non-humans
Pheno-mena of **i**nterest	*Experience of health professional of exposure to suffering* Detailed as: 'attitude of health personnel'; 'stress, psychological';	Experience of caring for patients who were suffering	Papers that did not refer to suffering Papers primarily focused on death and dying rather than suffering

	'suffering'; 'experience', 'impact'		
Context	*end-of-life / dying / palliative care* Detailed as: 'Palliative care' OR 'Terminal care'	End-of-life care Palliative care	Healthcare not related to end-of-life care; general medical care Suffering not related to healthcare or illness
Types of study		Qualitative, quantitative and mixed methods	Non-empirical articles: reviews, editorials, philosophical and theoretical articles
Language		English	Non-English
Timescale		Published between 1960 and August 2019	Published before 1960

Table 2: Medline Search Strategy

Data-base	Date Range		Search Strategy	Results
Medline	Jan 1960 – Aug 2019	1	exp physicians/ or exp physician-patient relations/ or exp students, medical/	218,825
		2	intern*.mp.	1,060,681
		3	1 or 2	1,254,568
		4	exp "Attitude of Health Personnel"/	151,887
		5	(experience* or impact*).mp.	1,923,216
		6	4 or 5 (1490906)	2,041,547
		7	exp palliative care/ or exp terminal care	90,922
		8	exp stress, psychological	123,927

		9	suffer*.mp.	288,399
		10	8 or 9	407,224
		11	3 and 6 and 7 and 10	372
		12	limit 11 to (English language and humans and yr="1960-current")	338

Articles were exported into an Endnote database. Duplicates were removed both electronically and by secondary review. After initial screening of titles and abstracts, full-text articles were assessed for eligibility. Figure 2 presents the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) data flow diagram for the study (Boland, Cherry, & Dickson, 2014; Moher, Liberati, Tetzlaff, & Altman, 2009). Appendix 2 summarises the studies selected for review.
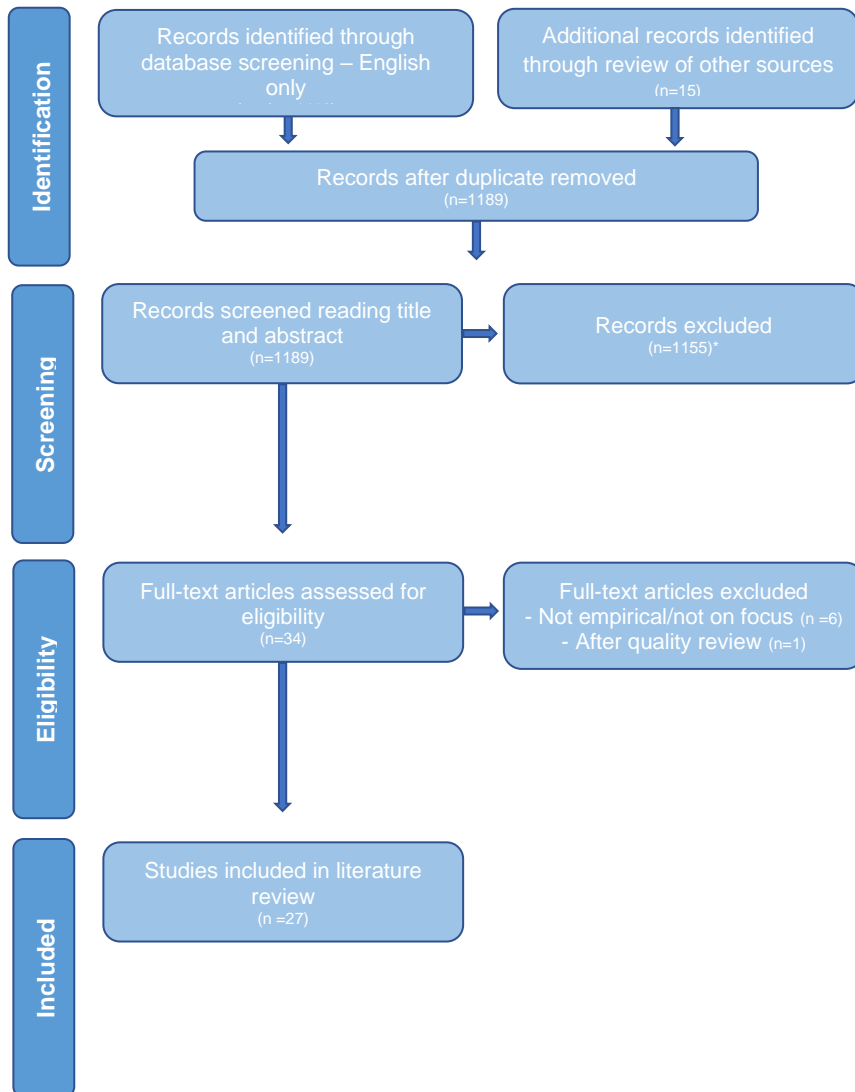
Figure 2: PRISMA Diagram Literature Review Flow Diagram

*Reasons for excluding articles after screening: focus not on suffering; focus on physician-assisted suicide, euthanasia or palliative sedation (n=289) or in nursing (n=200); review articles or conference abstracts, protocols

Articles were then subjected to quality assessment with the aim of excluding articles which did not meet the Critical Appraisal Skills Programme (CASP) (2010) criteria for qualitative studies. Additional criteria from Spencer, Ritchie, Lewis and Dillon (2003) and Cherry et al. (2014) were added to assist in achieving a more global assessment of the insights and interpretations of the authors.

Quantitative surveys were evaluated using the 'Critical Appraisal of a Survey' tool from the Centre for Evidence-Based Management (2016). One study (V. Jackson et al., 2005) was assessed with both qualitative and quantitative measures (Bryman, Becker, & Sempik, 2008). The quantitative component reported in the six other mixed-methods studies was minimal and not the focus. These criteria and the results of the assessments are detailed in Appendices 2, 3 and 4.

ISSUES OF QUALITY ASSESSMENT

There is ongoing debate about the nature and assessment of quality in qualitative research (Khan, ter Riet, Popay, Nixon, & Kleijnen, 2001; Reynolds et al., 2011). While there is increasing consensus that some form of evaluation of quality is needed (Hannes, Booth, Harris, & Noyes, 2013), the employment of such checklists does not guarantee consensus about the quality of research (Sandelowski & Barroso, 2002) and there is no consensus on the optimum tools to use (Hammersley, 2008; Sandelowski, 2015).

The acceptance of checklist-guided evaluation is evident in the widespread adoption of lists such as the Critical Appraisal Skills Program (CASP), Standards for Reporting Qualitative Research (SRQR) and Consolidated Criteria for Reporting Qualitative Research (COREQ), to guide authors in reporting research and reviewers in evaluating that research. However, criticality in the use of these lists is required. No tool is without flaws. Despite its widespread use, the validity of COREQ's development has been called into question (Buus & Perron, 2020). Many checklist criteria tend to emphasise the methodological rigour of data collection and reporting, rather than the theoretical and interpretative dimensions of conducting qualitative research. This criticism has been highlighted as a shortcoming of CASP (Hannes, Lockwood, &

Pearson, 2010; Hannes & Macaitis, 2012), the tool chosen in this study, because it is a generic, commonly used and accepted qualitative assessment tool. Furthermore, the employment of checklists does not guarantee consensus about the quality of research (Sandelowski & Barroso, 2002).

Hammersley suggests using lists as 'no more than a reminder ..that is always open to revision in the process of being used' (Hammersley, 2008, p.159). There is little to guide the reviewer as to the relative weight of the various components of any checklist, when making a final judgement of the quality of an article (Hannes, 2011; Khan et al., 2001). Evaluating the theoretical dimensions and credibility of a qualitative study requires more judgement on the part of the reviewer than quality assessment of quantitative studies. Sandelowski (2015, p.86) refers to this as 'taste', defined as 'a cultivated skill … the discernment involved in judging the value of research' which recognises the impact of the reviewer's expertise and perspectives in coming to a judgement about quality. The additional questions from Spencer et al (2003) and Cherry et al (2014) used in this study helped in the consideration of the internal validity of each article, the degree to which the results are likely to approximate to the 'truth'' of the study (Khan et al., 2001).

Narrative synthesis

Narrative synthesis is a three-step approach which summarises the primary research, explores relationships between the data and develops a synthesis that represents these relationships (Paterson, 2012). Narrative synthesis was achieved by identifying key themes across the selected articles, which were then organised into a conceptual schema.

The approach adopted for developing the conceptual schema was described by Foss and Waters (2016). Once the literature review question was decided and the search conducted, each selected article was reviewed to identify specific, relevant excerpts pertaining to: findings, claims and conclusions; definitions of terms; calls for follow-up studies and gaps in the literature; divergent opinions or constructs. Once identified, the excerpts were typed or cut out of the article. Each excerpt was then sorted into similar topics groups with the aim of identifying themes across the selected literature.

Themes were named and all excerpts related to that theme were organised under that name. The title of each coded theme was typed and printed out, in large font, and cut out into individual pieces of paper. These printed-out themes were then organised physically, as well as electronically on MindManager software. With repeated reordering and working with the themes, the final themes were named and ordered into a narrative or schema that authentically represents the literature (Lincoln & Guba, 1985). This thematic development was discussed with supervisors to assist with interpretation and synthesis.

3.3 RESULTS

ARTICLE SELECTION

There were 34 articles selected for full review. Of these, 28 met the inclusion criteria. One was subsequently removed after quality assessment, leaving 27 articles in the review. All articles were published in peer-reviewed journals. Only two studies were published before 2000 (Moore, 1984; Takman & Severinsson, 1999).

The review included 15 qualitative, 5 quantitative and 7 mixed-methods studies, primarily from Western settings (USA, Australia and Scandinavia). Two studies were from Asian settings (Malaysia and India), and explored the experiences of a range of health professionals working in palliative care. The Indian study had only one doctor, but is included given the Indian cultural context of this research. Six other studies explored experiences across healthcare disciplines, and one included the relatives of patients. The five Scandinavian studies were notable for their exploration of the doctor–patient relationship in different practice settings. The studies were also diverse in their medical settings, disciplines (specialist and general practice) and levels of experience (including medical students and junior doctors). Details of the included articles are found in Appendix 4.

A large body of literature on the nursing experience of suffering was excluded, but is notable in contrast to the scarce medical literature on this topic. Also excluded was an extensive literature exploring doctors' reactions to death, the stress of working in palliative care, burnout and grief, as the focus here is on the personal experience of observing their patient's suffering. Finally, the burgeoning literature on physician-assisted suicide, euthanasia and palliative sedation was excluded; while suffering is

considered in these studies, they do not explore the doctors' experience of patient suffering.

There is a scarcity of research on the experiences of palliative care doctors with suffering patients. The literature considers this topic obliquely, and focuses on the impact of patient death on doctors and medical students with identification of suffering as one component of the dying experience explored (V. Jackson et al., 2005; Moores, Castle, Shaw, Stockton, & Bennett, 2007; Redinbaugh et al., 2003; Rhodes-Kropf et al., 2005); difficult interactions and developing the capacity to care for patients who are suffering at the end of life (MacLeod, 2001); of caring for patients with cancer who may be identified as suffering (Johansen, Holtedahl, Davidsen, & Rudebeck, 2012) and of the suffering perceived in experiences of bereavement (Papadatou, Bellali, Papazoglou & Petraki, 2002). There was a noted lack of theoretical foundation specific to the relief of suffering by doctors working in clinical practice, to integrate physical and existential suffering (Johansen et al, 2012). Models have been proposed for the development of compassion in healthcare (Sinclair et al., 2016), empathy (Cuff, Brown, Taylor & Howat, 2014; Halpern, 2011; Pedersen, 2009) and relationship-centred care (Suchman, 2006). Conceptual models proposed for suffering (Best et al., 2015; Cancer Australia, 2011; Cassell, 1982; Rodgers & Cowes, 1997), emotions (Hacker, 2004) and grief and loss in healthcare (Gagne & Robichaud-Ekstrand, 1995) also provide context for this study but there is a lack of research investigating the actual experiences of doctors exposed to suffering in their patients.

There were three main themes which emerged from the process of narrative synthesis: the doctor-patient encounter; developing the capacity to be with suffering patients through professional and personal experiences; and the paradoxes, tensions and complexities involved in working with suffering. The experiences of doctors tended to be presented as positive (e.g.self-care, personal growth) or negative (burnout, compassion fatigue, stress). There was a striking lack of non-Western literature, specifically from LMIC countries, about doctors' experiences of patients' suffering. The limitation of English language publications may have contributed to this lack, however, this remains a significant finding, given the preponderance of need and unmet suffering in LMIC (Knaul et al., 2018; Krakauer & Rajagopal, 2016). Each of these themes and findings will be presented.

Shared humanness is the existential basis of the doctor–patient relationship (Johansen et al., 2012). This mutual recognition of humanness is expressed in the intersubjective encounter between doctor and patient (Takman & Severinsson, 1999) and is a 'critical factor in the clinician–sufferer relationship' (Hegarty et al., 2010, p. 292).

For both clinicians and patients, subject-to-subject encounter involves mutuality of being. Clinicians may understand the patient's experience and expressions of suffering and feel personally validated as a result, or may struggle to achieve this understanding, instead limiting their responsibility to the biomedical aspects of care (Takman & Severinsson, 1999). Patients may feel 'confirmed or excluded, or be given a sense of being empowered or discouraged' by the encounter (p. 1369). Clinicians need to manage the depth of the encounter from moment-to-moment (Breaden et al., 2012). This dynamic, relational, mutual encounter is illustrated in Figure. 3.
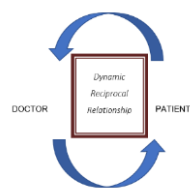
Figure 3. Doctor-patient relationship

Clinicians' encounters with suffering patients is frequently presented as three points in a continuum from connection to detachment in a biomedically focused interaction. Vegni et al. (2005) identified three patterns in how doctors relate to patients in pain: biological: in which the patient is depersonalised ; professional: in which 'the meeting is not just with the body's pain but with another person who is suffering' ; and personal: in which the doctor is emotionally overwhelmed in an 'emotional-relational explosion' (p. 23). Their study identifies the struggle experienced by doctors in navigating this spectrum of responses and the lack of attention given to preparing the person of the doctor to work in this subjective and demanding dimension of care.

Takman and Severinsson (1999) conducted unstructured interviews with eleven health professionals, including three doctors. Their phenomenological exploration identified two of the three patterns in clinicians' encounters which were relational and which fostered the doctors' increased understanding and knowledge of patients' expression of their suffering. This in turn increased patient confidence in their care. The third pattern was focused on biomedical dimensions of care at the expense of the relational, leaving the clinician feeling they had not understood the patient.

In their discussion of general practitioners (GPs) caring for patients with cancer, Johansen, Holtedahl and Rudebeck (2010) similarly identified degrees of connectedness involved which they called: the flexible mediator, efficient handyperson and personal companion. This third role was further explored by Johansen et al. (2012), revealing that GPs felt diminished by the biomedical model, in which the GP–patient relationship is devalued in favour of the biomedical knowledge of specialist practice.

The responses to existential suffering or 'groundlessness' which emerged from an exploration of engagement with suffering by healthcare staff, patients and family again presents movement across a continuum of responses, which is influenced by personal and interpersonal dynamics between health care staff, patients and families. Points along this continuum were described as: engaging groundlessness through letting go of previous self-knowing, taking refuge in the usual ways of being, and 'living in-between' (i.e., shifting between letting go and holding on). The findings of this group emphasise the dynamic, responsive nature of encounters, which are subject to moment by moment influences, decisions and interactions, rather than discrete positions consistently taken by different practitioners. As doctors may find it as difficult as patients to engage in groundlessness, and choose instead to take refuge in the safety of the habitual, supporting practitioners to develop greater awareness of these psychodynamic influences occasioned by exposure to death, is posited as an important area of further research (Bruce, Schreiber, Petrovskaya, & Boston, 2011).

Aligned to this concept of groundlessness, there is also the experience of vulnerability by clinicians (Beng et al., 2013 b). Vulnerability is an important facilitator of encounter but is seldom discussed and has not been well studied. Vulnerability was described in contrasting ways, as both being a difficulty for doctors to manage within the doctor-

patient relationship, and yet as having the potential to facilitate encounter and healing outcomes for both doctor and patient. The doctor–patient relationship is characterised by inequality of agency, with patients often at their most vulnerable. In their study of medical students' emotional responses to patient care activities, (Clay et al., 2015) students expressed sorrow about the depth of witnessed patient suffering, from unalleviated pain, death and vulnerability (Clay et al., 2015). A sense of personal vulnerability arising from an intimate and perhaps unexpected encounter may persist for doctors for many years (MacLeod, 2001) interviewed ten doctors about how their experiences learning to care for dying people. He found that formal preparation by medical education was lacking and that many doctors had experienced a 'turning point', sometimes traumatic, which changed their perspective and often enhanced their capacity to care for patients (MacLeod, 2001), recounting these experiences with vivid recollection even when they occurred many years previously.

However, doctors' personal experience of vulnerability may benefit both doctor and patient (Aase, Nordrehaug, & Malterud, 2008; Hegarty et al., 2010; Malterud & Hollnagel, 2005). Shared vulnerability may be a vehicle to facilitate mutuality and meaningful encounter (Boston & Mount, 2006). For doctors, this experience of encounter provides balance to the experience of vulnerability (Aase et al., 2008). (MacLeod, 2001)

Effective encounters involve connecting with the patient as person, and a mutuality of experience, in contrast to encounters characterised by a sense of division, isolation and lack of satisfying connection (Bruce et al., 2011; Takman & Severinsson, 1999; Vegni et al., 2005). The language and metaphors of effective encounter include 'creating openings' that foster dialogue (Boston & Mount, 2006, pp. 17–18), 'simply being present' (Whitehead, 2014, p. 273), 'being with' (Breaden et al., 2012, p. 896) or a 'more intense action of being attentively present' (Hegarty et al., 2010, p. 289).

Capacity to Be with Suffering

Whitehead (Whitehead, 2014) interviewed ten physicians about the impact of patients' death and their reactions to suffering. He identified the complexity of managing the

balance between personal and professional reactions to patient suffering and the development of the capacity to be with suffering. The development of this capacity will be discussed in two subthemes: the person of the doctor and the professional role.

PERSON OF THE DOCTOR

There is a lack of literature on how to prepare doctors to meet the suffering of their patients which this study will address. As Vegni et al. (2005) notes 'in a dramatic field such as that of the patient with pain, the emotional and subjective involvement of doctors in the process of care is crucial, but this involvement is still under-studied' (p. 23). In an intersubjective framework, the person of the doctor needs to come into focus. Below, two dimensions of the person of the doctor are discussed: personal life and professional life. These dimensions of person are differently integrated by doctors. Zambrano and Barton (Zambrano & Barton, 2011) studied 11 GPs experience of patient death. Some doctors exhibited no separation between their personal and professional person and others aimed to limit the professional to the confines of the work space. (MacLeod, 2001)As person, the doctor's beliefs, culture, spirituality, socialisation, support networks and relationships contribute to their individual capacity to engage with suffering (MacLeod, 2001; Zambrano & Barton, 2011). Doctors bring the person they are to the clinical encounter with the person of the patient.

DEVELOPING PERSONAL CAPACITY

The capacity to work with suffering involves a personal journey for doctors towards deeper professionalism (Johansen et al., 2012) and sustainable professional identity (Aase et al., 2008). This sense of development and growth was evident in many studies (Hegarty et al, 2010; MacLeod, 2001; Mulder & Gregory, 2000; Zambrano & Barton, 2011). However, how doctors integrate these experiences and develop their personal capacity to work in this area, is not well researched.

Having personally experienced suffering may provide a lived foundation of shared humanness, increasing doctors' empathy, attunement to and engagement with others' suffering (Boston & Mount, 2006; V. Jackson et al., 2005; Mulder & Gregory, 2000; Zambrano & Barton, 2011). Personal experiences of suffering may also influence choice of career (Fanos, 2007) and enable doctors to model courage, endurance and optimism for future improvement, and provide a credible basis for encouraging patients

(Malterud & Hollnagel, 2005; Mulder & Gregory, 2000). Such personal experiences may be disclosed or operate implicitly by increasing the doctor's capacity to face suffering with and for the patient (Boston & Mount, 2006).

Doctors recognise the importance of encounters with suffering patients to their own development as persons. However, such 'turning points' (MacLeod, 2001, p. 1722) or 'breakthrough experiences' may be 'brutal' or 'inhuman' (Whitehead, 2014, pp. 272–273), especially when the prevailing organisational and professional expectation, and underpinning theoretical view, is that doctors need to fix and solve suffering and are, themselves, somehow immune to suffering.

DEVELOPING PROFESSIONAL CAPACITY

van der Steen, Deliens, Koopmans, & Onwuteaka-Philipsen (2017) conducted a survey of 103 doctors, exploring physicians' perceptions of suffering in the last six hours of life. This group defined suffering as "a patient being disturbed by or aware of symptoms. This biomedical definition of suffering unsurprisingly resulted in a focus on the physicians' capacity to relieve symptoms, including their preparation for the death and provision of palliative sedation, as well as the clinical condition leading to death. However, their definition of suffering contrasts with the multidimensional definition adopted in this study. In contrast to this physically oriented finding, other authors reviewed identified that to work with the multidimensional suffering, doctors need more than objective knowledge and skills in symptom control; they need the professional capacity to remain with suffering without developing vicarious trauma and burnout (MacLeod, 2001; Whitehead, 2014). Doctors' perception of their professional role affects their experiences with suffering and integration of their emotional responses to distressing situations (Whitehead, 2014). For example, several studies found that when doctors perceive their role as encompassing relational dimensions, they report higher satisfaction (Beng et al., 2013 a; V. Jackson et al., 2008; Papadatou et al., 2002; Smyre, Yoon, Rasinski, & Curlin, 2015). For example, in a survey of doctors in the American Medical Association national database, Smyre found physicians who sought to relieve spiritual pain were less likely to report unacceptable suffering in patients suggesting that this perception influenced their capacity to be with and attend to suffering (Smyre et al., 2015) However, there is a lack of empirical evidence to inform best practice for professional development in being with suffering.

Formal training courses appear to be of limited efficacy (Fanos, 2007; Moores et al., 2007; Vegni et al., 2005; Whitehead, 2014). Self-awareness and reflective practice are beneficial (Breaden et al., 2012; Hegarty et al., 2010; MacLeod, 2001; Mulder & Gregory, 2000), and role modelling is influential (Redinbaugh et al., 2003). Junior doctors look to seniors for guidance and supervision and to have their emotional responses acknowledged, although this is often neglected (Rhodes-Kropf et al., 2005). There is a need to nurture a culture that values these relational aspects of care (Aase et al., 2008; Hegarty et al., 2010; Moores et al., 2007; Redinbaugh et al., 2003; Rhodes-Kropf et al., 2005; Whitehead, 2014).

PARADOXES, TENSIONS AND COMPLEXITIES

INTANGIBLES

The less tangible elements of caring for suffering are critical to encounter (Vegni et al., 2005) and are most powerfully gained through experience (MacLeod, 2001). Clinical wisdom or tacit knowledge, gained through integrated and reflected-upon everyday experiences, increases clinicians' capacity to recognise suffering and respond meaningfully (Johansen et al., 2012; Zambrano & Barton, 2011). This wisdom includes the ability to recognise and accept that some suffering is intractable and unavoidably generates clinical uncertainty (Bruce et al., 2011; Whitehead, 2014). Engaging with suffering requires 'courage, patience, and gentleness' (Hegarty et al., 2010, p. 289), further examples of the intangible qualities identified in this review.

An important theme to emerge in the data was the paradoxes and tensions are inherent in working with suffering and which contribute to the complexity of care. Examples include:

- letting go of control while still maintaining involvement (Bruce et al., 2011; Hegarty et al., 2010; Breaden et al., 2012)

  Bruce et al. (2011) describe existential suffering as involving 'hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and a disruption of personal identity' (p. 1). They acknowledge that 'engaging groundlessness' (p. 7) and learning to let go may not be possible for long periods, so practitioners need to develop skills to sustain themselves. However,

few studies have explored the experience and management of existential suffering in the palliative care setting.

- finding a balance between connectedness and detachment (Breaden et al., 2012; Johansen et al., 2010; Johansen et al., 2012; Zambrano & Barton, 2011), and vulnerability and closed self-protection (Beng et al., 2013 a; Aase et al., 2008)

Existential care is described as being detached yet staying with; and distancing oneself from emotions and attachments to allow clinical competence while also being empathic, open and able to form close relationships within the clinical setting (Aase et al., 2008; Beng et al., 2013 a; Breaden et al., 2012). Each doctor–patient encounter involves moment-by-moment decisions about the degree of openness and vulnerability offered (Aase et al., 2008; Beng et al., 2013 a; Bruce et al., 2011; Hegarty et al., 2010). Doctors set their personal limits on degree of connectedness and boundary parameters (Zambrano & Barton, 2011). Misplaced connectedness may be detrimental, causing emotional reactivity, stress and burnout (Beng et al., 2013 a). The factors which determine the nature of this connection-boundary setting are not well discussed in the current literature.

- finding a balance between action and presence (Aase et al., 2008; Whitehead, 2014)

Being present to patients is an important aspect of palliative care work and may be an area of distinction from other specialities However, doctors are also called to act, to solve clinical problems and intervene to relieve physical suffering. At times, it is difficult to reconcile these aspects of the palliative care role (Whitehead, 2014). Having a flexible approach, tailored to the individual patient, helps with this tension (Hegarty et al., 2010; Takman & Severinsson, 1999).

IMPACT ON DOCTORS, OF WORKING WITH SUFFERING PATIENTS

Working with suffering patients affects clinicians both negatively and positively. Negative impacts include burnout, compassion fatigue and moral distress (Beng et al.,

2013 a). The negative consequences of working with suffering are exacerbated by poor understanding of the relational dimensions of patient care (Johansen et al., 2012; Rhodes-Kropf et al., 2005; Smyre et al., 2015). Further, factors such as lack of a supportive organisational culture, work overload, poor interpersonal work relationships, emotional over-involvement with patients who are suffering, and diminished personal appraisal and coping strategies, all contribute negatively to the experiences of working with suffering patients (Beng et al., 2013 a). An example of a poor organisational culture is described by Aase et al. (2008) as 'a medical culture of competition, pride, prestige, where you were supposed to be tough and perfect', and where 'relational fragility had been experienced in situations in which they were crucially dependent on superiors or other members of staff and had been let down' (p. 769).

Conversely, positive experiences are fostered by a 'fellowship of mutual understanding' (Aase et al., 2008, p. 769) allowing expression of personal vulnerability and humanness. For example, Mulder and Gregory (2000, p. 26) describes 'a caring moment' as a source of intense satisfaction and learning for doctors. There is little published on these positive experiences; however, they are usually described in relational domains of care, fostered by the organisational and medical culture and doctors' beliefs that their role encompasses the relational with patients and their carers (Clay et al., 2015; V. Jackson et al., 2008; Johansen et al., 2012; Zambrano & Barton, 2011).

Cultural dimensions

Only two studies from non-Western settings explored the palliative care clinicians' experience of patient suffering. Loiselle and Sterling (2012) included one doctor in their interviews with 25 hospice workers, including ten health assistants, from a South Indian hospice. The paradoxes of relief and sadness following patients' deaths, and the need for workplace initiatives to support staff were noted. There was recognition of the potential for psychological hardening due to frequent exposure to death and dying which was moderated by mentoring by more senior, experienced staff members. The authors also noted the diversity of the socio-cultural and religious backgrounds of the health care providers as well as within the palliative care population. This diversity

is a feature of health care provision internationally (Denier & Gastmans, 2013). It challenges palliative care services to develop their capacity to recognise the cultural barriers which may be operating consciously or unconsciously to impact on quality of care, and requires further study.

Beng et al. (2013) focused on the experience of stress among 20 palliative care clinicians, including ten doctors, in a tertiary hospital in Malaysia and developed a Total Care Model of Palliative Care Stress. This model has three organising themes: health care, interpersonal care and self-care. This model identifies the interrelated suffering of health care providers, patients and families, when engaged in caring for the dying and the corresponding need for self-care. Stress arises when there is lack of balance between caring for others and caring for oneself. Strategies for selfcare need to be integral, comprehensive and consistently implemented.

Both these studies highlight the vulnerability of frontline workers. In the Malaysian health care study, a key issue was work overload. Emotional involvement, personal expectations of not doing enough to help patients and death anxiety were associated with poor self-care. In the Indian study, health care assistants were recruited from local villages, trained and worked in direct patient care with prioritisation of ongoing mentoring and support. Contrary to the stress identified among the doctors, nurses and manager in the Malaysian study, the Indian health care assistants reported a high degree of fulfillment and satisfaction from their role of caring for dying patients.

GAPS TO BE ADDRESSED

There are two main research gaps which this study will address. Firstly, there is a dearth of literature exploring the experiences of doctors working in non-Western countries. Secondly, doctors' experiences with working with suffering have been little studied (Johansen et al., 2012). There is a lack of understanding about how they conceptualise suffering, how they cope with exposure to suffering and manage their own emotional responses (Aase et al, 2008), how they are impacted upon by exposure to suffering, and how they learn to develop the capacity to work with suffering (Hegarty et al., 2010; Vegni et al., 2005; Boston & Mount, 2006; Johansen et al., 2012; Takman & Severinsson, 1999).

This contrasts with the more extensive literature of nurses' exposure to suffering in clinical work (Dane & Chachkes, 2001), which has led to conceptual nursing models of caring (Watson, 1997) and the relief of suffering (Lindholm & Eriksson, 1993;Dane & Chachkes, 2001; Morse, 2001). This study may generate data which will assist in theoretical conceptualisation of the relief of suffering in modern medical practice. This data may also contribute to insights into how doctors experience their encounter with patients, a perspective on the doctor-patient relationship which is not well represented to date.

3.4 CONCLUSION

This narrative synthesis of a systematic search explores doctors' experiences of working with suffering, and develops an interpretative, narrative synthesis of the empirical literature published since 1960. The literature review lead to an understanding of the importance of the doctor-patient relationship in the exposure to suffering, and the need to further examine the dynamic, reciprocal nature of this relationship. This in turn, resulted in the adoption of the dialogical encounter as the conceptual framework for this study.

The importance of the relational dimension of care emerges as key to the engagement with and relief of suffering. Relational care not only benefits patients but is central to doctors' capacity to sustain personhood in this work, providing for mutual growth and healing. The person of the doctor in this encounter is under-studied and presents scope for further research beyond the current focus on burnout and wellbeing.

The next chapter presents the conceptual understanding of the doctor–patient relationship, from a dialogical perspective, exploring this ontological understanding of the intersubjective nature of being human.

Chapter 4: CONCEPTUAL FRAMEWORK

The literature review in Chapter 3 identified the theme of the doctor–patient relationship in the clinical encounter and the mutual, dyadic, intersubjective exchange at the heart of every encounter. The intersubjective encounter is a critical element in the relief of suffering in the healing professions and the conceptual underpinning of this thesis.

In this chapter, I trace the phenomenological origins of intersubjectivity, focusing on the work of Martin Buber. The application and importance of intersubjectivity in cultural studies, psychoanalytic practice and the relief of existential suffering is then discussed. The relevance of intersubjectivity to palliative care practice is then examined. Finally, the concept of healing and the healing relationship is discussed.

Commented [O1]: add comment re dialogical becoming and spirituality

4.1 INTERSUBJECTIVITY AND MARTIN BUBER

PHENOMENOLOGY AND INTERSUBJECTIVITY

Edmund Husserl (1859–1938) first introduced the transcendental intersubjective concept (Beyer, 2015), for which his phenomenological concept of the 'lifeworld' was foundational. One's lifeworld may be the world experienced personally, formed by one's beliefs and perceptions, or the common lifeworld shared by members of a social group, such as a particular culture. It provides a system of meaning, which another is able to experience through intersubjective extension (Beyer, 2015). Intersubjectivity is an embodied phenomenon; that is, intersubjective recognition involves embodied perception through the senses and an imaginative or cognitive leap towards the 'other', in an empathic response (L. Finlay, 2005, p. 274). Intersubjectivity enables empathic attunement to another person, beyond one's own subjectivity (L. Finlay, 2005). Heidegger's (1889–1976) concept of *verstehen* similarly describes this intersubjective encounter as a 'felt subjective engagement with the lived experience of another, in which one subjectively witnesses the depth of experience of another' (Bradfield, 2012, p. 264), 'the relational dimension of human experience' (p. 265).

Merleau-Ponty (1907–1961) describes the intersubjective experience as 'the intertwining of my life with the lives of others, of my body with the visible things, the intersection of my perceptual field with that of others' (Merleau-Ponty, 1968, p. 49). He

identifies the 'interconnectedness of human existence' (Bradfield, 2012, p. 273) and stresses the incarnation, the embodiment, of our existence and experience. We express our belonging in the world through our body and its gestures, perceptions and speech. We also perceive the world through our bodies: we are in the world, interact with others through our bodies, and are able to reflect on consciousness from that base (R. Kearney, 1994). Kearney expresses Merleau-Ponty's 'phenomenon' of embodied consciousness as the '"in-between" realm—*l'entredeux*—which pre-exists the division into subject and object' (p. 75).

Religious and social philosopher Martin Buber (1878–1965) was primarily concerned with 'the central commandment to make the secular sacred' (Buber, 1996, p. 23). In his seminal and mystical text, *I and Thou*, Thou, the other, is present when 'I' confront or meet 'You' in relationship rather than experience you, that 'in each genuinely relational event there is 'a breath of the eternal Thou'' (Smith, 1966, p.33). This understanding of spirituality experienced and expressed through relationships links Buber's ontology to palliative care and the practice of compassionate response to the other (Okon, 2005).

Buber's dialogical roots can be traced to Hebraic spirituality, which is profoundly dialogical. His ontology of dialogue is one in which human beings become more fully self through dialogue. His view of intersubjectivity describes a subject-to-subject, interhuman, I and Thou encounter. It is through encounter, between two subjects, one a person, with another person, with nature or with God, that the human being comes to know him or herself. For Buber, we are fundamentally relational beings, created through such interrelatedness, through mutuality. He rejects a self-absorbed notion of development of personhood, insisting on relational being. In *I and Thou*, Buber articulates this discernment by presenting his two basic words: I-You and I-It. The I of the I-You basic pair is different to the I of the I-It basic pair, in keeping with the mutual, relational aspect of these basic words:

> When one says You, the I of the word pair, I-You is said, too. When one says It, the I of the word pair I-It is said, too. The basic word I-You can only be spoken with one's whole being. The basic word I-It can never be spoken with one's whole being. (Buber, 1996, p. 54)

He distinguishes the realm of these basic word pairs: 'The world as experience belongs to the basic word I-It. The basic word I-You establishes the world of relation' (Buber, 1996, p. 56). In the basic word, I-It, instead of encounter, there is experience, instead of subject-to-subject relation, there is subject-to-object experience.

Buber's dialogical ontology states that we are ourselves to the extent that we can relate to the 'other': 'The sphere of the interhuman is one in which a person is confronted by the other. We call its unfolding the dialogical' (Buber, 1996, p. 70). He stresses the fundamental importance of the intersubjective nature of developing as human beings:

> For the inmost growth of the self is not accomplished as people like to suppose today, in man's relation to himself, but in the relation between the one and the other, between men, that is pre-eminently in the mutuality of the making present . . . together, with the mutuality of acceptance, of affirmation and **confirmation.** (Buber, 1998, p. 61)

He anticipates the term 'the intersubjective field', which appears later in this chapter, by his recognition of the ubiquitousness of the reciprocal nature of relational being: 'Inscrutably involved, we live in the currents of universal reciprocity' (Buber, 1970, p. 67).

'Genuine dialogue' takes place through a 'turning of the being' (Buber, 1992, p. 78), to the 'other' and to 'mean' them, in the sense of '**making present'** as a particular person:

> The experiencing senses and the **imagining of the real** which completes the findings of the senses work together to make the other present as a whole and as a unique being. (Buber, 1992, p. 78)

These three features, imagining the real, making present and confirmation, are gathered under the term '**inclusion**'. They work together ontologically to realise, in the 'other', a 'becoming a self with me', in which the other self knows he or she is made present and 'this knowledge induces the process of his inmost self-becoming' (Brown, 2015; Buber, 1965, p. 61).

The term 'dialogical encounter' describes the therapeutic healing encounter that realises the moment-to-moment, relational knowing between two persons, involves

inclusion and moves towards the intersubjective healing moment of the 'between' (Brown, 2015). She relates these 'poetic terms' to the dialogic attitude in therapy and dialogic research (see Table 3).

Table 3: Conceptualisation of Buber's Poetic Terms in Relation to Family Therapy and Research (Brown, 2015, p. 194)

Buber's Poetic Image	Therapist/Researcher Attitude & Focus
The narrow ridge **Subject–object monologue in the I-It relation**	Attitude of 'We are different' Focus on otherness
Process of inclusion **Dialogue unfolding in the I-Thou process**	A. Imagining the real B. Making the 'other' present C. Confirming the 'other'
A. **Imagining the real**	Attitude of 'I notice you' Focus on listening and speaking
B. **Making the 'other' present**	Attitude of 'I recognise you' Focus on quality of the utterance
C. **Confirming the 'other'**	Attitude of 'I accept you' Focus on silence
The between **Intersubjective moment of meeting**	'Are you here?'—'I am here'.—'So am I'. The present moment

Thus, inclusion describes the processes that allow one to experience what the 'other' is feeling, thinking, willing and knowing (Friedman, 2008, p. 299). More than observing or noticing, it requires 'a bold swinging over into the life of the person one confronts, through which alone I can make that person present in his or her wholeness, unity, and uniqueness' (Friedman, 2009, p. 410). In this way, the 'other' is brought into being by 'the capacity to hold before one's soul a reality arising at this moment but not able to be directly experienced' (Buber, 1992, p. 66). Thus, for dialogical unfolding or encounter to take place, all who are participating in it must bring themselves fully to the dialogue (Buber, 1992).

THE BETWEEN

From his recognition of the need for relation to become fully human, and the relational essence of 'I', Buber explores the essence of the interhuman, which he calls the 'between', or *das Zwischenmenschliche*. The 'between' resides in the unspoken, elusive and spiritual domain in interhuman encounter and so, in large part, remains hidden, or at least resistant to description (Friedman, 1999). Most simply, it is 'that which occurs between men' (Buber, 1992, p. 93). It is the zone of connection, in which creative, meaningful exchange between two humans takes place, with each becoming present or fully real to self and other:

> Yet this [the psychological] is only the hidden accompaniment to the conversation itself, the phonetic event fraught with meaning, whose meaning is to be found neither in one of the two partners nor in both together, but only in their dialogue itself, in this 'between' which they live together. (Buber, 1996, p. 70)

In the 'between', encounter may be wordless, consisting of a smile, a look or an appreciation of the being of the 'other', which transcends the usual realm of human discourse and may happen 'when two strangers exchange glances in a crowded streetcar' (Buber, 1992, p. 69).

This 'between' is a communion, a shared union. The encounter may be unexpected but mutually recognised:

> I look at thee, thou unknown man or unknown woman, whom God has placed in my path. And behold, God, in silence, makes thee come alive to me, present to me. In thy eyes, I have glimpsed thy soul. My look has borne my soul to thee. (Gillet, 1977, p. 56)

Other terms resonate with this concept, such as Bollas's (1989) core self: 'the unique presence of being that each of us is; the idiom of our personality' (as cited in Yeatman, 2015, p. 4). The 'between' may be conceived of as a meeting of the core self, 'where in truth "deep calls unto deep" . . . on the narrow ridge where I and Thou meet' and fosters 'genuine community' (Buber, 1947, p. 204).

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R. Smith's (1966) understanding of the nature of the 'realm of betweenness' as a source of action, of "'creative' impulses seeking form" is cited in full as it helpfully articulates this ineffable concept:

> For the realm of 'betweenness' is not a state, far less merely an idea derived from looking at men in relation. But it is a realm in which action reigns, and it is a source of action. That is to say, in what Buber calls 'meeting', we find the source of the historical movements of men toward newness, new decisions, new structures, all human action, all creative impulses seeking form. . . . It is spirit, the elusive, the ever-present, the invisible yet the entirely historical vehicle of man's existence which is here indicated. (p. 32)

The importance of the 'between' as a concept is that it attempts to articulate the unknowable element of spontaneous, mutual, creative emergence of something new. Brown (2015) describes it as being and becoming manifest 'in the intersubjective moment of meeting, which generates effects on those involved and makes possible different ways of being and knowing' (p. 199). It calls not for words or objectivity, but for 'affective and embodied responses' (p. 199), an observation of great relevance to therapeutic dialogical encounters.

This understanding of the spiritual significance of mutual encounter pervades the writing of Dame Cicely Saunders. She writes that it was 'an encounter with one patient in 1948 that was the catalyst for the Hospice Movement' (Cicely Saunders, 2000, p.7) and expressed a belief in the need for 'our personal meetings with dying people if we are to remain human and true to the original commitments to openness to people' (Cicely Saunders, 2000, p.13). However, she also recognised the need to find a non-religious language that made sense to the modern secular world and patient, which nevertheless reached the depths of spiritual being: "Many, both helper and patient, live in a secularised society and have no religious language' (C. Saunders, 1996, p.1601). For example, Stanworth's research, conducted among dying patients at St Christopher's Hospice in the 1990's, reveals the expression of the spiritual through metaphor, silence and narratives (Stanworth, 2004). Buber's language of dialogical becoming, of encounter, of the 'between', offers a conceptual framework within which to explore this ineffable dimension of the clinical encounter. The 'between' is the place of the spirit lived by both partners in dialogue, and here, Buber's dialogical concept of

becoming articulates the spirituality so central to palliative care practice. This understanding of spirituality in terms of connection with an 'other', which I have adopted in the relational conceptual framework of this study, resonates with the definition of spirituality of the spiritual care reference group of the European Association of Palliative Care. Specifically, this group defines spirituality as 'the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.'(EAPC., 2014).

4.2 Intersubjectivity in Cross-cultural studies

The discussion of intersubjectivity to this point, has focused on what Coelho and Figueiredo (2003) call trans-subjective intersubjectivity, the between subjects, allowing shared meaning. However, there are many other perspectives on intersubjectivity and the widespread application of this concept includes the fields of social sciences (Biehl et al., 2007; Blumer, 1986), education (Biesta, 1998; Vashishtha & Panda, 2019) and social policy development (Gauri, Woolcock, & Desai, 2013).

Of particular relevance to this study is the understanding of intersubjectivity as an interpersonal phenomenon, which extends beyond the subjects, to the wider context of the social world and culture, through which gestures and symbols (for example, language) are mediated, learnt and communicate shared meaning (Coelho & Figueiredo, 2003). Here, the cultural world and social norms operate within the relational space and affect the outcome of the interaction. Vashishtha and Panda (2019, p.161) capture this understanding of intersubjectivity as 'knowledge laden spaces' in which not only alignment of understanding but also malalignment, mal-attunements and conflicts, what Buber described as mis-meeting, may occur.

The cultural dimensions of intersubjectivity are present within the interpersonal and particular dialogue of any two persons. Culture, in its past and present formulation for each person, in terms of ethnic origins, of the particular organization, group, role and belief system of the individual, operates within an interaction to shape the possibilities

of shared meaning or conversely, the failure to reach understanding. The cultural shaping of medical systems and the impact of the constructs adopted within this space, have profound bearing on the clinical encounter (Kleinman, 1981).

In clinical practice, the intersubjective encounter is also subject to these cultural influences (Lorié, Reinero, Phillips, Zhang, & Riess, 2017). Previous encounters with health carers are present in the particular encounter, shaping the capacity and willingness to be present and attuned to the other in this new encounter. There is substantial variance across cultures and within the individuals of any culture (Leung & Cohen, 2011). Aggarwal (2012) describes this complex interplay of ethnicity as culture, medicine as culture, and cultural hybridization arising from multicultural formation, which operates in a clinical psychiatric assessment and synthesis. This complexity is conceptualised in the next section by Stolorow's intersubjective field theory.

Cross-cultural studies attempt to bring to light the different subjectivities of each participant and to create opportunity for shared meaning and understanding. Adopting an intersubjective framework in this study validates the diverse subjectivities of participants and recognizes that meaning in this context arises from the intersubjective encounter between participant and researcher.

4.3 PSYCHOTHERAPEUTIC APPLICATION

Turning specifically to psychoanalytic theory as it relates to the relief of existential suffering, the concept of intersubjectivity is integral to psychoanalytic approaches (Atwood & Stolorow, 1984; Benjamin, 1995; Bollas, 1989; Boston Change Process Study Group & Nahum, 2008; Drozek, 2010; Orange, 2010; D. N. Stern, 2004; Stolorow, 2013; Stolorow & Atwood, 1996; Winnicott, 1971). Buber's dialogical understanding has led to the development of dialogical psychotherapy, in which 'healing through meeting' is central (Friedman, 2002). Here, the therapist must first 'be a person available to others as a human being and second be a professional trained in the appropriate methods of practicing psychotherapy' (Hycner, 1991, p. 22). This

emphasis on the centrality of shared humanness holds promise for the application of dialogical principles in palliative care practice also.

Two points of intersubjectivity are considered essential in psychotherapeutic change: the 'moment of meeting' between therapist and patient, and the implicit knowing of patient and therapist brought to the therapeutic encounter (D. N. Stern, 2004, p. 220; D. N. Stern et al., 1998). As these have great relevance in psychotherapy for existential suffering, they are worth considering in some depth here, as they likely also apply in palliative care.

Moment of Meeting

D.N. Stern (2004) postulates that dyadic change can occur incrementally, present moment by present moment, within the therapeutic encounter. He describes a different, special present moment called the 'moment of meeting' that 'implicitly reorganises the intersubjective field so that it becomes more coherent, and the two people sense an opening up of the relationship, which permits them to explore new areas together implicitly or explicitly' (p. 220). He insists on the importance of the present moment and the temporal dimension of change; just as the original experience was laid down in time, so must the new experience be intersubjectively lived in time to reorganise consciousness: 'If past experiences are to be changed, they must be rewritten or replaced by a new temporal experience occurring in the same time framework. The rewriting must also be lived through with its own temporal dynamics' (p. 221). This lived experience of a new understanding emerging within intersubjective, dialogical encounter, between therapist and patient, evokes Buber's 'between' and the capacity for becoming self through encounter.

Implicit Knowing in Therapy and Beyond

The second intersubjective component, implicit relational knowing, is redolent of elements of inclusion; namely, imagining the real and making present. It is where most therapeutic breakthrough and effective change occurs (D. N. Stern et al., 1998). Implicit relational knowing is 'part of the nonconscious processing, including "unformulated experience"' (D. B. Stern, 1997), that has never been put into words, has never had to be, or never could be' (Boston Change Process Study Group & Nahum, 2008, p. 129; D. B. Stern, 1997). Implicit knowing is operant in all aspects of

interpersonal relationship (D. N. Stern, 2004), not just in psychotherapy, and involves a finely tuned, sophisticated capacity to read another's behaviour and respond in a manner the person has learned to be protective or constructive of one's self. Implicit knowledge has clinical corollaries, termed 'tacit knowledge' (Carlsson et al., 2002; Polanyi, McIntosh, & Kosny, 2005) or 'clinical phronesis' (Schultz & Carnevale, 1996; Stolorow, 2004). Tacit knowledge is knowledge gained over time through experience coupled with theoretical knowledge and reflection. It involves encounter and engagement (Polanyi et al., 2005) to comprehend what is called for in a given situation. Similarly, clinical phronesis emphasises engagement with patients to develop clinical wisdom and the capacity for responsible care and decision-making (Schultz & Carnevale, 1996). As implicit knowledge is often difficult to verbalise, it is inadequately valued (Carlsson et al., 2002). Qualitative studies focused on the intersubjective dimension of clinical practice, such as those conducted by Dahlberg and colleagues (Bremer, Dahlberg & Sandman, 2012; Nyström et al., 2003; Wireklint & Dahlberg, 2011), may address this gap in understanding of the importance of implicit knowledge in clinical practice.

4.4 RELEVANCE TO PALLIATIVE CARE

A framework for palliative care delivery that facilitates the occurrence of a therapeutic, intersubjective, 'moment of meeting' within dialogical encounter would be highly relevant to end-of-life care, in which suffering frequently lies within the traumatic, existential landscape of grief and loss (Cassell, 1982; Charmaz, 1983; Kleinman, 1992; Lethborg, Aranda, Cox, & Kissane, 2007; Priya, 2012). However, there is some question as to whether such incremental, moment-by-moment, dyadic, lived-in-time change can operate within modern medical practice, where the doctor–patient relationship is hampered by the biomedical framework. As Johansen et al. (2012) write: 'If medicine is seen as applied science of biomedicine, neither patient as person nor the doctor as person has central roles' (p. 570). Even in palliative care, with its explicit goal of the relief of suffering and doctrine of patient-centred care, current trends (e.g., towards brokering of care, outsourcing of tasks to other services and increasing referrals without adequate service-capacity growth) are challenging the development of a meaningful relationship with patients.

Yet as described above, a glance or smile may be enough to bring about an intersubjective experience of 'between' or this 'moment of meeting'. This could occur as a surprise within a relationship, with factors other than length of exposure to each other being more important in facilitating such moments. For example, a stance of readiness for encounter, of openness to the 'other', must be present. Stolorow (2013) recommends the correct therapeutic stance towards another person's emotional trauma as to offer an 'emotional dwelling' (p. 384). This requires us to 'tolerate our own existential vulnerabilities so that we can dwell unflinchingly with his or her unbearable and recurring emotional pain' (p. 388).

Unlike my literature review articles, the non-empirical literature outside the scope of my review contains references to intersubjectivity theory. For example, Papadatou (2009) draws upon the concept of the intersubjective field to describe the many influences on the encounter with the dying and bereaved. These include health carers and influences from the wider community and culture, as well as organisational and care-setting contexts (see Figure 4).
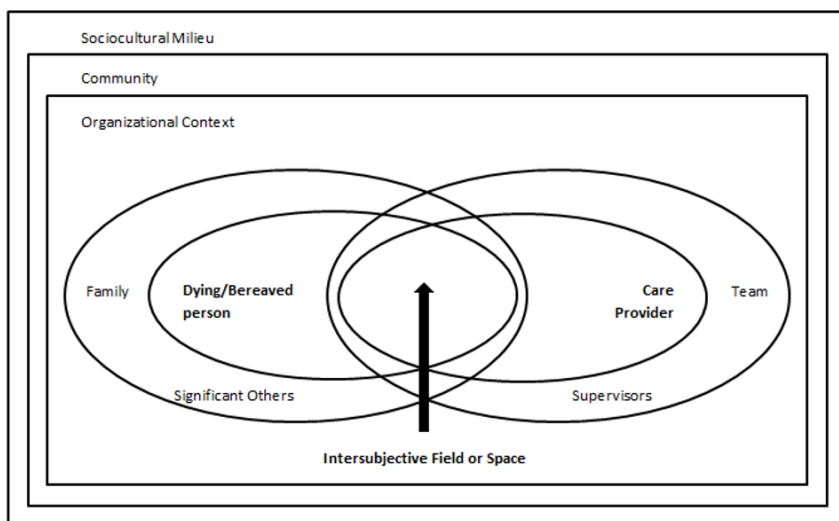
Figure 4: The Context of the Caregiving Relationship
Reproduced with permission from Papadatou (2009, p. 16, fig 1.1).

Thoresen and colleagues (Thoresen, Wyller & Heggen, 2011; Thoresen & Öhlén, 2015) also appreciate the intersubjective space in their observational studies in hospice and palliative care experiences in Sweden. Their compatriots also draw on intersubjectivity to provide conceptual understanding in studies of holistic caring and lifeworld (Dahlberg, 1996) in emergency units (Nyström et al., 2003) and ambulance services (Wireklint & Dahlberg, 2011).

4.5 HEALING

Relation is central to Buber's ontology of becoming self. 'All actual life is encounter' (Buber, 1970, p. 62). Such becoming may be termed 'healing', the restoration or development of personal integrity, as opposed to the personal disintegration which identifies suffering. Healing may be evinced by personal growth, improved self-esteem, new coping ability, new sense of meaning, deeper spirituality or change in life outlook, and a greater appreciation of life (Egnew, 2005; Guenther, 2011; Morse, 2000; Tedeschi & Calhoun, 1995). Such outcomes again conjure the sense of the 'between', of new creative impulses. The moment of meeting is a healing moment.

Several authors have recently drawn upon Buber's ontology to describe the healing relationship in medicine and to encourage a dialogical foundation to the practice of medicine. Scott, Scott, Miller, Stange and Crabtree (2009) developed an empirical model of healing from narrative interviews with doctors about the clinical relationship. They conceptualised valuing, appreciating power and abiding as consistent with Buber's concepts of inclusion, mutuality and commitment to returning to the I-Thou intersubjective relation over the lifetime of the relationship. In their model, they also identify the key competencies of emotional self-regulation, mindfulness, self-confidence and knowledge needed for a healing encounter. Cohn (2001) states that for Buber, 'relationship and dialogue are not issues for medicine; rather, medicine is a matter of relationship and dialogue' (p. 170). She identifies the components of the I-Thou relationship as: spontaneity, subjectivity, reciprocity (mutuality), recognition, and acceptance of the unique 'other' (i.e. the element of confirmation in inclusion). Abramovitch and Schwartz (1996) draw on Buber's dialogical approach to propose three stages in a medical encounter: an initial stage to establish relationship; a second stage which moves towards an I-It impersonal, task oriented interaction; a third

'healing through meeting' stage, in which there is integration of the biomedical and the dialogical elements of the interaction, enabling shared decision-making.

Mutuality deserves special consideration in the doctor–patient dialogical encounter: 'Mutuality admits of degrees' (Tallon, 1987), and within the helping relationships, the I-Thou relationship holds the promise of mutuality (Friedman & Damico, 2011). The normative limits of mutuality in the clinical relationship allow for 'mutual contact, mutual trust, and mutual concern . . . but not mutual inclusion' (Friedman, 2002). The patient is not expected to imagine what the clinician is thinking and feeling. However, Cohn (2001) develops the concept of mutuality as it relates to the doctor–patient relationship further, recognising that 'a physician's very being, like other individuals, depends on a relationship with others, patients' (p. 171). Here, the importance of dialogical encounter for the wellbeing of clinicians comes to the fore. Exquisite empathy, a deep, intimate, therapeutic alliance of presence and connection, such as occurs in dialogical encounter, was found to be protective against vicarious traumatisation in social work practice (Harrison & Westwood, 2009). Such empathy aligns with the I and Thou healing relationship. described as providing a sense of meaning, sustenance and reward even when working in difficult circumstances (Scott, Scott, Miller, Stange, & Crabtree, 2009) Clinicians capacity to recognise themselves as potentially or previously suffering human beings, also fosters a dialogical healing relationship. In Jung's (1985) concept of the wounded healer introduced in Chapter 2, the shared subjectivities of patient and clinician are closely aligned, facilitating the opportunity for 'moment of meeting' between the now-suffering patient and the potentially or previously suffering clinician (Frank, 1995).

4.6 Conclusion

In this chapter, I have reviewed the phenomenological literature and Buber's concept of dialogical becoming, as expressing the intersubjective interactions of human beings. I then discussed his concept of 'healing through meeting' and the potential for emergence of the 'between', the spiritual dimension of interconnection. I posit that this concept of 'healing through meeting' which was further developed into the practice of dialogical psychotherapy, by Buber scholar, Friedman, holds promise in the practice of palliative care when this is focused on the relief of suffering, especially when this is occuring in the existential or spiritual realm of personhood. I discussed the importance

of intersubjectivity in cross -cultural interactions drawing on the intersubjective field theory to describe the sociocultural influences on intersubjective encounters (Aggarwal, 2012; Gauri et al., 2013).

I noted the scholarship of medical writers who have drawn extensively on Buber's intersubjective, I-Thou concept, to propose a dialogical framework for the practice of medicine. These scholars recognise the mutuality of the doctor-patient relationship within the inherent inequality of the partners. There is a need to explore and discern further, the nature of the doctor-patient relationship in end of life care, in order to better understand how to sustain the practitioner who is frequently exposed to suffering and death. I suggest that retaining capacity for connection, for human meeting, allowing for the emergence of the 'between', is a key element in fostering the wellbeing and humanity of doctors. Clinicians working in palliative care are immersed in an ocean of suffering and may choose to remain on the surface for fear of their own safety. However, within Buber's intersubjective framework, it is impossible to remain superficial when encountering suffering, without some degree of denial of our own humanity, operating as the 'I' of I and It dyad, the I of experience rather than relation.

The relief of suffering of patients and self-care of doctors are not distinct, but rather two aspects of the dialogical encounter. Just as the patient comes to the doctor seeking relief of suffering, with the doctor being, or providing, the transformational object of relief, so the doctor becomes 'I' in relation to the 'Thou' of the patient, and potentially more fully whole through developing greater clinical wisdom, creativity, understanding, compassion or skill (Friedman, 2008). If this dyadic exchange operating in the zone of implicit knowledge, the spiritual zone of the 'between' created through this encounter, is not integrated into the clinician's therapeutic awareness, they are at risk of objectifying both the 'other' (the patient) and the self (the doctor). It is not clear if modern palliative care doctors in Australia and India see themselves as providing a relational home for patients who are suffering, or whether they recognise the mutuality of their dialogical encounter.

Chapter 5: METHODOLOGY—
A NARRATIVE APPROACH

Chapters 2–4 have provided the research context of the relief of suffering, presenting the palliative care literature on this topic and the conceptual framework within which this study is situated. In this chapter, I present the philosophical paradigm underpinning the study methodology (i.e., the ontological and epistemological position upon which the study is based), the narrative methodological considerations, narrative interviewing and the insider-outsider dialectic. I then discuss the methods adopted in the study, and detail the approach to data analysis. I also discuss the choice of qualitative narrative research, arguing that this achieves the requisite coherence between the philosophical paradigm, aims and objectives, methodology and methods of this study.

5.1 ONTOLOGICAL AND EPISTEMOLOGICAL POSITION

Qualitative research is fundamentally inductivist, interpretivist and ontological; that is, concerned with the nature of reality (Bryman, 2008). It is emic, seeking to understand social reality from the perspective of the individual, and looking at how individuals make sense of their world.

My ontological position is one of critical relativism, defined as understanding that a 'pre-social reality exists but we can only ever partially know it' (Braun & Clarke, 2013, p. 26). Within this position, I adopt both a phenomenological and hermeneutical approach. Ricoeur is credited as fusing these theoretical ontological positions in his studies of self-identity, created through narrative accounts of one's life (Rice & Ezzy, 1999). Building on the concepts of lifeworld (Thoresen & Öhlén, 2015), *verstehen* (Bradfield, 2012), the interconnectedness of human existence (Bradfield, 2012) and the in-between (R. Kearney, 1994) discussed in Section 4.1, I recognise the importance of entering into the lifeworld of my participants, and the relational nature of exploring their reality. The constructed lifeworld of the participant doctors were understood as unique to their experience of the world, across a life continuum.

The narrative research approach, here used to explore doctors' experiences, is hermeneutical and interpretivist. Narratives are interpreted discourses, both by the

participants in the 'how' and 'what' of their narratives, and by me, through dialogue with participants and the narratives themselves (Riessman, 2008). Further, they are co-constructed, in dialogical terms, whereby the encounter is mutually creative and the means by which we as human beings 'become' (Buber, 1970). Consistent with the constructionist theoretical approach, narrative research 'views discourse about the world not as a reflection or map of the world but as an artefact of communal exchange' (Gergen, 1985, p. 266). The 'facts' of information gathered in the interviews are socially constructed within a particular intersubjective context.

From this position, the data collected through my narrative interviews with doctors are not static facts reporting on fixed events, but representations, explored and narrated to me, as colleague/researcher, within the context of a research study with a declared, particular focus. The narratives emerge in time and place and within relationship, are dynamic and contextual. Likewise, the narrative interviews are interpreted by me, over time, iteratively, within contextual boundaries of each hearing, subject to the development of my conceptual understandings, and formed in the myriad ways in which persons change and develop.

5.2 Narrative Methodology

Choosing the Narrative Approach

The aim of the study was a cross-cultural exploration of doctors' experiences of working with patients at the end of life, in order to develop further understanding of how they recognise suffering and how they seek to respond and relieve it. This required a methodology that would allow for explorative discourse, directed by the participant. Narrative is a meaning-making human activity. Therefore, qualitative narrative methodology, which explores the ways in which individuals use storytelling to make sense of life events, was chosen to explore doctors' understanding of their experiences.

Narrative inquiry is also especially well-suited to the study of suffering, as experiences of suffering and healing are naturally shared through storytelling (Hydén, 2008). Narratives are recognised as an especially powerful means of approaching difficult experiences, helping the storyteller to integrate and interpret the events narrated (Riessman, 2008).

Human lives are culturally and relationally constructed. Narratives are a powerful means of revealing the fabric of human lives, in and across time. They are a potent resource for communicating the experiences, emotions and the meanings attached within relationships and cultures, to events, behaviours, and actions. Because people are in constant flux, in a constant state of becoming, the open-endedness of narratives provides an ethical approach to giving an account of human life (B. Smith, 2016).

Narratives also produce research that is highly accessible to a wide audience, and so is effective for knowledge translation. The capacity of narrative in medical education to enhance compassion and empathy (Charon, 2001) and as a reflective, self-care strategy (Bolton, 2006) also holds promise. Adopting a narrative methodology offered an opportunity to explore this further, and to gather narratives about working with suffering, which could be of educational benefit.

Finally, the narratives of Indian doctors are largely unrepresented in global palliative care literature. Presenting their narratives helps to fill this gap, and here allows for cross-cultural comparison of the particularities of the lifeworlds of Australian and Indian doctors.

LOOKING AT NARRATIVES

> 'God created mankind because he loves stories'
>
> Jewish proverb (J. Sacks, 2005, p. 11)

Stories have an important place in human discourse and social engagement. From Aboriginal dreamtime, to epic tales of Greek and Indian mythology, to daily accounts of events and experiences, stories abound. As Luke (1995) explains:

> All those stories that deal with basic human themes draw their power from the archetypal world that is common to people of all cultures and of all times, but the images in each culture will, of course, differ greatly and it is for us to penetrate through these varying pictures to the universal wisdom that underlies them. (p. 97)

Narratives[1] are important vehicles for humans to make sense of their lives; they are connected to our very being. Ricoeur states that 'a life is no more than a biological phenomenon as long as it has not been interpreted' (Riessman, 2008, p. 190) and it is with interpretation that the story arises. Stories shape identities by providing a plot to interpret life events and the world (Elliott, 2005; Freeman, 2013; Ricoeur, 1991; Thomas-MacLean, 2004), helping to construct our self-narrative (Oke, 2008) and sense of personal integrity (Neimeyer, 2000), to cope with life events (Neimeyer & Levitt, 2001; B. Smith & Sparkes, 2005) and connect to others (Charon, 2001; Stanley & Quill, 2011). This identity-formation function is of particular value in exploring doctors' responses to suffering and creation of therapeutic self-narratives. Stories are also instrumental in shaping and creating a sense of order from disorderly, chaotic experiences (Salmon, 2013). In this way, stories may be therapeutic for both teller and listener (M. K. White, 1995).

NARRATIVE RESEARCH

Narrative inquiry is concerned with the exploring ways in which individuals use storytelling to interpret life events and understanding subjective experience (Bingley, Thomas, Brown, Reeve, & Payne, 2008). Its particular strength is that it is a means of making sense of experience (Frank, 2002). Based in constructionist paradigms, and distinct from ethnographic approaches, narrative inquiry treats stories as crafted accounts, of interest for both their content and structuring and the context in which they are told, including the audience listening to the story.

According to Riessman (2008), 'narrative analysts interrogate intention and language—*how* and *why* incidents are storied, not simply the content to which language refers' (p.11, italics in original). As such, narrative inquiry seeks to identify units of story for analysis, keeping those units intact, as compared to the more frequently adopted thematic analytic approach in qualitative research (Andrews, Squire, & Tamboukou, 2013; Bingley,2020; Bingley et al., 2008; Polkinghorne, 1995; B. Smith, 2007). Narrative analysis' honouring of the integrity of the voice of the

narrator, aligns it closely with the phenomenological and hermeneutical positions, which place the lifeworld experiences of the person at the centre of enquiry. The narrative method lends itself to the study of the particular, the individual (Fins, Guest, & Acres, 2000; Riessman, 2008; C. Thomas et al., 2009).

The field of narrative research is highly dynamic and multifaceted, with approaches that range from intuitive readings of text and identification of genre (Frank, 2010) to systematised, formulaic explorations of text that draw heavily from linguistic studies (Gee, 1986). Building on the work of Mishler (1995), Bingley (in press) identifies three aspects of narrative: symbolism (relating to structure), emplotment (relating to function, meaning) and interactional dialogue (relating to context).

Linguistically derived narrative research such as Gee's units of analysis method, tends to focus on the symbolism, and thus structure, of narratives, and the capacity of structure to generate meaning (Andrews et al., 2013; Elliott, 2005). Narrative research approaches that are more relational or meaning-focused include dialogical, genre and biographical types of analysis. However, as noted with structural analysis, meaning is inherent within and communicated by language and form, so there is clearly overlap between these approaches.

DIALOGICAL NARRATIVE RESEARCH

The present study has a strongly dialogical conceptual orientation; accordingly, the dialogical narrative approach to narrative analysis has been used as one stream of analysis, both in the examination of the dialogue between me and the participants and in engaging with their narratives themselves.

Dialogic narrative analysis is interested in how story is shaped in dialogue. For Russian literary critic, Mikhail Bakhtin (1984), 'To be means to communicate dialogically' (as cited in Friedman, 2001, p. 27). In a research setting, the dialogue between participant and researcher is a critical component of the narrative formation. 'Dialogical research requires hearing participants' stories not as surrogate observations of their lives outside the interview but as acts of engagement with researchers' (Mishler, as cited in Frank, 2005, p. 968). This requires deliberate and continual engagement and reflection on the part of the researcher to identify the mutual effect on the dialogue and ensuing narratives (L. Finlay, 2009). Such reflection

takes place partly by keeping a field diary, but primarily through writing about the narratives, in a cyclical and iterative manner (B. Smith, 2016). See Section 5.5 for the method of conducting the DNA.

GEE'S STRUCTURAL ANALYSIS

The other narrative method used in this study is Gee's linguistic narrative analysis approach. While Gee's linguistic narrative analysis may at first seem at odds with the dialogical narrative approach, seeking out the rhythm, pitch, intonations and emphases of the narrator's performance facilitated dialogue with the text and exploration of meaning, helping to more clearly reveal the narrator's perspective. It is a means of ensuring close adherence to the voice of the participant, representing the linguistic dictates of talk. By adopting this approach, the researcher is made more aware of the prose of the narratives, taking time to 'imagine with' them, while remaining true to the constraints of language itself (Gee, 1986). This method is also described in detail in Section 5.5.

5.3 INTERVIEWS IN NARRATIVE RESEARCH

NARRATIVE INTERVIEWS

The narrative interview derives its particular character from the constructionist paradigm. The narrative is identified as a co-construction between participant and researcher (Holstein & Gubrium, 1995). The narrative interview is a discursive co-creation emerging in that particular encounter (Mishler, 1986), in which there is 'mutual reformulation and specification of questions, by which they take on particular and context-bound shades of meaning' (p. 53). Interviews are open-ended and unstructured (Corbin & Morse, 2003) and aim to facilitate storytelling and emergence of the worldview of the participants. (Mishler, 1986; Riessman, 2008; Taylor, 2007).

The narrative interview typically comprises the following phases:

- pre-interview or preparation phase
- tentative or initiation phase
- main narration or immersion phase
- questioning and clarifying phase, also called the emergent phase

- conclusion (Corbin & Morse, 2003; Jovchelovitch & Bauer, 2000; Wengraf, 2001).

This format encourages expression of 'immanent' issues of importance to the participant, rather than being limited to 'exmanent' issues; that is, the interests of the researcher (Jovchelovitch & Bauer, 2000).

The interviews were conducted in a dialogical, relational manner, guided by a general topic guide (see Appendix 7; Rubin & Rubin, 2012). They were conversational and allowed for moment-by-moment dialogical response to what emerged within the intersubjective space between me as interviewer and the participant doctor. This moment-by-moment exploration contains 'ambiguity, uncertainty and unpredictability' (L. Finlay, 2009, pp. 1–2). I aimed to allow the participant to determine the direction of the interview as much as possible. Sharing, prompting, probing and clarifying questions were part of the co-construction process of the interviews.

MY ROLE AS NARRATOR

'OUTING THE RESEARCHER'

In the interviews, I was not seeking to be impartial, but to be an active participant in dialogical exchange and genuine conversation. This may explain why one participant, Abhit, said: 'ah, I just feel that we are conversing the way we have been for the last 15 years'.

I bring a palliative orientation to interviewing, which involves training in communication skills focused on listening, attunement, open-ended questioning, identifying and naming emotion, clarifying and reflecting back to the 'other' (Baile et al., 1999; Clayton et al., 2007; Fallowfield & Jenkins, 2004). Although medical interviews tend to be dominated by doctors' agendas (Mishler, 1986), interviewing colleagues diminished this power imbalance.

Bradfield notes the 'parallels between the investigative/research process and the psychoanalytic disposition' (Bradfield, 2012, p. 263). I feel that my palliative care 'disposition' also brought an attunement towards the intersubjective space, which influenced the conduct of the interviews. This was acknowledged by several

participants, including Ranjani, who said at the end of her interview: 'It's also therapy for me you know it's therapy for me because I've voiced my innermost feelings, it's just a platform to discuss, reflect on what I've said'.

Insider/Outsider Dialectic

My being a doctor-colleague-researcher had a varying and difficult-to-predict influence on my study and the stories revealed and shared. This unpredictability introduces an important dimension to the study, as the stories told are particular to the dynamic between participant and researcher. As a doctor conducting research on other doctors, Löyttyniemi's (2005) concept of 'knowing' is relevant. I begin from a stance of knowing much about the doctor's world, having experienced it in my own body. I embody this world in my way but also in a shared way, so that many of the participants' narratives resonated with me personally.

I do not sit clearly within an insider or outsider perspectives as a researcher in this study (L. Finlay, 2002). I trained as a specialist in palliative care in the UK and have worked in Australia since 1995. I have volunteered and worked in palliative care in India since 1994, and have extensive experience of the Indian palliative care community. I consider myself an insider in India in terms of my long association and collegial relationships with many doctors there, but an outsider culturally and practically, living as I do in Australia. My position in Australia is more dominantly inside the world of the participants. Therefore, rather than an insider or outsider, I may be better described as an 'inbetweener' (Milligan, 2016).

My 'knowing' stance as researcher/interviewer and colleague to the participant doctors carried the potential to constrain the depth of sharing and conversation. It was expected that colleagues might censor their conversation to present a certain type of professional competence. However, the reverse was more apparent, and 'knowing' appeared to facilitate sharing. Shared professional understanding and experiences may have increased the participants' trust and ease of dialogue (Chew-Graham, May, & Perry, 2002). This prior 'knowing' also emphasised the importance of careful reflexivity (Etherington, 2007) through field-diary reflections and discussions with my supervisors.

5.4 METHODS

THE PARTICIPANT SAMPLE

I planned to recruit doctors from the Australian and Indian population of palliative care doctors. A purposive sampling method was chosen, in order to achieve a diverse group of doctors for the study in order to address the objectives of the study. Achieving a range of ages and years of experience was an important feature of the recruitment in order to explore how doctors' sense of self, both personal and therapeutic, is developed and sustained over time. A sampling matrix was developed in advance to capture characteristics of participants (gender, age, experience, primary discipline) (see Table 4). I did not seek out specific numbers for each category, but rather used the matrix as a guide to monitor the diversity among the respondents during the recruitment phase. However, I did aim for equal numbers of participants from Australia and India, and a total of 16-20 participants overall. This number was estimated to provide a rich dataset in keeping with qualitative methodology (Braun & Clarke, 2013).

The characteristics listed in the sampling matrix were chosen as they were likely to impact on the experiences of the participants. Gender differences have been recognised in the literature on the impact of death and dying on oncologists (Fanos, 2007) and medical students' experiences of patient deaths (Redinbaugh et al., 2003). Level of seniority, role perception, and speciality background likewise are reported to influence doctors' experiences with death and dying (Jackson et al., 2008; Moores et al., 2007), and so may impact on experiences with suffering also.

Table 4: Matrix for Sampling of Participants

Gender	F	M	
Age	<40	40–60	≥60
Years in clinical practice	<10	10–20	≥20
Country of practice	Australia	India	
Primary area of specialisation	Palliative care	Oncology	Anaesthetics
	General practice	Other	

INCLUSION/EXCLUSION CRITERIA

Respondents were included if they met the study inclusion criteria:

- palliative care physicians with more than 1 year of palliative care experience
- currently practicing medicine
- English speaking
- available for at least one interview of 1–2 hours duration.

Doctors were excluded from the study if they were:

- junior physicians with <1 year of experience in palliative care
- non-medical
- supervised by the researcher.

RECRUITMENT

Three key palliative care organisations in Australia and India—ANZSPM, the Indian Association of Palliative Care (IAPC) and Pallium India—circulated an expression of interest (EOI) flyer advertising the study to their members. These groups have prior experience advertising research studies to their membership. The study was also promoted through palliative care meetings in both countries and the professional networks of the researcher.

Diversity across the sampling matrix was achieved simply through the study's advertising strategy alone, and did not require targeted strategies of recruitment in addition to the circulated advertisement. I did not need to directly approach any additional doctors. . Equal number of males and females, and approximately equal numbers of < 20 year and > 20 years experience responded to the advertisement and were eligible for enrolment. Two other respondents were ineligible: one was not a physician and the second did not speak English.

Eighteen palliative care doctors were recruited to the study, nine from each country (see Table 5 for a demographic summary). All but two participants (both Indian doctors) were known to me before the study, including two Australian doctors (Tanya and Andrew) who had volunteered in an Indian palliative care development project that I coordinate.

Table 5: Demographic Summary of Participants

No.*	Participant**	Gender	Age at interview	Years in practice	Speciality training
1	Nisha#	F	63	≥20	Anaesthetics
2	Vashti#	F	60	≥20	Radiation Oncology
3	Sarita	F	50	10–20	Anaesthetics
4	Ranjani#	F	47	10–20	General Medicine/Palliative
5	Ravi#	M	56	≥20	Radiation Oncology
6	Abhit#	M	67	≥20	Anaesthetics
7	Joseph	M	38	10–20	General Practice
8	Praveen	M	39	10–20	Anaesthetics
9	Sharma#	M	38	10–20	Radiation Oncology
10	Elizabeth	F	65	10–20	General Practice/Palliative Medicine
11	Eliza	F	44	10–20	Palliative Medicine
12	Tanya	F	52	≥20	General Practice/Palliative Medicine
13	Patricia	F	56	≥20	Palliative Medicine
14	Ruth#	F	46	10–20	Palliative Medicine
15	Andrew#	M	45	≥20	Palliative Medicine
16	John	M	39	10–20	Palliative/Oncology
17	Tom	M	53	≥20	Palliative Medicine
18	Luke#	M	42	10–20	Palliative Medicine

* Participants 1–9 are doctors working in India.
\# Participants interviewed by videoconference (n=9; 6 Indian, 3 Australian)
** pseudonyms

Participants agreed to participate in an interview of 1–2 hours duration, with a possible second interview if necessary. The limits of confidentiality were emphasised (see the information and consent form in Appendix 8). This included the state of Victoria's requirement to comply with the legal and ethical obligations of disclosure of conduct of a health practitioner where the practitioner has placed the public at risk of harm because of a significant departure from accepted professional standards (*Health Practitioner Regulation National Law (Victoria) Act* 2009) and the fact that absolute confidentiality cannot be guaranteed on internet connections should the interview be held by videoconference. Finally, participants were informed they could withdraw from the study at any time, up to two weeks after the interview.

During interviews, phrases such as 'Is it alright if we talk a little more about this?' were used to gain ongoing consent, which is necessary when discussing sensitive subject matter (Sheldon & Sargeant, 2007).

INTERVIEW

Interviews were conducted in English, either in-person or by videoconference using Zoom software. The quality of the videoconferencing was poor at times when interviewing doctors based in India. Analysis of all 18 interviews focused on the audio recordings and transcripts only. In-person interviews were conducted in a range of settings according to availability and convenience. Participants could pause their interview at any time to attend to clinical tasks. For example, interviews with six of the Indian doctors were interrupted by phone calls, other staff, family or conference attendees. In contrast, only two Australian interviews were interrupted. The interview with Luke was conducted over two sessions separated by several weeks due to time constraints in the first interview.

Interviews were conducted within two months of recruitment, according to the availability of the participant and researcher; all interviews were completed within 10 months of opening the study. Interviews lasted a mean of 84 minutes (range 51–117 mins), with interviews with Australian doctors generally longer (mean = 98 mins) than with Indian doctors (mean = 69 mins). At the end of the interviews, I checked each participant's comfort with our ongoing collegial relationship, and that they felt

comfortable about what they had shared. No participant expressed a need for psychological support following the interview.

All interviews were conducted by the same researcher. The first nine interviews were conducted over five weeks. The next six interviews were conducted over three months, including three during the IAPC conference in February 2015. The final three interviews were conducted over 5 months. Field notes taken both during the interview, and immediately after each interview, enabled me to reflect on key ideas and experiences of different participants. Digital recordings were listened to after the interview and the transcripts were produced within a week of the interview. In this way, each interview informed the subsequent interviews, leading to further exploration of evolving topics of interest and experiences which appeared to be familiar to several participants.

Seven participants were interested in reading the transcript of their interviews. All participants were able to contact me to share any further experiences. During the analysis phase, 12 participants chose a pseudonym for their narratives.

ETHICAL CONCERNS

Ethical approval was provided by the Peter MacCallum Cancer Centre Hospital Research Ethics Committee (HREC) and the Lancaster University Research Ethics Committee / Faculty of Health and Medicine Research Ethics Committee (see Appendix 9). The study was conducted according to the Australian National Health and Medical Research Council's National Statement on Ethical Conduct in Human Research and the World Medical Association's Declaration of Helsinki 2008. Post-study approval of an amendment to the study was likewise granted by both ethics committees in 2018, allowing release of personal information (i.e., digitally recorded videoconference material) for teaching and conference presentation (see Appendix 10).

There were two key ethical issues raised by the Peter MacCallum Cancer Centre HREC Firstly, mandatory disclosure to Victorian health care regulatory authorities, of patient harm if this emerged in the interviews, in particular if a participant should disclose having deliberately caused a patient's death. All participants were informed

of this in the consenting process and reminded again at the start of the interview; no participant disclosed such experiences.

The second concern of the HREC was the potential for negative effects on participants' wellbeing, arising from discussion of their work with suffering patients and will be discussed in more depth.

Care of participants is a core concern for narrative researchers (Josselson, 2007) and needs to be attended to throughout a study, from the recruitment and consenting processes, the interviewing and data collecting stage, ensuring a safe space for sharing, the protection of confidentiality and anonymity when reporting and storing data, and holding true to the voice of the participant during the analysis and presentation of research reports. Furthermore, in presenting an interpretation of personal narratives in a report, there is always the potential to get it wrong in the view of the participant, to misunderstand their experience. This potential harm cannot be completely avoided and Josselson (2007) wisely advocates humility in the researcher's interaction with participants. We can never be sure that our exploration of another person's life does not inadvertently cause distress or harm.

In this study, there was recognition of the risk of renewing previous traumatic experiences. Participants were reminded about the psychosocial supports available to them through the study, at the end of the interview. However, the availability of such supports varied between the two countries. No-one acknowledged any harm. In fact, both groups of doctors expressed some bemusement at the notion that participating in the interview might have caused them psychological trauma; this notion was particularly dismissed by the Indian doctors, many of whom exhibited a pragmatic and intellectual attitude towards the topic. Several expressed gratitude and appreciation of the opportunity to explore this dimension of their practice and reflected that there were few opportunities for them to do so.

RELATIONAL ETHICAL STANCE

There is an attempt to combine the widely accepted research ethical principles of informed consent, avoiding deception, privacy and confidentiality, and accuracy (Christians, 2011) with relational ethical principles in which 'all actual life is encounter' (Buber, 1970, p. 62). Managing this relationship in narrative studies is not simple or

obvious. Within this 'lie some of the murkiest and most subtle of ethical matters' (Josselson, 2007, p. 545). Neither participant nor researcher can know in advance what will transpire within co-constructive, dialogical development of the interviews nor how this will impact upon them. The use of self as an empathic interviewer, and eliciting narratives about sensitive areas with participants, calls for continual reflexivity and self-examination, both during the interviews and in the analytical phase, in order to honour this relational ethical stance (Haraldsdottir, Lloyd, & Dewing, 2019; Josselson, 2007).   In this study, the power relationship was relatively equal at the outset of each interview, but the subject matter invited disclosure of vulnerability and distressing situations. As interviewer, I endeavoured to monitor the safety of each participant closely and balance their wellbeing and integrity with the goals of the study.

The emphasis of the HREC on avoiding harm was, when situated within a relational ethics frame, a minimalist, constrained requirement. The Committee's concerns also pointed to an anomaly, that doctors may be more harmed by talking about suffering than by their actual work with suffering.   Relational ethics in concerned with the intersubjective nature of the interaction, and emphasises connectivity, attunement to the other, and dialogue. In discussing intersubjective dynamics in research, Bradfield (2012) notes the ethical tension arising from the conflation of the roles of researcher and, in his case, psychoanalyst. My own role in palliative care involves active listening and empathic engagement with patients. Bringing these professional skills to the research interview facilitated dialogue, but also necessitated reflexivity to avoid loss of objectivity and ensure ongoing attention and adherence to the goals of the research.

Another relational ethical consideration arises in the sharing of transcripts with interested participants. Forbat and Henderson (2005) note that sharing transcripts creates another relationship in research, that between the transcript and the re-presentation of the interview, and caution that reflexivity is needed about the processes of doing this. The purpose of sharing transcripts in this study was to provide participants with an opportunity to comment further on their narratives, to clarify any errors in the transcript, and to provide them with a record of their interview, for their personal use.   One participant subsequently engaged in an email dialogue, after reading her transcript and the researcher's analytical reflections on one of her

narratives. This reflective sharing allowed for a deeper relationship with each other and also lead to the participant agreeing to having a short section of her videoed interview, in which she was identified, included in a conference plenary in India. Other participants who were interested in seeing their transcripts did not engage further with the researcher following receipt.

CROSS-CULTURAL RESEARCH AND ETHICAL IMPLICATIONS

Conducting cross-cultural qualitative research presents particular ethical considerations. Riessman (2005, p.473) cautions against 'ethical universalism', that is applying ethical moral principles across cultural contexts without consideration of and adaptation to the sociocultural context in which the research is being conducted. For example, notions of privacy and confidentiality may vary across cultures (Ngozwana, 2018) as in this study, where Indian participants were less concerned with being interviewed in a private space and were more informal in their interaction during the research. For example, Vashti chose to conduct the interview in the shared office of the palliative care department, and Sarita, Joseph and Praveen in a conference space in view of other delegates. Patricia was the only Australian participant who was interviewed in a public space in the hospice where she worked.

In addition, the researcher's own culture cannot be denied as an influence in all aspects of the project, from the formulation of the question itself, the way data is collected and most importantly, the insights of the analysis. From my many years of working in India, I claim a familiarity with Indian communication, both verbal and non-verbal, and an acceptance and inclusion by the Indian palliative care community, allowing an ease of relationship. In addition, all but 2 of the Indian doctors were known to me before the study and this relationship in part fostered their participation in the study. However, while I brought considerable familiarity with Indian palliative care culture to this study, my primary cultural background is Western and my only fluent language is English. I acknowledge that I am myself a product, of cultural hybridization (Andrews, 2007), as a child of Dutch migrants to New Zealand, and later, my own migration initially to England, then to Australia. Living and working in the East End of London, England and Melbourne, Australia gave me rich experiences of diverse, multicultural worlds. This lived experience of cross-cultural formation indeed

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sensitised me to experiences of 'otherness', and of being an outsider in a personal sense. This in turn acted in some part, to help me be receptive to, and go with the diverse narratives across the participant group to 'where I want to go: someplace that I have not been before and where I may well not know what questions might be relevant until I am well on my journey'. (Andrews, 2007, p.492).

INTERVIEWING COLLEAGUES

When power inequalities exist between researcher and participants, cross-cultural differences may be heightened and require great sensitivity to manage (Wurth, Langewitz, Reiter-Theil, & Schuster, 2018). In this study, the power dynamic between researcher and participant was less unequal, due to our shared clinical role as palliative care doctors. However, given the sensitive nature of the topic being explored, rigorous reflexivity and vigilance to the participant's cues were priorities throughout the study. Etherington (2007) places emphasis on reflexivity as a means to achieve the transparency and dialogue needed for creating ethical research relationships especially when researcher and participants have previous relationships as in my study. This was achieved through keeping reflective field notes, and discussion with supervisors, throughout the study.

CONFIDENTIALITY

Participant details and interview data were kept confidential according to the National Statement on Ethical Conduct in Human Research 2007 and the Australian Code for Responsible Conduct of Research 2007. A master list of names and matching number/pseudonyms was created and kept separately from any identifying data. Electronic digital files were encrypted and transferred to a professional transcriber for de-identifying and transcribing. The transcriber deleted the digital and word files after completion of transcribing. All electronic data related to the interviews (digital recordings, transcripts, participant data) were saved on password-protected systems and hard copies kept a locked, filing cabinet. The study data will be kept for a minimum of 15 years after the study.

The results of the study, in addition to being used for this thesis, will be published in peer-reviewed journals and submitted for presentation at relevant palliative care, oncology and other conferences.

5.5 DATA ANALYSIS

Listening to the interviews: Immediately after the interview, extensive field notes were made to describe features of the interview, body language, voice tone and the co-constructed nature of the interview. The transcripts and recordings were next read and listened to several times, taking an 'empathetic position', noting their effect upon me (B. Smith, 2016, p. 216). An overview narrative, or meta-story, was created for each participant.

Coding: Initial analysis of the interviews was conducted using ATLAS.ti software. The digital recordings and anonymised transcripts were uploaded into ATLAS.ti and named according to date of interview-participant id -interview #- type of data >(transcript)-gender- age- speciality. For example, Nisha's interview transcript was named 20141119 IP1 int1 tr f 63 AS.docx. Each transcript was reviewed and descriptive labels were highlighted and named. From the 18 interviews, a large number of such initial codes were collected. From this initial step, groupings and categories were identified. For example, responding to suffering code, included 'being present', 'being with suffering', 'building trust -with patient', 'building trust-within team', 'communication' with several subheadings and coping also with several subheadings, 'healing' and 'holistic care'.

ATLAS.ti is a powerful qualitative tool but is also complex. Mastering it for the purposes of interrogating my small dataset exceeded the benefits and threatened to draw me away from the narrative focus and towards a more granular, thematic analysis. After working with ATLAS.ti for several years during my analysis of data, I decided to step away from it and keep the codes at story level and according to the six defined summary code groups listed in Table 6. (see Appendices 11 and 12 for exemplar quotations from themes 'recognising suffering' and 'responding to suffering'). I continued to make use of ATLAS.ti to maintain my research diary, memo keeping and study process tracking, and for its powerful document-management functionality.

Table 6: Narrative Codes and their Definitions

Code	Definition
Personal journey stories	How the doctor describes their personal and professional development.
Suffering stories	Where the participant describes patient suffering.
Recognition stories	Where the participant describes the features of suffering and how they detect it (e.g., assessment, probing, intuition).
Responding stories: personal, professional	Where the physician describes what they did to relieve or respond to suffering. These may include stories where they did not respond well, were unhappy with their response or were unable to respond.
Intersubjective experience /Dialogical encounter	Where the participant describes an encounter that is strongly mutually experienced for doctor and patient in a healing way. The relational aspect of the encounter appears to be at the core of the relief of suffering either as perceived by the storyteller, or as perceived by the researcher hearing the story, and includes stories where the wider relational context, the intersubjective field, is described. This group includes references to healing, including the concept of the wounded healer, and the therapeutic dimension of interview if noted by the participant.
Other	Self-care, professional role, communication, gender, coping, challenges, pain. These areas were related to the topic of suffering and how doctors' respond but not central to the conceptual framework of the study.

Interpretation: As discussed in Section 5.2.3, this study used two complementary approaches to narrative data analysis: Gee's structural approach and the dialogic narrative approach (DNA)..

Analysis using Gee's structural approach

From the initial focus on coding and identifying categories of narratives, using ATLAS.ti, the analysis moved on to working with discrete narratives, displayed in prose-poetic format according to Gee's system. Gee's (1991) units of analysis is a linguistically and structurally oriented method which involves analysing narratives according to five defined levels of structure:

1. the line and stanza—the ideas and perspectives on characters
2. syntax and cohesion—the links between lines (e.g., 'so', 'then')
3. main line/non-main line—identified by linguistic features such as tense, indicate the main plot and off-line plot

4. psychological subjects—the use of pronouns (e.g., 'I', 'we'), which identify the points of view during a narrative

5. focusing system—evidenced through pitch and stress placement; shows the meaning or intention of the narrator.

The first level, line and stanza, is the foundation of the narrative and consists of the idea unit: 'the central idea around which a line of narrative is syntactically and intonationally organised' (Gee, 1991, p. 22). Accurately arranging narratives into Gee's units requires listening to the speaker's pitch glide changes. Idea units are indicated by a single pitch glide of the voice (falling, rising-falling, falling-rising), which points to the focus on the sentence. If there is more than one idea unit in a line, they are separated by "/". Each line has one topic or main idea. Lines are then grouped into stanzas: 'the building blocks of extended pieces of discursive language', which hold one central idea (p. 12). These often pair up into 'strophes', which in turn group into 'parts', similar to the acts in a play. In this study, most narratives are analysed to only level 1 as shown in Chapter 6. Utterances of the researcher have been removed.

Appendices 5 and 6 show example narratives, displayed in line units and stanzas and for Appendix 5, to level 4 of analysis. Each line within a narrative is numbered. When excerpts are selected for the thesis, to illustrate a key idea, the line numbering indicates that some sections have been omitted from the excerpt

Gee's approach focuses on the narrator's meaning-making, through language, pitch, tone, emphasis, the linguistic tools used to convey meaning. Gee argues that adhering and attending to these linguistic structures identifies the focus and the constraints of interpretation, that these provide the boundaries of interpretation and help the listener to hear the meaning intended by the narrator(Gee, 1991). Therefore, Gee's approach extends beyond content and is concerned with how the narrator achieves meaning-making.

As the features of each narrative were delineated, and the process of formatting into lines, units, stanzas, parts, took form, as stanzas were named, and in the repeated reading and listening to the flow of talk, there was a concurrent process of interrogation of the narratives according to Dialogical Narrative Analysis processes described in the next section.

Analysis using a Dialogical approach

DNA was undertaken in addition to Gee's analysis for three reasons. Firstly, DNA is an approach which honours the context of story-telling, is cognisant that narratives are particular to that interaction between researcher and participant, and are told as meaning-making, co-constructed enterprises, which was an important feature of the dialogical interviews of this study. Secondly, DNA asks questions of the narratives, and attempts to dialogue with them as entities in themselves. This added another dialogical layer to this study. Finally combining Gee's with DNA enabled multiple perspectives within narrative methodology, a type of narrative methods triangulation.

The DNA followed the guidance of B. Smith (2016). He recommends DNA when the aim is to both examine how a story is co-constructed and what is said thematically, while taking this further to ask 'what as actors do stories do and how well are people served by their stories?' (p.213). Smith provides guidance on conducting DNA but cautions that there is no codified technique for this method, and that this is a deliberate avoidance of rigid structure impeding movement and interpretation. In general, once narratives are identified and transcribed, interpretation requires continuous writing as the form of analysis, in which the researcher 'gets to grips with stories' (p.216), is immersed in the stories and comes to recognise themes, relationships and patterns, threads, within and across stories. In addition, he recommends dialoguing with the stories by developing various questions to ask of the narratives. In my study, my main question was 'What happens in the doctor–patient relationship in the relief of suffering?' and sub-themed questions are listed in Box 1. These questions evolved from the conceptual framework and were aimed at helping maintain this analytical focus on the exploration of the intersubjective dimension of the relief of suffering.

In summary, Gee's structural approach helped to identify stories, and the structure and content of those stories, while DNA encouraged analytical dialogue with those stories. The resulting analysis was then presented around a particular analytical theme (i.e. the dialogical encounter) (Smith, 2016) .

Box 1. Sub-themed questions

- How do doctors recognise suffering?
- Is awareness of preparation for encounter described? (e.g., listening, opening, probing)
- Is there a sense of opening up, of meaningful dialogue, between the doctor and patient?
- Is there a sense of newness created between them?
- Is there a sense of reciprocal relationship between them?
- Does the doctor refer to personal growth or distress as a result of this encounter?
- Is the impact expressed as a positive experience or as a distressing harmful experience?
- Is healing described?
- What language is used to describe encounter?
- What does this story do for the narrator and the listener?

SELECTION OF NARRATIVES

In hermeneutic phenomenological research, the researcher dwells with the data, to allow 'the phenomenon to reveal itself and speak its story' (F. Finlay, 2019). My indwelling with the data was informed by the dialogical framework for this study. All interviews contained narratives of dialogical encounter and responses to suffering. The process of selection was reflexive and dialogical (Etherington, 2004). Those narratives that provided the richest examples of the elements of the dialogical encounter and which illustrated the many facets of such encounter were selected.

I recorded my reflections during analysis, including questioning my selections of narratives. For example, I questioned why I chose to work on the stories of the Indian women doctors first, and why I found the Indian interviews particularly moving and engaging. I felt drawn to the differences that emerged between the experiences of those participants and my own professional experiences. For example, in Nisha's interview, several particularly moving stories affected me more strongly than the familiar experiences described by the Australian doctors. Sitting with these reflections over the course of the analysis resulted in a deepening understanding of what these

narratives were doing, their performance, and how to allow them to speak their stories of dialogical encounter.

The trustworthiness of the processes employed in analysis is key to the validity of the findings (Lincoln & Guba, 1985, 1986; Riessman, 1993; Silverman, 2013). However, validation of narrative interpretive accounts is not a matter of following prescriptive formula. Riessman (1993) describes a number of ways to approach validation, namely the plausibility of the findings, the coherence of the interpretation, the correspondence or checking back with participants to obtain their take on the interpretation (although not necessarily their agreement as interpretation lies with the researcher), and whether the work stands the test of scrutiny of the field.

Triangulation is a frequently used means of strengthening the validity of a work. In essence, triangulation involves incorporating more than one source of data (as in mixed method studies) or perspective in a study, in order to cross-check or enrich the interpretations (Bryman, 2008). Rice and Ezzy (1999, p.38) view triangulation as a means of developing a sense of the complexity of a phenomenon, rather than identifying the 'truth' of an interpretation. They specify 'researcher triangulation' (p.38) as one type, in which the perspectives of multiple researchers, and possibly also participants, are included in the research process. This type is used here to enrich and expand the analysis and also as a component of reflective practice, in which my interpretations are reviewed by another. Asking for the insights of my supervisors, inviting the participants to comment on their transcripts, and sharing the analysis with colleagues, deepened the interpretation. It helped to navigate away from assumptions and overfamiliarity with the data and topic, which at times, obscured my ability to recognise insights. For example, when Ranjani shared her distress and helplessness, my supervisors detected despair in her narrative, whereas I, as a palliative care provider myself and familiar with the sense of helplessness being described, did not hear the depth of the emotional response of this participant.

Another approach to validation was to refer my findings to the wider literature, to check for resonance and correspondence with preceding research.

5.6 Conclusion

In conclusion, this chapter has outlined the relational ontological approach which is interested in how people experience their world. It is concerned with the lifeworld of doctors working with suffering, their subjective experience of embodied encounter within this world. Two narrative methods were combined to analyse the data, combining a dialogical approach with a more structured linguistic approach to facilitate interpretation. These interpretations are presented in the next chapter.

Chapter 6: FINDINGS

6.1 INTRODUCTION

In this chapter, the synthesis of the narratives is organised around the focus of dialogical encounter, which is the overarching theme of this thesis, described in Chapter 4. The findings are presented around three sections related to dialogical encounter[2] : the 'I' of the doctor and mutuality in the dialogical encounter, Buber's concept of inclusion, and the 'between'. A fourth section considers the terminology of healing and the fifth and final section explores cultural dimensions related to dialogical encounter and the relief of suffering in India.

I preface this narrative synthesis of findings with a narrative from Abhit that reminds the reader of the multidimensional nature of suffering. He described the dialogical nature of the exploration of suffering, explaining that deeper areas of suffering are only revealed if a relationship of trust and friendship has been established. Abramovitch and Schwartz's (1996) description of establishing trust, as the first stage of the medical dialogue, resonates here.

> **Stanza Very often I do not get deep enough**
> 1.   And I know quite well, that when I ask the question,
> 2.   first only the physical things will come out,
> 3.   I know that I have to probe deeper and deeper,
> 4.   and I also know that very often I do not get deep enough.
>
> **Stanza When I spend enough time and effort with the person**
> 5.   Once in a while when I spend enough time and effort with the person,
> 6.   and when the person is willing to talk,
> 7.   only then I may get as deep as the spirituality issues,
> 8.   or even deeper, about issues related with sexuality
> 9   .or with very, very personal thoughts about relationships within the family /which ordinarily one wouldn't want to speak to an outsider.
>
> **Stanza I would like to be that person's friend enough**
> 10.   So I know it doesn't always happen,
> 11.   but that is my goal,
> 12.   I would like to be that person's friend enough
> 13.   so that he is able to bring out what is most important to that person.
>
> Abhit

6.2 THE 'I' OF THE DOCTOR IN THE I-THOU DIALOGICAL ENCOUNTER

Participant palliative care doctors from both countries strove for dialogical encounters with their patients in responding to suffering. In such a response, in which the person of the doctor meets the person of the patient, the 'I' of the doctor is a fundamental component. For five participants, this subjectivity within the doctor–patient relationship was predominantly shaped and developed by previous professional encounters with the suffering of their patients. For three others, personal encounters and experiences emerged as highly influential in their capacity to be with suffering. However, the boundary between personal and professional was 'porous', as Patricia, described.

PROFESSIONAL EXPERIENCES

When asked about his formation as a doctor, Abhit pointed to the influence of his encounters with patients. He spoke about a patient he had cared for before becoming aware of palliative care. This patient had a deep effect on him, leading to a sudden and formative change in his approach to pain management—an example of MacLeod's (2001, p. 1722) 'turning point'.

Box 1.
Stanza One patient who really changed suddenly
1.   but one patient who really changed suddenly that
2.   was after I started treating pain, not before,
3.   that I was giving pain relief for a man with ca tongue,
4.   giving a mandibular nerve neurolysis relieving his pain,
5.   and he committing suicide the day after the next

Stanza Stripped me from the pain clinician
6.   I certainly think that was one thing
7.   that stripped me from the pain clinician more, from the interventional person
8.   more to palliative care more.
9.   Because I mean he, /I had no idea what he felt,/had no idea what his feelings were or how,
10.   what his role in the family was

Abhit

Ravi described the suffering of patients with head and neck cancer in India as 'abject misery'. He recounted a list of common symptoms arising from this cancer: pain, inability to swallow, fungating and bleeding wounds and associated odour.

Box 2.
Stanza That becomes very pathetic
1.   The problem is that you can read the terror on their face
2.   when they are very sure that nothing is going to make them swallow
3.   or get rid of the pain unless there is something,
4.   so they're actually begging you to relieve them,
5.   asking you to take their life out,
6.   so that becomes very pathetic so,
7.   and they're actually asking for some form of mercy killing

Ravi

He spoke of developing capacity to be with suffering through the mentorship of his senior colleague and recognised the potential to be deeply affected by working with suffering and dying patients.

Box 3.
Stanza Not emotionally broken by it
1.   I still remember one professor,
2.   who would take me out from the hospital to a nearby small café
3.   where he used to have a cup of tea,
4.   and then we would unwind to find out how you dealt with death and dying,
5.   so there is some death and dying in the world,
6.   everybody used to pull up,

7. so that the person who's attending on the dead patient is not emotionally broken by it.

Ravi

Deepening awareness of personhood and the intersubjective experience in clinical encounters appeared to enhance doctors' capacity to relieve suffering and sustain their selfhood in palliative care practice. Joseph had initially been fearful of death and avoided patients who were dying. However, while working in a busy gastroenterology ward in southern India, his consultant had assigned him to work with dying patients. After six months, he experienced a deep inner change, leading him to become a palliative care doctor.

Box 4.
Stanza Those moments were very painful for me
1. So that was, and I should not be there I used to run off,
2. because those moments were very painful for me, very painful.
3. After that something happened,
4. so that's how I got a calling,
5. and my life changed,

Joseph

From this vocational orientation, Joseph has come to stress the spiritual dimension of care and the patient's experience, which he feels enables them to overcome their suffering.

Box 5.
Stanza We just need to get a connection into them
1. because deep down you are finding meaning in everything, everything.
2. This we see in the people.
3. So we just need to get a connectedness into them, that's it.
4. So we don't give options counselling, we go with them

Joseph

Andrew offered a narrative early in his interview, which described his inability to relieve the intractable pain of a man in his care, in the first week of his consultant career. Three years later, when walking through the cemetery next to his new house, he came upon this man's gravestone with his photo embedded. He passes by this grave often on walks, and described him as a reminder:

Box 6.
Stanza We don't have all the solutions to everyone
1. of many things, you know of how we really have to do our best,
2. or I have to do my best,
3. how we don't get it right, we don't have all the solutions to everyone,
4. but we've got to just keep on trying.
5. Yeah I suppose of just retaining humility in what we do,
6. that we don't have all the answers
7. and that there are people behind all of what we do, or our patients,

Andrew

Sharma identified that patient stories affected him both professionally and personally, sensitising him and gradually changing him.

Box 7.
Stanza Changes you personally as well as professionally
1 So I would say yes it changes you personally as well as professionally,
2. but it changes you very gradually, which I think is good, nothing should be, you know, gradual
3. so it changes you and it just becomes a background thought process for you,
4. whenever you see someone, you try to correlate it with the last case
5. and you try to do something better for this case

Sharma

Patricia felt that the boundary between personal and professional formative experiences on her maturation as a clinician was porous. She recognised that being unable to share patients' experiences set her apart and was highly formative of her as a person. Her research and professional experience also led her to reflect on this aspect of the study and protecting the confidentiality of the patients she spoke about in her interview.

Box 8.
Stanza It's a bit of a porous boundary
1 It's a bit of a porous boundary between the two
2. Except that the patient experiences you can't share,
3. so you do have a kind of, I think what happens is you get a burden of those things that you are –
4. they do affect you,/they do contribute to you,
5. but they're not sharable really outside the clinical domain.
6. And there's probably an issue with the ethics of this thing isn't it,/telling these stories

Patricia

One of Patricia's narratives demonstrates the need to develop doctors' professional capacity to have dialogical encounters within normative limits of the doctor–patient relationship. When still a medical trainee, Patricia had cared for a 20-year-old schizophrenic Chinese woman with terminal leukaemia having anticancer treatment as a committed patient with acute psychosis (see Appendix 6 for the full narrative). Having returned to medicine after a career in social work, Patricia described being seen by the team as a mature person and being given greater responsibility as a result. With this patient, however, she felt caught between her many roles and relationships, including advocating for better psychiatric care for this patient, fulfilling her role as haematology resident-in-training, and attempting to provide psychosocial care to the patient and the nursing staff, who were distressed about the direction of medical treatment.

Box 9.
Stanza I'd gone beyond some kind of a – a connection
75.   So yeah that was a, that was pretty/Yeah that was /and I still often think about her
76.   But in the end, /and you now it took me a while afterwards to realise
77.   that probably being so involved with her
78.   hadn't helped me care for her well in the end.
79.   Like I recognised that I'd gone beyond some kind of a – a connection
80.   to one that was actually unhelpful.
81.   I was so distressed by what was happening to her
82.   that I couldn't actually make, couldn't actually help her anymore

Patricia

This experience was traumatic for her. Although continuing to explore and value the relational dimension of care, she learned to manage this for herself and her patients; to absorb the emotional distress of her patients but not carry it with her. Developing self-awareness and reflective practice were important for this.

Box 10.
Stanza You're a sponge
1.   So you're a sponge to soak it up
2.   I think is probably part of what you're doing.
3.   So you've got to be there and be aware and soak it,
4.   but not keep it, not hang onto it, not own it.

Patricia

Personal experiences were also highly formative for the person of the doctor and influenced their professional practice. Eliza's experiences of bereavement—of her separated partner, the suffering of her young daughter within this bereavement, and on the death of her father (whose moment of death she had missed, devastating her)— sensitised her to the suffering of patients, particular when their suffering resonated with her own.

At times, this meant only sharing personal experiences with the patient. While at others, the awareness of resonance was more implicit and understood to influence their encounter. She felt the concept of the wounded healer (Jung, 1985) described her experience of increased capacity to empathise as a result of her own suffering.

Box 11.
Stanza The most powerful thing in my life
1.   And this has been the most powerful thing
2.   that has happened to me in my life in general
3.   but also in my practice
4.   and I am really able to recognise that,
5   in fact it was the first thing I talked about,
6.   so it really that idea really resonates with me

Eliza

John had also experienced bereavement. Unknown to me at the start of the interview, John's father had died only two months earlier, after a short and intense illness. John revealed this within the first three minutes of the interview. His overarching narrative, at that time, was one of disillusionment with palliative care, leading him to question many of the premises and promises of the palliative care narrative. He felt his personal experience would act to prevent him from facile responses to his patient's suffering and from putting more emphasis on protocolised care over personalised care.

Box 12.
Stanza I have lost faith in palliative care
1   I must say I have lost faith in palliative care to a certain extent,
2   I haven't lost faith in some of the science of it,
3   but I have lost faith in do we actually do what we say we do

John

John described an encounter with the palliative care team in which they failed to appreciate the privacy and intimacy of the family's gathering around his father's bedside. He situates the mismeeting in both time, 'right now', and space, experiencing the team's offer of help as intrusive of personal space.

Stanza My father's space
1   we became, /or I became very territorial about my father's space,
2   and even you know in the last 2 days before he died
3   and the palliative care team came to see him,
4   and I was very bitter at that stage, and said I don't think –

Stanza Now is not a good time
5   you know there were actually, /Dad was Buddhist /and so the rituals and stuff that was being undertaken,
6   and it was a completely inappropriate time,
7   so I stopped them at the door and said now is not a good time,

Stanza We don't need that right now
8   and I don't even know who it was, /but she said to me don't you need, /we're just here to help,
9   very well meaning, /and I've done it myself,
10   I said no we don't need that right now,/ thanks very much, /please leave.
11   And I felt terrible, I felt really bad afterwards,
12   I thought you know what this is not about them, it's about us now

John

Both John and Eliza spoke of their personal experiences as carers and family members, rather than their experiences as doctors. Doctors are potentially suffering bodies (Frank, 1995), bringing their shared humanity to the doctor–patient encounter.

Vashti also drew on personal experience of illness to encourage and, at times, challenge her patients to maintain hope and resilience in their suffering.

Box 13.
Stanza I still remember now I'm 60
1.   I was 10 when I was in London,
2.   and so I still remember now I'm 60,
3.   I still remember how I used to made the umpire.
4.   Being made the umpire was something okay,
5.   you're part of it, so you know, you can participate in this,
6.   but I always felt you know that because I was handicapped
7.   that many opportunities in life were not coming my way, you know,

Stanza I use it sometimes as a weapon

---

22. and I think it still holds true till today,
23. I still feel that, you know,
24. I use it sometimes as a weapon,

Stanza Let's do it together
25. I say to patients
26. so you're complaining so much about your problems,
27. see how I became a doctor
28. and how I help you know, made something of my life,
29. come on, come on let's do it together,
30. let's take this suffering on board /and let's find a solution for it,
31. and it worked

Vashti

Note: Line numbers are interrupted, showing that the second part of the extract is from later in the narrative.

Luke also recognised a sense of emotional disconnection with other people as a result of his work with suffering. He found day-to-day events and struggles trivial in comparison to encounters with the suffering of his patients.

Box 14.
Stanza Maybe I've got empathy fatigue
1. But you know, for them, it's such a big deal
2. that they had a friend die of a brain tumour,
3. and in some ways maybe I've got empathy fatigue for that sort of thing,
4. like because it's almost as if, it's almost as if the shock that someone dies,
5. or the shock that someone gets sick you know,
6. whereas you see how much people are going through all the time

Stanza Living in parallel worlds
7. Well I think that's, it does add up in its own way,
8. but it's hard to, I think it's hard to –
9. you're probably living in parallel worlds in some ways

Luke

Likewise, Praveen described the suffering of doctors working in the speciality of palliative care caused by this immersion in suffering, which distinguishes them from the rest of the population.

Box 15.
Stanza Always tend to see bad faces
1 this is a speciality
2 where you always tend to see bad faces, /crying faces,
3 where you tend to hear always untoward words,

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These narratives demonstrate that the development of the person of the doctor is shaped to varying degrees by personal and professional encounters and life experiences. At times, participants had difficulty integrating these two dimensions resulting in a sense of dislocation from relationships with self and others.

MUTUALITY

Mutuality takes many forms. It relates to the impact on doctors of encounters with suffering, as well as the opening of self to vulnerability and shared humanness within the normative limits of the doctor–patient relationship.

Joseph was aware of receiving from his patients and saw this as a source of strength and meaning for him personally.

Box 16.
Stanza Strength and meaning
1.   This is what I see,
2.   they give us a lot of strength and meaning,
3.   rather than you know we try to find out things,
4.   people give a lot of meaning to us –

Joseph

Being able to receive within dialogical encounter enables patients to give, and reduces the imbalance between doctor and patient. Joseph also spoke about the joy he experienced from the concern extended towards him by patients. He was in awe at the generosity of the patients he encounters.

Box 17.
Stanza The patient is concerned about the other person
1.   So this patient you see, /when I visited her
2.   the first thing she's telling the family /bring some tender coconut for him (Laughs)
3.   See these are the things which, you know,/ they're more concerned about,
4.   the patient is concerned about the other person,

Stanza That also keeps us going

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5. I said, why all this, you tell me what's the problem with you?
6. they're worried about/ see the cultural variation,
7. that also you know keeps us going, you know, that concern, you see
8. They are concerned

Stanza So that brings joy
9. so that brings joy and brings strength for us for us,
10. inner joy, for us, /inner joy, inner joy, inner joy
11. that cannot be described,/ I can't describe that to you,
12. joy is different from happiness

Joseph

For Eliza, the emotional connection with patients was an important component of her work in palliative care. She found the experience of encounter intensely rewarding and stressed the importance of real connection and understanding with patients and families.

Box 18.
Stanza I love that emotional response
1. When you have that emotional connection to people,
2. when you're supporting them through the you know, the care
3. or even supporting a patient through their illness,
4. you know I get sad for them
5. but it's not something that, I don't take it home with me,
6. but I can have an emotional response in the moment
7. and I love that emotional response.

Stanza It fills me with energy
16. And it doesn't make me miserable
17. and I don't take it home and get sad and distressed,
18. it actually/ it fills me with energy,
19. and I guess that's part of why I do what I do
20. because the role I play,
21. and being present to these people /while they're going through their difficult time
22. is really, it just feeds my soul, you know.

Eliza

Dialogical encounter was the most powerful form of self-care for Tanya—being able to connect with patients, to be with them in a meaningful way.

Box 19.
Stanza More self-care in the refilling through spiritual care

1. To me there's more self-care in the refilling through spiritual care than anything else,
2. and that experience of being with somebody
3. and knowing that, in some way, I may have, helped them in some way,
4. is my self-care.

Stanza That's the deepest self-care
5. It's not about the, that's, to me that's the deepest self-care,
6. when I receive something spiritual as a result of that, that's the deepest self-care.

Stanza Our encounters with people can actually fill our glass
7. This you know going for a run or eating well,
8. that's all important,
9. but that's self-care to me on a much more superficial level,
10. and I think sometimes we forget that our encounters with people can actually fill our glass.

Tanya

Even when upsetting, dialogical encounter was a source of personal growth for Nisha. Towards the end of her interview, she told a narrative about a young man with metastatic osteosarcoma, whose illness and death had affected her and her team deeply (see Appendix 5 for the full narrative). She mourned the cruelty of his diagnosis, occurring at the prime of his life, and the devastating social effect this had on his family.

Box 20.
Stanza he was the main income generator
1. he was the main income generator for the family, /
2. because he had 4 other siblings,/ the youngest of which was 2,
3. and he as a 20-year-old had just got married

Nisha

She diagnosed lung metastases as causing his increasing breathlessness, but he could not accept this news, and sought other advice from a doctor who claimed it was tuberculosis, not cancer.

Box 21.
Stanza He had a peaceful death
30. Of course within about 2 weeks he was back, /terribly breathless,
31. and he passed away in hospital in front of us.
32. He had a very peaceful death,

Stanza So much suffering there
33.   but it was, um, (pause) there was so much suffering there,
34.   because he was so sure, /he was so certain in his mind /that he wasn't going to die
35.   And for the family it was their eldest son /who had just got married, the main wage earner.

Stanza We've never forgotten him
36.   So it was just, /and for us as a team it was very, very difficult,
37.   everyone cried of course
38.   and we've never forgotten him

Nisha

In follow-up email discussion with Nisha, she shared that thinking about this man still brought her to tears some years later. She remembered his smile on entering the office after his long walk on his crutch, signalling triumph at his independence and a renewed daily hope. The team had visited his parents after his death, and the father had wept, having thought there would not be any interaction with the team again. She wrote of the shared healing for the family and the team over the following months of ongoing bereavement care.

Mutuality is a prominent element of the dialogical encounter but is often overlooked in discussions of the doctor–patient relationship. There is naturally an emphasis on the doctor's duty of care to the patient. However, within the dialogical framework, the two participants in encounter need to be present to each other to make healing through meeting possible.

MISMEETING

At times, rather than recognition and meeting, mismeeting occurs where the doctor speaks about failing to achieve connection and an understanding with the patient. Failing to achieve dialogical encounter could be deeply challenging and distressing. There were many factors identified which prevented encounter: time, social barriers, patient's depression and despair which could not be reached, as well as the subjectivity of the doctor, including discomfort with helplessness and lack of control.

Examples of different types of mismeeting are illustrated in the following narratives. Sarita spoke of a very poor woman, whose total suffering (Woodruff, 2004) deeply affected her. Despite the efforts of the entire team, this patient refused many offers of assistance for herself and her children, and remained with her abusive husband. Sarita's narrative emphasises her sense of powerlessness to help this patient, whose social circumstances were so extreme and difficult to comprehend. Her final words, 'maybe we don't see them', suggest that once seen, this suffering is hard to live with, revealing the depth of human misery and the potential impotence of the medical practitioner. In sharing this narrative, Sarita searched for reassurance that she and her team had done their best, that their competence as clinicians could withstand exposure to extreme suffering.

Box 22.
Stanza There was nothing I could do for her
28.   So even when she was in a bad state he used to come to the wards drunk
29.   and there was nothing I could do for her,
30.   I couldn't – I mean she didn't want to go back to the ashram,
31.   and I don't know they would've taken care of somebody who was that sick.

Stanza It kept bothering me
44.   So that did bother me for a long time, ke,
45.   not that I could've done anything
46.   but for a long time, it kept bothering me
47.   the poor thing, and good thing she died, she had no support,
48.   <u>but</u> – what about the children.
49.   So that, even my nurse was affected
50.   and she said ma'am, how could you say it's a good thing she died,
51.   what about the children.

Stanza We did try to help her
58.   We did try to help her,
59.   I mean financially, medicines and we said we'd get schooling for the children,
60.   And ah I don't know, she was 32, 32
61.   I don't know, I can't say why –
62.   there's so many things going wrong for her, /so many things going wrong for her, [yes, yeah]
63.   and her husband was so unsympathetic
64.   and ah she had no support.

Stanza Poor thing
77.   So she seemed okay but (whines)
78.   Mmm, and actually even if we'd got hold of that social problem,
79.   we wouldn't have been able to handle it,
80.   we don't have the resources to treat that kind of thing,
81.   so, I mean I feel so sorry, you know, poor thing, 32 year old

Stanza Maybe we don't see them
82.   I mean, I don't think, see, even though we are treating a lot of poor patients,
83.   we're not the poorest of the poor,
84.   so we have patients coming in who are lower middle class,
85.   so this kind of patient is less,
86.   not that they're not there, many many more ones are there,
87.   but maybe we don't see them

Sarita

Ranjani also recognised the role poverty as a main cause of suffering for many of her patients. She spoke of her distress at not being able to relieve this form of suffering, and also her inability to relieve existential suffering. She confides that she needs to escape to acute medicine at times, to feel useful and competent again.

Box 23.
Stanza I totally feel helpless
1   And I totally feel helpless, totally feel helpless
2   and I'm sometimes, not sometimes, most often I wonder what am I doing here, you know,
3   what is our role. /And it just, what can I say, it really makes you think as to what your role is

Stanza So it really troubles
19   But even with that, how much suffering are we actually relieving I have no idea
20   you know so it really troubles
21   and what are we trying to do here is a big question mark.

Stanza I need to go to the medicine side
22   So and, sometimes you feel low,
23   I need to go to the medicine side, you know, I practice medicine
24   maybe there's some diseases that I can give relief for

Ranjani

Sarita observed that constant exposure to suffering may lead to a turning away from perceiving and recognising the person, with a shift towards 'recording'; she reported seeing this in her junior medical officers at times.

Box 1.
Stanza One resident that I was so upset with
1   I mean, I had one resident that I was so upset with,
2   because you know she was counselling a patient who had,
3   she had got a recto-vaginal fistula and was incontinent,

4   and she'd been counselled n times for a colostomy /and every time she refused it,   **Stanza Hasn't she got used to it yet?**   5   and then when she came for that particular consultation,   6   she said that, this bothers me /and the odour and um   7   so the resident didn't say anything to her,   8   but then she came in and said hasn't she got used to it yet?   **Stanza This could be her own defence mechanism**   9.   So I mean I found this insensitive of her   10.   but then I thought she has been doing it for the whole day /she's counselling people   11.   and this patient has refused for n consultations,   12.   so now she is insensitive to it,   13.   so this could be her own defence mechanism, that's how she's handling it,   Sarita

John described his personal experience of mismeeting, when he was a carer for his dying father. He situates his narrative in time, in what was needed 'at the moment', 'right now'. He notes that the doctor's attempts to empathise were jarring for him and did not connect to what he needed at that moment. The subtle language of encounter is revealed in this narrative, a language which was not understood in this clinical interaction.

Box 2.   **Stanza It's not something that I want to hear now**   1.   Even in the final family meetings with the haematologist, a different haematologist, /who I knew,   2   he was telling us about the death of his mother,   3.   it's like/ and I was sitting there thinking, oh you know, I get your story and I sort of understand what you're trying to say,   4.   but actually it's not something that I want to hear now,   **Stanza Not really what we want right at the moment**   5.   the decisions that you reached are not the same as the decisions that we're going to reach,   6.   and I see that you're just trying to empathise maybe,   7.   but you know it's not /thank you, it's not really what we want <u>right at the moment</u>,   8.   it's what you decided is not really-   **Stanza In the spirit it was offered rather than how it's making us feel**   9.   And maybe it's just him trying to say I've walked in your shoes   10.   and you know, if you just take it at that point/ then yeah no that's okay,   11.   but I'll take it in the spirit it was offered rather than how it's making us feel

6.3 INCLUSION

The critical element of Buber's dialogical encounter, the concept of inclusion, permeated the narratives. Discussion of its role in doctors' experiences of suffering is broken into three categories, following the work of Brown (2015): imagining the real, making present and confirmation. Ruth's insistence on shared humanity as foundational in the relief of suffering introduces this section.

Box 3.
Stanza Human-to-human thing going on
1.   until I see you as a human,
2.   so if I acknowledge you as a human
3.   then we've got some kind of human-to-human thing going on
4.   and we might be able to then address the suffering.

Ruth

IMAGINING THE REAL: 'I NOTICE YOU'—LISTENING AND SPEAKING

One aspect of imagining the real in the context of this study is noticing patients through listening. This was emphasised by all the participant doctors. Indian participant doctors spoke of 'probing', whereby they encouraged patients to share the multidimensional aspects of their suffering, such as their fears for the future and the impact of their illness on their roles, relationships, family and sense of self. Imagining the real involves recognising the particular nature of the person's suffering by connecting to their subjective experience. Ravi recognised this poses a challenge to doctors more comfortable with objective measures.

Box 4.
Stanza Learn how to recognise the subjectivity of the symptom
1.   there is a big difficulty in recognising suffering,
2.   simply because it is not quantifiable
3.   you should learn how to recognise the subjectivity of the symptoms in the patient
4.   and then start treating that.

Ravi

He also felt that it was the role of the doctor to initiate conversations about non-physical suffering, as patients would not expect the doctor to be interested in them in that way.

Box 5.
Stanza They don't actually verbalise that suffering
1.   but they don't actually verbalise that suffering,
2.   since it is not socially acceptable to disclose your emotional suffering to a stranger
Ravi

Vashti emphasised the importance of embodied listening and the connection to healing: 'just giving them a chance to ventilate itself is something which starts the healing process'.

Box 6.
Stanza You're listening with your whole being
1.   You know give them that opportunity,
2.   give them the feeling that you're not listening only with your ears, /you know you're not listening only with your ears
3.   but you're listening with your whole being'
Vashti

Ruth also spoke about the importance of listening in an embodied way.

Box 7.
Stanza Listening with your heart
1.   I think it's like using all of your senses and your brain
2.   and people might say it's listening with your heart or something you know

Ruth

Like Vashti, for Eliza, listening to patients' stories is also a therapeutic act.

Box 8.
Stanza It relieves a lot of distress
1   it's about exploring it with them
2.   and then working out what you can and can't do
3.   and often you can't take it away,
4.   but I think just that recognising it, validating it, discussing it
5.   relieves a lot of distress,
6.   makes people feel heard and listened to

Eliza

She encouraged her team to look beyond behaviours to the suffering motivating difficult behaviours. Looking beyond evokes the sense of imagining the real; that is, the person who is suffering.

Box 9.
Stanza Being able to look beyond
1.   by recognising that someone's, what's on the surface is not necessarily what's underneath,
2.   but it's about suffering, you know this kind of,
3.   and being able to look beyond the immediate presenting sort of behaviours /or whatever you want to call them,

Eliza

For Elizabeth, encouraging patients to tell their story, listening without interruption, in order to form connection, was the most important aspect of her clinical role.

Box 10.
Stanza Trying to connect back in
1   Who's this picture of you as a young person, what is it.
2   So that sort of stuff, trying to connect back in to the other part of their life (later)
3   they just need to be able to tell the story and feel connected in the telling of the story

Elizabeth

Implicit knowing is another dimension of imagining the real and was evident in Tanya's narrative of recognising suffering. The palliative care team realised unspoken traumas could be behind a hospitalised patient's anxiety at night. They suspected sexual abuse, which was confirmed after the patient had died. By 'imagining the real', the team could carefully modify the delivery of care, communicating their understanding and care non-verbally to the patient.

Box 11.
Stanza We all knew that something was going on underneath all this
9.   and we all knew that something was going on underneath all this,
10.   we just did not know what it was.
11.   And we did not find out what it was /until after she died,
12.   and we all knew/ from the beginning /here was going to be one /that we were going to need to use phenobarb for, and we did,

Stanza I think there was an understanding
38.   So we didn't have to say any more than that
39.   And she knew I knew,

40.   I didn't know who was involved in it,
41.   but I knew that something in the past had happened to her
42.   I think there was an understanding but we didn't go any further than that,
43.   and we didn't make it very obvious to others,
44.   because that's not what she wanted

Tanya

In summary, many doctors spoke of the importance of listening to patients, and inviting their stories, as a way to form connection and develop trust.

MAKING PRESENT: 'I RECOGNISE YOU'—RESPONDING

In dialogical encounter, the capacity to be present to the 'other' facilitates deep recognition of personhood. Making present refers to the recognition of the Thou of the 'other'. This was expressed by several participants, who described it as being a witness to the life of the person, not just their suffering, and associated this with the human need to be seen and acknowledged.

Patricia described this witnessing as a communication that tells the patient that someone is aware of them and of the complete story of their life, which is coming to an end. As doctors, we are 'human flash that says you know, you're still here, it's been a life you know, you're worthy'.

Box 12.
Stanza It's a human need that you don't go down alone
1   but it's a human need that you don't go down alone isn't it.
2   You know that someone is aware of what's happening to you,
3   is aware that you are a human being,
4   you know the complete story of your life is just coming to an end here,
5   you know that whole mysterious thing is about to wind up,
6   and it needs to be acknowledged,
7   that's part of being human,
8   it needs to be acknowledged.

Stanza It's witnessing the whole life
9   People don't go and die under a bush you know.
10   So it's not just witnessing suffering,
11   it's witnessing the whole life
12   and the personhood that's come there, you know

Patricia

Ruth also spoke of the healing dimension of recognition, using the term, 'bearing witness' to describe this recognition, and more, the confirmation of the 'other'.

```
Box 13.
Stanza  A lot of suffering is about being understood
1.    Oh no it's like bearing witness isn't it /you know you bear witness to people
2.    and that's part of it you know /having somebody to –
3.    you know I think a lot of suffering is about being understood /or having your
      condition understood
4.    and so feeling that you're being understood /by somebody like a doctor
5.    is quite important to people
6.    and particularly if that helps you know in other ways, you know

Stanza  Feeling like you're accepted
7.    just that in itself can help suffering
8.    feeling like you're seen,
9.    feeling like you're understood,
10.   feeling like you're accepted.

Stanza  Is in itself a healing process
11.   However you are, however wretched you feel,
12.   feeling like somebody else can bear witness to that
13.   I think that in itself is a healing process

Ruth
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Sarita recognised that turning towards the patient, making them present, is an intentional act in the encounter with them. She describes that many patients mistrust doctors in India. While initially insisting that it is not hard to recognise suffering, her narrative evolved to later acknowledging that what may be obvious to her, may not be so to others in her team or to referring colleagues. Her narrative illustrates the moment-to-moment responsiveness within clinical encounter, in determining whether to engage deeply or not. This determination is influenced by both pragmatic (e.g., time, resources) and intangible factors (e.g., receptiveness of the patient, finding the balance between doing and being with).

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Box 14.
Stanza  see only the wound
1.    and sometimes you um – you I mean you, I think I see that now
2.    I didn't think that there was much difference earlier,
3.    but your junior person might just see the wound,
4.    and may not see the effect that wound has on the whole quality of life /and the
      whole day /and the suffering,
5.    they might just see the wound /and give metrogel dressing /and dressing for the
      maggots /and counsel the family about how to take care of the wound –
6.    but what it's doing to her?

Sarita
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Perceiving involves depth recognition, deep calling to deep (Buber, 1947). Joseph found that as the relationship with patients deepened over time, perception changed and the capacity to understand and alleviate their suffering increased.

Box 15.
Stanza You get deeper and deeper
1.   Yes, see each time it changes,
2.   and each person as you keep seeing over the days, /the perception changes,
3.   you get deeper and deeper,
4.   finally it is the value of the person /which makes you know much more what exactly to support,
5.   it's not the materialistic effect or something like that, it's the value of the person.

Joseph

Making the other present is recognised by participants as a healing act, which requires deliberate engagement, turning towards the 'other'. The failure to do so, deliberate or unconscious, is a form of abandonment of the patient and experienced as a diminishment of the person.

CONFIRMATION: 'I ACCEPT YOU'—SILENCE

Confirmation in dialogical encounter refers to the full acceptance of the 'other', and beyond that, a recognition of what is possible. As Brown explains it, 'I accept you and see your potentiality' (Brown, 2017, p. 426). This can involve taking risks and becoming vulnerable before the patient.

Joseph was caring for an elderly priest who had withdrawn from institutional care due to an experience of neglect in hospital. He found the relationship with this priest profoundly confronting, due to the severity of his symptoms but also having to question the priest's decision to remain at home.

Box 16.
Stanza Terrible suffering
1.   But this person was a little different for me,
2.   he was intensely suffering
3.   because he had undergone three surgeries with complete disfiguration
4.   of his face, jaw, and third time, once on the right side/ once on the left side
5.   it was very unique,
6.   and very localised and advanced –

Joseph

Joseph described the day when he had to ask the priest to consider moving to a hospice for care. His narrative was detailed, taking 8 minutes, and had the sense of debriefing: reflecting on his decision-making and expressing his grief at the death of the priest soon after he was moved to the hospice. He had felt compelled to challenge the priest's refusal of care, both for the sake of the priest and of the priest's sister, who had cared for him for 8 months, 24 hours a day and was exhausted. Joseph risked his relationship with the priest by suggesting a care home. His narrative also demonstrates other qualities that distinguish the I-Thou relation, including openness, mutuality, presence and directness (Friedman, 2002).

Box 17.
Stanza I just spoke to him openly
7.   but that day some communication I just spoke to him /openly,
8.   then outside I felt bad, that I did this, because
9.   I was trying to you know, focus on the/ remove his privacy you know,
10.   being in a room by himself,

Stanza It's very difficult, I recognised that
11.   but the need was that he needed to be cared
12.   and his sister had to have a little respite break at least
13.   because 8 months of 24 hours service,
14.   it's very difficult
15.   so I recognised that in the teacher, but couldn't avoid it

Joseph

For the priest, the move required forgiveness and renewed trust, new engagement with his community of priests, removal from isolation and fear of further neglect and disappointment, and a renewed reliance on the kindness of strangers. For Joseph, speaking like this to the priest made him feel vulnerable. Further, since Joseph could not be there for the priest's move into the care home, he also needed to trust in the care of others.

6.4 THE 'BETWEEN'

The 'between' emerged in narratives that spoke about new beginnings, creative impulses or transformations. Both doctor and patient were involved in these spontaneous moments of meeting in which emerges 'something . . . which cannot be built up in any other way' (Buber, 1965). The 'between' calls for 'affective and embodied responses' and resists capture by words.

The most striking narrative of the 'between' was told by Eliza. She had spoken about the importance of remaining with patients and families: 'just sticking with it', 'being present, not running away from the awfulness of suffering'. She then recalled a 'case' of a previously highly intelligent 86-year-old man with dementia who, for two years, had been a resident in a psychogeriatric unit because of his aggressive behaviour. He had had a recent fall, fractured his hip and presented to the hospital for surgical fixation of his fracture. He had developed aspiration pneumonia, was in terrible pain and had to be shackled to restrain his aggressive and confused behaviour. Witnessing this shackling was particularly distressing for Eliza, who referred to it several times in her narrative.

Box 18.
Stanza We just had a conversation with her
1.   And the suffering that his daughter was experiencing was awful to see,
2.   so we went in and had a chat with her
3.   and we sort of said well you know, what would your father want in this,
4.   you know she was, she had his medical power of attorney
5.   and he had an advanced care plan, / and that limited things like this, you know.
6.   And you know, we just had a conversation with her

Eliza

Eliza stressed the importance of the conversation in which she suggested a new approach in line with this man's advance care wishes. After conversations among themselves, the family chose to start analgesia, withdraw the shackles and commence medications for agitated delirium. The patient died a dignified death that was, importantly, in accordance with his advance care wishes. Eliza's tone changed as she reflected on this case. She was awestruck at the newness of the situation, the transformation, that she witnessed and narrates. She referred to the family being 'at one', a term that suggests recovery of integrity, unity and wholeness—that is, healing. There was nothing extraordinary in the manner of this transformation. Simple conversation, revisiting the clinical assumptions and decisions, valuing the person and their relationships, 'a sensible approach', but all taking place within a dialogical encounter.

Box 19.
Stanza Talk about relief of suffering
7.   And the, oh my goodness,
8.   when we went into the room the next day, (pauses here to emphasise)

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9.   the daughter, /talk about relief of suffering, /talk about relief of her suffering,

Stanza I have never seen such a transformation
10.   I have never seen such a transformation in 24 hours
11.   from the woman I met, to the woman the next day.
12.   She was, the room was, you know / there was this peace in the room,
13.   he was at peace
14.   and she was so at peace

Stanza They were so at one
15.   and they were so at one with this situation
16.   and the approach that we were taking, you know,
17.   there was no, /they were so happy with it

Eliza

The metaphor of space, as found in the literature (Bruce et al., 2011), was used by Patricia, a palliative care doctor in Australia, to allude to the 'between' element of the dialogical encounter. Patricia had begun Buddhist meditation, which was helping her to sit with suffering and respond to it without becoming overwhelmed. This 'sitting with' suffering allowed her to be silent and listen to the patient, to be receptive to their experience in the present moment.

Box 20.
Stanza A bit of a safe space for them
1.   Carrying a bit of their pain,
2.   carrying a bit of their fear,
3.   and just trying to create a bit of a safe space for them,
4.   where they can say what they need to say or not, you know
5.   and they'll just know that I guess to give them some space
6.   where they can trust that they'll be cared for.

Patricia

She felt that many palliative care providers were 'profound empaths'.

Box 21.
Stanza Profound empaths
1.   think a lot of people in palliative care are actually quite profound empaths,
2.   probably more than they're even aware of,
3.   so they're reading and tuning into the emotional cues
4.   subliminally or consciously

Patricia

She went on to describe how creating a space for the patient also allowed the doctor the space to respond to the patient.

Box 22.
Stanza You allow yourself the space to actually just respond
1   And it's because you know it comes with the skill of history taking, storytelling,
2   you know if you give the person space to really,
3   and make it as comfortable for them to actually let you know /what's really going on for them,
4   and you just let that come, /and then you can,/ then you give them space
5   you allow yourself the space to actually just respond to it,
6   not fix it, but just respond to it.

Patricia

Tanya had volunteered in Indian palliative care. She had found the depth of suffering witnessed in India profoundly confronting, in part because of the limited resources available to relieve it. However, she also recognised that having many resources and technologies available can become a barrier to connecting with patients.

Box 23.
Stanza We lose the essence of what it's about
1.   Yeah, I think our resources distract us to making dying very medical,
2.   we are enabled in that way that we can focus on the technical stuff,
3.   and sometimes I think we lose the essence of what it's about, the essence of (LONG PAUSE)

Tanya

In her narrative, the sense of depth, of deep calling to deep, is present, where language, religious and cultural differences are surpassed by the depth connection of the 'between', in which healing and new knowing take place. She recounted visiting a patient's home to find him in his dying moments. The family had initially expected the overseas doctors to save their father, but had come to accept he was dying. She was struck by the encounter's peace and spirituality.

Box 24.
Stanza It really is about the being
27.   And you know so many more times it could be like that,
28.   but I think sometimes we get distracted on /you know the bit of gurgling /or the
29.   we must do this or we must check the hands or we must do this, the doing,
30.   where really it's about the being for most people, isn't it
31.   It really is about the being/Just to be there

Stanza It was really incredible
34.   Yeah, and to get from yelling at us, /no you must save him, /you must save him,
35.   to everybody sitting calmly and laughing and grateful
36.   and it was really incredible,

Tanya

Tanya's narrative indicates that this dimension of palliative care is possible in the poorest of settings, and may be more likely when there is little else to offer beyond presence. This empty-handedness calls upon the personhood of the doctor more than their professional skills and competence.

6.5 LANGUAGE OF HEALING

In Buber's terminology, 'healing through meeting' refers to therapy which is centred upon relation in which the 'between' moment of meeting and newness may emerge (Friedman, 2002). However, in the narratives, there was a common aversion to the words 'healing' or 'healer'. For Abhit, being described as 'healers' would undermine the credibility of palliative care practitioners, who were still not highly regarded in India. He agreed that the work of relieving suffering involved healing but felt that palliative care would be alienated from the medical world by using this term.

Box 25.
Stanza Avoided using the word, healing
1.   And in answering that question towards the last part,
2.   I deliberately or unconsciously /but I now recognise deliberately
3.   avoided using the word 'healing',
4.   only because the aura that that word carries with it today.

Abhit

For Andrew too, the word 'healer' had negative connotations. He understood healing to require considerable time and a particular capacity, which he did not think he had. For him and his team, 'dying healed' was 'not at all achievable'.

Box 26.
Stanza How do we do that?
1.   here in [city] we've got a very senior and I suppose influential palliative care doctor
2.   and he really talks about the importance of working with patients so that they die healed, (smiles)

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3.   and I mean we've talked about this in our team as well is that
4.   yes that's beautiful/ but when we've got an average of 6 days contact
5.   with most of our patients at [name of hospital],
6.   how do we do that? We can't do that
Andrew

In contrast, Luke felt his practice of palliative medicine had been helped by adopting an 'Asklepian' approach, which he had read about from M. Kearney (2000). This approach involves moving away from trying to fix every problem, towards enabling the patient to take more control of their own healing.

Box 27.
Stanza I've changed on a journey
1.   So I suppose I've really, I think I've changed on a journey
2.   from this idea of a Hippocratic or you know, a medically involved, external model of fixing things,
3   to more of a, this idea of a healing model of trying to you know,
4.   allowing people to make their own decisions /and allowing people to decide what they want.
Stanza You're there to help them on the journey
22.   he describes it as Asklepian approach to healing
23   And that the person themselves can only, they're the only ones that can heal themselves
24.   and you're there to help them on the journey
25.   and some people will be healed, die healed
26.   and some people won't die healed
27.   and it's not really whether they died healed or don't die healed,
28.   it's really about how well you're giving them the opportunity to do that.
Luke

Ravi was also comfortable with the concept of healing and agreed that he had a healing role. For him, there was a spiritual element to healing.

Box 28.
Stanza It's a healing process
1.   So it's a healing process,
2.   That means everybody in that family could lay to rest their suffering
3.   So laid to rest the suffering of not just the patient but the rest of the family,
4.   that means you are healed/ Healed their spirit, maybe you can call it that,
5.   maybe you have not healed their body,
6.   but you healed their spirit, that's more than enough for you.
Ravi

6.6 CULTURAL DIMENSIONS OF RESPONSE TO SUFFERING

In this final section, I present culturally determined narratives that suggest differences to practice between the participant doctors from the two countries. Participants from Australia were of diverse ethnic backgrounds, including Indian, Vietnamese, English and Eastern European. However, all had lived and practiced in Australia for many years and identified as Australian. The following comments on cultural dimensions are therefore qualified by this observation and acknowledgement of the dynamic and complex nature of individual cultural influences and practices (Geertz, 1973).

Several participant doctors spoke about asking the patient directly if they were suffering. In India, *badha* (Telugu; 'suffering') and *kasta* (Hindi; 'misery' or 'hardship') were among the words used to explore this dimension of experience from the various languages spoken by the Indian doctors in this study, which also included Bengali, Malayalam, Tamil and Urdu. However, for many participant doctors, words describing 'suffering' were not often used in clinical care, as this was perceived as too confronting for patients and families.

In Australia, Elizabeth reserved the term 'suffering' for extreme experiences, while Luke and Eliza felt the word 'suffering' could be more generally applied. However, as Abhit said: 'I wonder whether we would be the decision-makers about whether there is suffering at all. It's entirely up to that person, isn't it?'

Sharma emphasised that suffering is a relational phenomenon in India.

Box 29.
Stanza There's a lot of other sufferings
1. Suffering in cancer patients, /or for that matter in any patients,
2. it's not only physical more so in India,
3. it's apart from the physical suffering there's a lot of other sufferings.

Stanza All other people also suffer
4. The patient suffers, /the family suffers, /and the entire friends and all the neighbours
5. they also suffer in India,
6. because India is a very closely-knit society,
7. so once a person suffers, all other people also suffers

Sharma

The expectation to communicate with carers rather than patients was acknowledged by many Indian participants. Some called this collusion, while others accepted this as consistent with the strongly relational dimension of life in India. They contrasted this with the more autonomous lifestyle of Western countries, such as Australia. However, most participants agreed that increased openness of communication involving both patient and family was desirable.

Box 30.
Stanza Collusion is a big problem in India
1   breaking this collusion is a big problem in India,
2   collusion is a very big problem in India,
3   I think maybe more than the Western countries,
4   because here the person who is earning for the family
5   he generally thinks that he can take decisions for others,
6   and males generally think that they can take decisions for their wives and their children and their old parents.

Stanza Don't tell it to the patient
7   So many times they just say whatever you tell
8   you just tell us or tell me,
9   but you don't tell it to the patient itself or my other family members.

Sharma

Sharma also identified the many diverse cultural nuances in India, when he spoke about recognising suffering. This serves as a reminder against thinking this cross-cultural study of Australia and India is looking at only two cultures.

Box 31.
Stanza I know their culture
1   So I think I understand them in a better way
2   as compared to my other colleagues who have been staying all the time in Delhi and big cities.
3   So I think for me it's very easy,
4   I just when they come to my hospital
5   I can understand their language, I speak their language,
6   so for me it's easy because I know their background well,
7   I know their culture, I know their thought process

Sharma

Some of the Indian participants explored the issue of spirituality and acceptance of suffering. Most rejected the notion that Indian patients could accept and overcome

suffering due to some heightened spirituality. However, Ravi recognised that some patients did try to overcome suffering through inflicting physical pain or penances.

Box 32.
Stanza God wanted him to suffer pain
1.   the patient himself may have a very peculiar religious fundamentalism
2.   or I should say a religious feeling
3.   that God wanted him to suffer pain,
4.   and so he has to endure it,

Stanza A form of penance
5.   so we have seen all varieties of these patients.
6.   And the last category is actually not very uncommon in India,
7.   who pierce – the Hindus piercer the body with hooks, with spears, with needles, with thorns as a form of penance.

Ravi

Vashti felt that while the notion of karma still featured in Indian approaches to suffering, doctors erroneously failed to explore suffering out of an assumption that patients accepted it as their karma.

Box 33.
Stanza They believe that it is their fate
1.   I think Indians are very stoic people
2.   and Indians take a lot of suffering,
3.   you know they believe that it is their fate, /they have to suffer,
4.   and if they suffer they get a better life the next life

Stanza I think that they want to be heard
9.   But if you really go into the inner most feelings of patients and caregivers,
10.   which is what we do day in day out,
11.   I don't think they believe that any longer,
12.   I think that they want to be heard,
13.   I think they want the best what to say brought out into the open
14.   and someone to listen to their problems.

Vashti

Poverty was identified by all Indian participants as a major source of suffering in the Indian population, in contrast to the suffering seen in Western settings. In addition to poverty directly causing suffering, it also influenced patients' and families' attitudes towards curative options. Praveen saw differences among the more or less affluent patients for whom he cared.

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Box 34.
Stanza He does not much bother about his children
1   so for example a rickshaw puller who comes to my OPD [outpatient department],
2   his son may have cancer,
3   there are other 8 kids with him,
4   so I have seen that he does not much bother about his children,
5   ok he will not live, ok, let's go, get discharged,

Stanza Rickshaw puller will not say much
6   but a wealthy people who is very much aware,
7   he will spend lot of time in saying,
8   doctor, cannot you do more thing for this patient,
9   can you please refer us to a higher centre, / give all this treatment.
10   But a patient you know /rickshaw puller or tiller puller /will not say much

Praveen

Abhit emphasised the devastating effects of iatrogenic financial suffering due to the burden of healthcare costs on impoverished families. Expensive investigations and treatments, modelled on Western medicine, caused financial ruin for many families and generations.

Box 35.
Stanza Degree of suffering induced by the medical system becomes so huge
1   but the degree of suffering induced by the medical system,
2   becomes so huge in the Indian context,
3   because we are using your system of medicine,/the Western system of medicine,
4   we are copying it mostly,

Stanza He cannot afford it
9   So when the poor man from the village
10   who can hardly buy enough to have 3 meals for the family a day, /gets ill,
11   and the doctor says do an MRI scan, /we can do nothing without that,
12   now that's an example.
13   So I mean like the reality being that he cannot afford it,
14   the MRI scan is insisted on,
15   so the man sells his home,

Stanza Patient and the whole family is emotionally and socially killed
24   We copy the technology, /the high tech thing inside our ivory towers,
25   and when we do that,/ without consideration for the human being,
26   you keep on addressing the disease and trying to kill the disease,
27   but the patient and the whole family is emotionally and socially killed
28   even before you get rid of the disease

The scope of doctors' influence in India included giving more directive advice than in Australia. Nisha spoke of her work with women carers in northern India, many of whom had been abused and poorly treated by their husbands, and who abandoned them when they developed terminal cancer. Nisha saw suffering arising from 'something that is a disturbance, even in relationships within the families when they're sick'. Therefore, reconciliation of the married couple was a component of the relief of suffering. Her advocacy for, and empathic attitude towards, the suffering of women in northern India provides some context for this encouragement of reconciliation. Perhaps the widow who returns and cares for her dying husband is restored to a better standing within the community than the widow who abandons him, especially when there is no other system of care available.

Box 36.
Stanza There is no way I'm going to look after him
1.   We had one patient with a very large wound
2.   a buccal mucosa cancer and very large wound,
3.   and his wife was adamant /she said there is no way I'm going to look after him
4.   and it took almost 6 months for us,
5.   and I have a beautiful picture of her holding him just before he died

Stanza Mending that relationship
6.   Mending that relationship
7.   and her accepting that yes he has mistreated you but you need to forgive him,
8.   because now he's dying /and he needs to die peacefully
9.   with having heard you say that you forgive him

Nisha

Cultural differences included the nature of patients' spiritual interpretation of suffering reported by participants in India, and the strongly relational dimension to suffering in India. Also in India, communication with patients was hampered by collusion in which families and caregivers try to prevent open discussion with the patient. Suffering caused by the financial burden of medical treatment was stressed in India.

6.7 CONCLUSION

The concepts of dialogical encounter, inclusion, the 'between' and healing have been discussed here, followed by cultural dimensions. In the next chapter, I will discuss these findings with links to the existing literature.

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Chapter 7: DISCUSSION—
THE ENCOUNTER IN PALLIATIVE CARE PRACTICE

In this chapter I discuss the findings and consider these in relation to the aims of the research, informed by the literature review. I draw on Buber's I-Thou dialogical understanding of human becoming in my interpretation of the narratives of the participants.

I identified four key elements of the encounter, the dialogical nature of responding to suffering, the 'between', mutuality and inclusion. I first give an overview of the findings and then discuss each of these four elements. The significance of dialogical encounter for practitioners working in diverse cultural settings, particularly resource-poor settings, is then considered. The discussion concludes with the suggestion that the framework and terminology of dialogical encounter offers practitioners a rich conceptual basis for further development of the capacity to relieve suffering.

7.1 OVERVIEW OF FINDINGS

That suffering is a distressing, aversive, multidimensional experience (Chapman & Gavrin, 1999; Cherny et al., 1994) was emphasised by all participants. They attempted to assess suffering holistically (Best et al., 2015), and to identify more than the physical dimensions arising from poorly controlled symptoms. They recognised the personal nature of suffering, and that the determination of whether an experience was 'suffering' was, as Abhit said, 'entirely up to that person'. Many narratives about suffering described the physical, psychosocial, emotional and existential dimensions of suffering, typified by Sarita's narrative of the young, homeless woman dying of metastatic cancer, leaving her young children to an abusive husband. This understanding of suffering is consistent with the literature, as was their acknowledgement of the distress engendered in doctors by patient suffering (Best et al., 2015; Cherny, 2015).

Participants recognised the need to connect to the person of the patient, to understand their suffering and respond effectively. Both Indian and Australian participants emphasised the importance of the therapeutic relationship and whole-person care. Participants developed means consistent with their own subjectivity to connect with

the subjectivity of their patients. Participants spoke of 'forming connection' to describe the intersubjective relationship, resonating with Buber's inclusion (section 4.1). This connection was characterised by being in the moment, being open to the 'other', accompanying them and facilitating healing rather than fixing. Encounters were described that were transformative of suffering, evoking the sense of the 'between'. While the majority of participants disliked the term 'healer' or 'healing', there was general acceptance of the concept of healing to describe the relief of suffering and its relevance to palliative care practice.

Care emerged as bidirectional (Vafiadis, 2001), consistent with the mutuality that characterises the dialogical encounter. Participants received in encounter, describing feelings of joy, wonder, renewal and self-care from their interactions with patients.

Australia and India are both highly culturally and ethnically diverse countries. However, their shared origins of palliative care practice, derived from the UK model (Spruyt, MacLeod, & Hudson, 2007; Rajagopal, 2015), brings a common understanding to the practice of palliative care for the participant group.

Differences between Australian and Indian participants' experiences related to the context of suffering (for example, impact of poverty, lack of resources) and culturally influenced differences, such as understandings of the doctor's role, of autonomy and communality, and of communication with patients and family. Indian participants identified financial suffering as having the greatest impact on their patients, affecting their role and their entire family's fortunes. The strongly relational culture in India was described by the Indian participants as both a source of strength, and of shared suffering, for patients and their families/carers.

The overarching theme of dialogical encounter and its culmination in the intersubjective moment of meeting, the 'between', is now discussed, along with its relevance to the relief of suffering in palliative care.

7.2 DIALOGICAL ENCOUNTER AND THE EMPTY-HANDED DOCTOR

'Forming connection' was how study participants described their attempts to understand the patient and the particular nature of their suffering. Indeed, several participant doctors were attracted to palliative care because they could form close

connections with patients in this specialty. Joseph, for example, saw his palliative care practice as a calling, imbued with spiritual significance, and emphasised that forming connection with patients was central to his practice. Patricia felt that many palliative care providers were 'profound empaths' who were motivated by this orientation towards connection. Rather than connection, Abhit spoke of being a 'friend enough' for the patient to trust and confide in.

The nature of such connecting was variously described as being there, being in the moment, accompanying, being open to the 'other', and facilitating healing, rather than fixing a problem. The need to listen, to attune to, to be authentic and genuine were all described by doctors as ways to bring their own humanity to the clinical encounter and thus facilitate connection. Several participants (Ruth, Patricia) talked of the act of witnessing suffering as important for healing.

Forming connection appears to describe dialogical encounter, in which the person of the patient and the person of the doctor have a meaningful encounter and recognise the 'other' in each other, conducive to the possible emergence of the transformative 'between' (Buber, 1970). No one adhered to the 'detached concern' medical model of distancing oneself to achieve objectivity (Coulehan, 2009; Lief & Fox, 1963; Underman & Hirshfield, 2016). Rather, connection was seen as essential to the relief of suffering. As described by Ruth, it was necessary to 'see' the patient as a human first, to connect human-to-human, before attempting to relieve suffering. This is described in Abramovitch and Schwartz's (1996) model of the medical dialogue, in which I-Thou relational knowing is the first and foundational stage of the doctor-patient relationship.

Understanding suffering as a distressing experience of disintegration of the person and their relationships (Cassell, 1982; Lickiss, 2012) provides a rationale for the capacity of dialogical encounter to relieve suffering. Within such encounter, there is a meeting of persons. The doctor who seeks to recognise, to turn towards the 'other' of the patient, to 'see' that person in the midst of their suffering, validates that person's potential for reintegration, for a new sense of personal coherence (Antonovsky, 1993) and restoration of relationships with self and others. Because suffering is personal, its relief requires 'a healer who has made a connection to the sick person and has reached within himself or herself for the resources that go out to the . . . suffering patient' (Cassell, 2013, p. 84). This emphasis on connection evinced by participants

is also advocated in the literature within conceptual models of healing (Egnew, 1994, 2005). This study provides further evidence that a meaningful doctor–patient encounter is a requirement for the relief of suffering.

The image of the empty-handed doctor is relevant here. Sheila Cassidy's (1988) illustrates this concept of empty-handed dialogue, as doctor and patient sitting naked, facing each other, in conversation. Empty-handedness refers to being present to each other, subject to subject, human to human. Much of medicine including palliative care calls for technical skills, from the diagnostic workups to the surgical, radiotherapeutic and pharmaceutical interventions. Many particpants described these skills as well as their efforts to relieve social and family suffering through practical means such as providing work, food, clothing, accomodation, and paying for the schooling for their children. However the suffering encountered in patients at the end of life often lay in the psychological, spiritual and existential domains rather than in the physical and social domains. Here the doctor may stand empty-handed, without resources, having only their personhood and presence to offer. In several narratives (Tanya, Eliza, Joseph, Luke), such presence resulted in healing.

Dialogical encounter moves from fixing (experiencing the other as object to be manipulated), to this more intersubjective dimension of presence and confirmation of the other, to relational being-with, and inclusion. It is the meeting of the subjectivities of the doctor and the patient which offers the potential for healing and relief of suffering. The subjectivity of each is the 'touchstone of reality' upon which from which healing may emerge (Friedman, 2002, p.19). Similarly, in the relief of suffering in palliative care, presence, 'going along with them' (Joseph), invites reconnection and reintegration for the patient.

To respond to suffering in this way for each particular patient requires attunement, receptiveness, to the other, within that particular relationship. An image of such receptiveness is taken from the Australian Kunja myth of Budgial, who protects the woman who is fleeing from harm, by adapting his subjectivity, namely by changing into a turtle. Not able to remove the danger, Budgial provides shelter. The image of Budgial included in this thesis has a multicoloured shell, and is floating in the currents of the ocean (Figure 5). Likewise, the therapist or physician responds to the varying

subjectivities of his/her patients, moment-by-moment, and attempts to provide an emotional shelter for healing.

Figure 5: Budgial, the Turtle Man
Reproduced with approval from the artist (Kunja Wild Life Art, 2017)

Another aspect of empty-handedness is the mutual inability of doctor and patient to make healing happen. Healing moments may be facilitated but not created by the doctor. They emerge from the encounter, spontaneously and mutually, the between dimension. Allowing subject-to-subject encounter, rather than the subject-to-object task-oriented experience, to determine the relationship in that moment, calls for vulnerability and openess to the other, as human to human. Such relating is full of risk; dropping the authoratative stance and assumptions about the patient, coming empty-handed, requires humility and 'a beginner's mind (Hammer, 2007, p.110). If medicine were to move more in this healing direction, there will be a greater need for supervision and reflective practice to ensure that both practitioner and patient are not harmed. This will be discussed more in Sections 7.3 and 8.1.

A movement towards a more dialogical approach in healthcare offers a way to avoid dominance of the biomedical voice and elimination of the relational voice (Bakhtin, 1981). Mickūnas (2016) draws on the metaphor of a melody to describe the dialogical turn; as in a melody composed of all the notes, in dialogue, both or many voices may be heard: 'each partner founds the dialogue and in turn is founded by it' (p. 5).

Monologue brings about 'a "discursive death" to the other who remains unheard' (McConnell & McConnell, 2014, p. 385). Engaging in dialogue opens space for the doctor to have a 'trajective discourse', travelling with the patient into their lifeworld, integrating the objective aspects of disease evaluation with the personal nature of the patient's experience (Hawkins & Sacks, 1993; O. Sacks, 2012). In dialogue, the discourses of medical knowledge and of the patient's existential experience of illness may be harmonised, to the best of the physician's ability. Approaching the patient within this relational frame, mindful of the 'form of potential' (Metcalfe, 2013), alters the understanding of the doctor–patient relationship. It moves away from a biomedical concept, and beyond patient-centred care with its focus on autonomy and empowerment (Nolan, 2004), towards relationship-centred care (Suchman, 2006; Tresolini & Pew-Fetzer Task Force, 1994) in which multiple discourses are valued.

VALUING ENCOUNTER

This sheltering, receptive image of the medical role described above contrasts with the omnipotent, powerful, curing doctor which operates in modern medicine. Being in, struggling with, and coming to accept, this place of empty-handedness, or groundlessness (Boston et al,2006), to glimpse its potency, offers healing to both doctor and patient. But coming to a capacity to hold this space, to be alongside the patient in their suffering, is difficult and demanding. Several participants confided a deep sense of failure, powerlessness and helplessness. Joseph described his struggle early in his career when caring for dying patients and Ranjani spoke of her need to retreat to general medicine to restore her sense of competence and usefulness, perhaps feeling more secure in an authoratative stance. Others spoke of failing patients when communication was unsuccessful, or when they had to deliver information about their disease progression and immanent death. This experience of helplessness described by several participants is not isolated or unusual. Being with and listening to people in their suffering is described as 'one of our most difficult duties as human beings' (Frank, 1995, p. 2). Doctors' and other health carers' distress at exposure to suffering, death and dying is well documented (Cole & Carlin, 2009; Meier et al., 2001; Shapiro, Astin, Shapiro, Robitshek, & Shapiro, 2011). They suffer when delivering bad news (Espinosa, González Barón, Zamora, Ordóñez, & Arranz, 1996) and may experience profound helplessness when confronted with suffering (Back et al., 2015).

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To counter this experience of inadequacy in the face of progressive disease and suffering, a value system is needed that more explicitly supports the relational dimensions of healthcare (Johansen et al., 2012). The tension between the biomedical and existential dimensions of healthcare remains. The prevailing emphasis in healthcare continues to be on saving lives and acute care medicine. Despite this worthy goal, there are growing concerns of increasing disenfranchisement of healthcare providers and loss of compassion (Das & Charlton, 2018). There is also a loss of satisfaction reported when caregiving loses its sense of meaning and alignment with personal values (Ekman & Halpern, 2015). Therefore, it is not just exposure to suffering but the loss of meaning and purpose that aggravates doctors' distress.

When doctors are supported by a medical culture that values interpersonal support, self-care and meaning-making for the health carers, wellbeing is better sustained (M. Kearney et al., 2009; Johansen et al., 2012). Interpersonal relationships described in relationship-centred care (Suchman, 2006; Tresolini & Pew-Fetzer Task Force, 1994) were identified as important by several participants. Ravi's informal debriefing as a student by his senior colleague was formative and Patricia remembered the lack of such support at a critical time in her training. Supportive interpersonal relationships with colleagues help doctors cope with the 'loneliness and powerlessness related to their vulnerable professional position' (Aase et al., 2008, p. 767). Attending to the dialogical in all interpersonal relationships offers a renewal of healthcare at organisational levels and within the doctor–patient relationship.

Healing through Meeting

While most participants, formed as they were by the biomedical, scientific rationalism of the twentieth-century physician, resisted the application of the words 'healer' to describe themselves, many were acutely aware of the healing dimension of patient care and appeared oriented towards this dialogical dimension. For example, Andrew strongly disagreed that healing was possible in his consultative work, while Ravi and Luke described their role as healing through accompaniment, and enabling people to heal themselves. This suggests that some participants recognise their role as extending beyond the conventional understanding of the medical role, with its emphasis on the physical aspects of illness and disease, to encompass a more

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holistic, healing role. In healing through meeting, meeting is both the goal and the means to that goal (Friedman, 2002).

The concept of healing has been considered earlier in this thesis (see glossary and Section 4.5) and involves a sense of movement towards personal growth and wholeness. The healing that arises through through dialogical encounter is called 'healing through meeting' in dialogical psychotherapy, (see Section 4.2), which has a capacity to 'restore the atrophied personal centre' (Friedman, 2002, p. 14) of the client. Barnard (1985) posits that the physician has a priestly role, through being involved in response and healing. He acknowledges resistance to this position, as was evident in the reaction of many participants. An earlier author claimed that the actual task of medicine was 'to emancipate man's interior splendour' (Mortimer ,1974, p.82). These authors all suggest the mystery and the non-physical dimension of healing are at the heart of medicine and therapeutics. This understanding of the call of medicine to engage with the depths of a person, is supported by the willingness of participants to engage in a person-to-person encounter with patients, to respond to 'the call of an Other as a Thou' (Stumm, 2014, p. 389). This notion of call and response is discussed in Section 7.4.

This dialogical understanding of the medical encounter derived from Buber's I-Thou ontology is beginning to find a place within the medical literature (Cohn, 2001; Scott et al., 2009). However the capacity to foster such encounter is hampered by the current understandings and realities of the medical role. For example, it is known that meaning-based psychotherapy is effective in the relief of total suffering (Cancer Australia, 2014; Vachon, 2012 b). However, psychotherapeutic expertise and services are not widely available in the palliative care setting. Only one participant (Eliza) referred to her team working closely with a psycho-oncology service at her hospital. In general, palliative medicine doctors are not exposed to psychotherapeutic education within their training. To date, the focus in India and Australia has been on communication skills development (Clayton et al., 2007; Rajagopal et al., 2015), although reflective practice is a professional quality requirement for the Australian palliative practitioner (Royal Australasian College of Physicians, 2010).

Given the parallels between psychoanalysis' focus on alleviating existential suffering and the work of palliative care doctors, doctors in the palliative care field would benefit

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from an awareness of psychoanalytic therapy dynamics. This is supported by the experiences with suffering described here. Brief individual psychotherapeutic approaches, such as developed by Rodin (2009), may provide palliative care doctors with opportunities to develop their own skills in this dimension of practice. Participants revealed a depth of clinical practice and understanding upon which to build, to enhance these skills.

This recognition of the centrality of healing through meeting, of the interpersonal dimension of care, encourages its promotion across all aspects of medical practice, not just in palliative medicine. Others have recognised the importance of relational care in nursing, social work and pastoral care (Martinsen, 2011a; Nyström et al., 2003; Ten Have & Gordijn, 2014; Thoresen et al., 2011; Vincensi, 2019; Wireklint & Dahlberg, 2011). Exploring ways to embed this understanding more widely in healthcare may go some way towards reducing the so-called epidemic of burnout, disillusionment and distress of medical practitioners, because enhancing the dialogical humanised practice of medicine improves doctors' wellbeing as well as patient care (Cole & Carlin, 2009; West et al., 2016).

The 'Between'

Eliza's narrative of transformation of a clinical scenario richly illustrates the 'between'. This emergence took her by surprise and caused her to wonder at the change she witnessed in the family and patient. It was spontaneous but facilitated by what she described as 'just' having a conversation with the family. The feature of unexpectedness, spontaneity, is inherent in the 'between' (Cohn, 2001).

Buber (1992) talks of 'genuine conversation' as 'acceptance of otherness' (p. 65). Such genuine conversation requires honesty and openness from both partners. Both need to speak what they are really thinking: 'When the dialogical word genuinely exists, it must be given its right by keeping nothing back' (p. 79). However, 'keeping nothing back' refers to 'the legitimacy' of what is said (p. 78), that what is spoken is a 'dialogical word' (p. 79), spoken to enhance unity and wholeness and not something isolating or monological. Eliza's simple description belies the potency of dialogue and its capacity to transform (Cohn, 2001).

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Like Eliza, Tanya also witnessed transformation, on a community palliative care visit to an unconscious, dying man in a remote part of India. She described this as a spiritual encounter, one of simply 'being there'. The family were reassured, and there was a sense of deep connection between the dying man, his family and the healthcare team. This touches on the core of the palliative care philosophy: that the dying person is brought back into community, into communion, with others (Saunders, 1981; Thoresen et al., 2011).

Eliza and Tanya's narratives illustrate the potential within dialogical encounter. Rather than a monologue coming from either a doctor or patient perspective, there is movement towards shared understanding and the creation of a new 'being together'. A contrasting narrative told by John shows that palliative care is not immune to monological practice. John found the palliative care team intrusive at the bedside of his dying father. The team were surprised at John's reaction and questioned his rejection of their offer of assistance, adding to his discomfort and anger. This experience of the professional voice attempting to displace the voice of the family has previously been noted as a risk for palliative care (Pellegrino, 1998), just as it is in other areas of healthcare.

Joseph spoke of 'going with them [patients]', as distinct to counselling patients. He appreciated that, over time, the understanding developed within the doctor-patient relationship. This turning towards and welcoming the difference, the alterity, of the 'other' is at the heart of the dialogical encounter and of hospitality (R. Kearney, 2006). Difference is an opportunity rather than a problem, because without the 'other', one is unable to become fully self. The 'between' requires encounter (Dahlberg, 1996; Martinsen, 2011b; Nyström et al., 2003). Turing to imagery again, the symbol for the Japanese word '*Ma'* (see Figure 6), which means space, openness, or stillness, evokes the idea of the 'between', a sense of something arising from an interaction.

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Figure 6: *Ma* (Nitschke, 2011)

Recognising the transformative, creative nature of dialogical encounter when the 'between' is occasioned is important for health carers working with suffering patients. The relationship within which care is given may profoundly restore wholeness, or may add to the suffering of the patient and family (Cassell, 1982; Dahlberg, 1996; Martinsen, 2011b; Nyström et al., 2003; Wireklint & Dahlberg, 2011). This study shows that the 'between' renews both patient and caregiver. It was seen to occur in all settings of care of this study, from community practice to hospital-based services, in affluent and poor settings, and in diverse cultures. In accordance with the dialogical understanding of human becoming, this interhuman creative impulse offers a sustaining impetus for patients and caregivers. Beyond caring for people until death (Saunders, 2000), palliative care providers, in dialogical practice, are encouraged to recognise their patients' potential for ongoing *becoming* until death. Re-orientating mainstream service delivery towards facilitating such intersubjective moments of meeting offers potential for renewal of patients and caregivers alike.

Following this examination of the dialogical encounter and the 'between' in palliative care, I now discuss two key elements—mutuality and inclusion—as they relate to palliative care practice and my study.

7.3 MUTUALITY

The mutuality dimension of dialogical encounter was an important finding of this study and consistent with the psychoanalytical, phenomenological and medical literature reviewed in the Chapter 4. For example, the healing relationship model describes the I and Thou dialogical nature of this relationship, and the importance of the asymmetry of mutuality between doctor and patient. These authors recognise the positive impact of being able to form such healing relationships of this type for the experienced clinicians in their study, who described satisfaction and enjoyment of their work rather than demoralization or burnout. 'We suspect that clinician burnout occurs when clinician-patient relationships are primarily I-It' (Scott et al. 2009, p.7). The principle of mutuality or relating is a core dimension of Buber's ontology, which Berry calls a 'philosophy of relating attitude' and that this dimension consists of degrees, never in full (Berry, 1985, p. 37).

In this section, three aspects of mutuality in this study are considered: the evidence of mutuality occurring within the normative limits of the doctor–patient therapeutic relationship, the impact on the doctor when mutuality is acknowledged or denied, and the benefits and harms for patients.

REALITY OF MUTUALITY

The reality of mutuality within a therapeutic relationship has been recognised in developmental psychology (Winnicott, 1987) and psychiatry (Casher, 2013) but receives little attention in clinical practice.

Mutuality is expressed in several ways in this study. They learned from their patients as they witnessed an array of human experiences and responses, and they grew as persons in response to the depth experiences shared with patients. For example, Joseph found 'a lot of strength and meaning' from patient encounters. He spoke of receiving practical care, such as the coconut milk offered by an elderly patient whom he visited at home. Tanya felt the most powerful form of self-care came from her relationships with patients. Ruth accepted patients' friendship and emotional connection as 'the return for [her] participation'. It is possible even more examples of patients caring for doctors were not shared, as although the experience of this study was of openness and willingness to share, Candib (1987) reports that doctors are generally hesitant to share vulnerabilities. Physicians are therefore not the only ones who offer to the 'other' in the clinical relationship. Patients also have much to give (Geller, 2006).

It is understood that while mutuality exists within this therapeutic relationship, it is not fully mutual in the sense described by Buber (1970): the patient is not required to turn towards and be focused on the wellbeing of the doctor. However, even within the 'one-sided' inclusion of therapy, there is 'still an I-Thou relationship founded on mutual contact, mutual trust and partnership' (Friedman and Damico2011. p.119). This mutuality enables a greater sense of shared humanity and dialogical renewal.

The moral understanding of the doctor–patient relationship as a unidirectional flow from doctor to patient (McWhinney, 1989) proved unsustainable for several participants, such as Ranjani, when confronted with existential or intractable dimensions of suffering. The mutual or bidirectional understanding of palliative care

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emerging from this study renews focus on the person of the doctor in the dialogical encounter (Vafiadis, 2001), as discussed next.

THE IMPACT OF MUTUALITY ON THE DOCTOR

Section 6.2 of the findings brought the experiences of the person of the doctor in the dialogical encounter to the fore. Several participants acknowledged growing in selfhood through their clinical encounters, as described in the literature (Cohn, 2001) and consistent with a relational ontological stance. This reciprocal engagement of the person of the doctor with the patient was experienced as self-care (Tanya, Joseph, Patricia), a catalyst for joy (Joseph), renewal (Eliza) and finding meaning (Ruth). These experiences support the literature, which proposes that depth encounters with patients help to sustain health professionals' sense of self (M. Kearney et al., 2009).

Having a strong sense of self and being willing to bring their own subjectivity, their personhood, to the clinical encounter, enabled the participants to develop meaningful connections. Recognising and realising shared humanity fosters the capacity for mutuality in encounter (Berry, 1985). For example, Sharma shared his knowledge of local landmarks and culture with patients coming from his district, to put them at ease and build trust. Vashti was open about her own medical struggles, if she felt this would encourage her patients to endure their own suffering. Having a strong sense of self also assisted with enduring the limitations of their capacity to relieve suffering. This appeared to develop into a form of acceptance and wisdom, and was more commonly found in participants with more than 20 years' experience in palliative care. Abhit described this as learning 'to see the suffering, remove what we can, and then live with the rest' (see Appendix 12). Patricia illustrated the development of selfhood in her narrative, found in Appendix 6. This traumatic experience as a junior doctor arose from both patient–physician and physician–physician relationships. She had integrated this experience into her professional identity, as a reminder of the importance of boundaries and self-care. She had adopted several practices to enhance self-awareness. Learning to acknowledge one's sense of helplessness or limitations enables calmer movement towards identifying what can be done, and less avoidance of the distress associated with encounters with suffering (Back et al., 2015).

However, these experiences may negatively affect doctors in life-long, personal and professional ways. As shown in the narratives of mismeeting in Section 6.2.3, less experienced doctors, such as Sarita and Ranjani, expressed a greater ongoing disquiet and struggle, sometimes verging on despair, at their perceived inability to meet their patients' needs. Several other participants in this study told stories of difficult encounters while junior doctors, suggesting that this vulnerability may be greater earlier in one's career. Rather than burnout arising from meeting the patient in their suffering, their narratives point to mismeeting, the inability to turn toward and connect to the patient, due to their own distress and subjectivity. It is not the exposure to suffering per se which leads to physician distress. Rather for many, it was the incapacity to express shared humanity.

Such struggle is not unexpected. Learning to be with suffering is often not explicitly taught in medical training (Outram & Kelly, 2014). Most of the participants in my study described learning to meet their patients in their suffering through difficult personal experiences, either in their professional practice (Abhit, Ravi, Joseph, Andres, Patricia, Luke, Ruth) , or private lives (Eliza, John). Patricia's narrative is an example of the hard-earned development of the capacity to be with suffering patients. Loss of her therapeutic stance, of calm presence, resulted in shared distress, and over-identification when she was a young doctor. She realised that she was not able to help the patient unless she retained her self-hood. In contrast to this overidentification, inclusion allows for an appreciation of the suffering of the other while retaining separateness. It is putting one's foot in the same river as the patient, but not being washed away by that river. 'We do not lose our centre, our personal core, in an amorphous meeting with the other' (Friedman, 2002, p.19). From a solid base of self, the doctor turns toward the patient in openness and attentiveness, of receptivity and acceptance, to meet and be present to the patient in their self. Such inclusion may lead to dialogical knowing in which a new understanding emerges between the participants of the dialogue (Brown, 2015).

Rather than rely on the current practice of learning by painful mistakes and personal suffering, there is a need for more attention to developing this dimension of medical practice in the education of doctors. There are many examples of efforts to facilitate this development which have as a component the sharing of experiences and

dialogical learning (also referred to in Section 2.1.2.) They include the parallel chart in narrative medicine (Charon, 2006), integrating humanities into medical curriculum (Shapiro, Astin, Shapiro, Robitshek, & Shapiro, 2011; Shapiro, Coulehan, Wear, & Montello, 2009), Balint groups (Balint, 1964), Schwartz rounds (Schwartz Centre, 2020), supervision and reflective practice (Bolton, 2006; DasGupta & Charon, 2004; Law & Shafey, 2019). Many of these strategies are employed and encouraged during medical student years but in my experience, are often not carried on into practice years. This study suggests that failing to give ongoing attention to the development and strengthening of the person of the doctor who works with suffering, is damaging to both patients and doctors. Very few doctors in this study engaged in supervision or received psychological support to enhance reflective practice with the exception of Patricia who spoke of mindfulness practice, Ruth of supervision, and Andrew of a close relationship with his priest-friend with whom he discussed his work. Joseph also sought direction from a spiritual counsellor at times, although mostly relied on his own discernment for direction. Given the importance of the therapeutic self in the work of palliative care and relief of suffering, this is an important observation and calls for further examination.

Likely to be linked to this omission of supervision and support for encouraging reflective practice, there was an observed tendency to retreat into I and It type of relating when doctors felt overwhelmed by their experiences of patients' suffering. Descriptions of 'going to the medicine side'(Ranjani), observing insensitivity to suffering by juniors (Sarita) or recognising a disconnect with everyday life's complaints (Luke), suggested that at times, doctors continue to distance themselves from patients who are suffering. When the focus was to fix the problem and this was not possible, they experienced distress as illustrated by Sarita's narrative of mismeeting in her efforts to solve the many problems of the very poor woman with whom she was unable to form a healing relationship. 'Fixing' is in the realm of I and It. If relating occurs as an I and It interaction, both participants are diminished, both objectified. This therefore impacts on the doctor's sense of self, leading to loss of recognition of self as well as of the other. I and It relating is acknowledged as a necessary part of interpersonal interaction in medicine and allows for carrying out of tasks, such as the assessment of physical signs, examination of the patient, carrying out procedures and tests (Abramovitch & Schwartz, 1996). But if this is the only dimension in which the doctor

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and patient meet, the humanity of both are impacted. If medical practice remains solely in this domain, or loses the ability to integrate the relational I and Thou domain, this predisposes doctors to the suffering of burnout, compassion fatigue and moral distress (Abramovitch & Schwartz, 1996; Cohn, 2001; Scott et al., 2009).

The examples of deep satisfaction, sense of reward, self-care, and being cared for by their patients, derived from depth encounter, are important confirmations of the potency of dialogical practice in sustaining doctors' selfhood, fulfillment and wellbeing. However, there is a recognizable need to validate the therapeutic relationship as being on a par with the curative function of medicine. This might avoid the kind of retreat to medical side described by Ranjani, in order to obtain relief from the sense of personal failure and helplessness of daily practice in palliative care in her hospital. Commonly, doctors' validation tends to be derived from success in academics, research, curative or diagnostic successes, leadership or financial success. There is less validation of the physician whose compassionate practice transforms the lives of the patients in their care.

Cassell advocates that medicine develops a systematic approach to learn from clinician's experiences rather than the current ad hoc, individual pathway of personal development. He refers to 'therapeutic power' which arises when clinicians are taught to integrate subjectivities, rather than be overwhelmed by the subjective suffering of patients (E. Cassell, 2004, p.ix). In this study, both the patient's subjective experience (as reported by the doctor) and the subjectivity of the physician are seen to influence the outcome of the clinical encounter. It is incumbent of medical educators and organisations to foster the personhood of both patient and clinician.

In practice, collegial relationships and mentoring by older doctors was shown to be valuable for several Indian participants. Dialogical teaching between spiritual master and pupil is a tradition for communicating religious insights in Hindu and Buddhist traditions and thus familiar to many doctors in India (Dialogue of Religions, 2005). In addition, many participants from both countries valued the opportunity for intersubjective sharing within the narrative interview. The capacity of narrative to strengthen identity, sense of self and personal coherence (Gubrium & Holstein, 1998), and to bring subjective, embodied experience to consciousness (Ochs & Capps,

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1996), was evident in participants' reflective comments and supports the use of narrative to support medical practitioners. (Arnold, 2016; Clay et al., 2015; Bolton, 2005, 2006; Frankel et al., 2019).

Recently, the focus on physician wellbeing has been more obvious in the literature, including the recognition that reciprocal, personal relationships with patients are beneficial, regenerative and 'deeply soul satisfying' (Schwenk, 2018) and that doctors' health needs are not well understood (Brooks, Early, Gendel, Miller, & Gundersen, 2018). This study supports the benefits of acknowledging and strengthening the capacity for mutuality within the doctor-patient relationship.

The Impact of Mutuality on Patients

Just as doctors are made more fully human in relationship, so are patients. Sarita was distressed at her junior doctor's impatience with a patient in asking 'hasn't she [a patient] got used to it [fungating wound] yet?' But she was aware that she also failed to see suffering at times. Patient outcomes are thus affected by doctors' distress, burnout and compassion fatigue (Dyrbye & Shanafelt, 2011). Mutual relation and interdependence are critical for optimum delivery of healthcare but often ignored or deliberately avoided, as described by Ruth and Patricia, in their observations of doctors who chose to 'not go there'. The openness of participants to receive within the doctor–patient relationship enabled patients to contribute, even within their suffering situation. This capacity to contribute to others has been identified by patients as an attribute of a good death (Steinhauser & Clipp, 2000). Reciprocal relationship facilitates the relief of suffering through mutually enhancing the sense of self of doctor and patient, restoring or sustaining wholeness in both.

7.4 Inclusion

'Inclusion' as described by Brown (2015) was introduced in Section 4.1.1 as a dialogical feature with the elements of imagining the real, making present and confirmation. Ruth captured these elements of inclusion in her description of bearing witness to suffering, portraying it as 'feeling like you're seen, feeling like you're understood, feeling like you're accepted'.

'Feeling like you're seen' describes imagining the real. Participants emphasised the importance of listening, and being genuinely interested, as clinical tools that facilitate imagining, perceiving and seeing. Another means of imagining the real was attending to the resonance of suffering within the person of the clinician, the inner responses that provide powerful insights into the patient's experience.

Participants shared many examples of noticing nonverbal communication cues to identify suffering. Participants spoke of 'something in the way he spoke to his family or the attitude in which he is sitting' (Sarita); of seeing it 'in their mannerism, you can see it in their emotions and their words which they tell you' (Sharma).

Overlooking such cues, just 'seeing the wound, but not what it was doing to [the patient]' (Sarita) was also described. Seeing was said to be a deliberate act, involving a decision to tune into what was happening to the other person. The reverse—ignoring suffering—was also described as a conscious decision. Ruth felt that doctors chose 'where not to go' (Appendix 12) and Abhit reported having been taught by senior doctors to 'run away from the suffering, turn our backs to the suffering and just look at the diseases'. Not seeing, or mismeeting was recognised as a protective mechanism employed against psychological distress, albeit resulting in poor care for patients and reciprocal distancing from selfhood for the doctor, as previously discussed.

The factors that lead to lack of recognition are often organisational- and workload-related. Sarita recognised the stresses on her junior doctors and the risk of their being overwhelmed emotionally. Burnout in junior doctors in India has not been well researched but early studies show high levels in interns and residents associated with workload (Ratnakaran et al., 2016). In busy services, multiple tensions and time constraints must be balanced, which participants in both countries acknowledged affected their capacity for meaningful healing encounters. However, the simple measures described to facilitate imagining the real do not add additional time, instead calling for an orientation towards the 'other' within a dialogical mode of relating.

Imagining what it is like for the 'other', being curious about their experience, is described as the emotive dimension of clinical empathy (Stepien & Baernstein, 2006) and as 'attuned, curious listening' (Halpern, 2011). Such imagination is also essential

for dialogue. Patients recognise the importance of this imagination in bringing their unique suffering to light. Broyard (1992) wrote: 'My friends flatter me by calling my performance courageous or gallant, but my doctor should know better. He should be able to imagine the aloneness of the critically ill, a solitude as haunting as a Chirico painting' (p. 42).

'FEELING LIKE YOU'RE UNDERSTOOD'

Ruth's second phrase, 'feeling like you're understood', describes 'making present', or recognising the 'other'. At the outset of my study, in formulating my research question, recognition and response were regarded as separate stages in the relief of suffering. However, it became clear through the doctors' narratives that recognition was central to their empathic response to suffering. Recognition has been described as the defining task of the doctor (Candib, 1987). Suffering, like pain, is a 'destroyer of language' (Gunaratnam, 2012, p. 110). The success of a physician depends on their ability to recognise and understand, on 'the acuity with which he or she can hear the fragmentary language of pain, coax it into clarity, and interpret it' (Scarry, 1985). An example of the sensitivity involved in interpreting the language of suffering is found in Abhit's narrative of the man who suicided despite successful pain management. Abhit had not recognised the potential effect on the man of the follow-up arrangement of returning only if his symptoms necessitated it; this told him he was incurable, prompting his suicide. The cognitive and affective imagining within the empathic response is clearly part of the dialogical nature of encounter and is an essential aspect of the relief of suffering. Attempts to recognise what is happening to the patient, described as 'affective recognition' (Honneth, 2001), is part of effective, ethical care (Gunaratnam, 2012).

John's encounter as a caring son with his father's haematologist left him feeling isolated, disappointed and disconnected. This non-recognition, or mismeeting (Brown, 2017), is a recognised form of iatrogenic suffering; that is, suffering caused by the action or inaction of a physician (Arman et al., 2004; Kirby et al., 2015). Physicians' sharing of personal stories may facilitate recognition, intimacy and a sense of shared humanness, but in John's narrative, the sharing went awry and was instead distancing (Candib, 1987). The relational reciprocity and mutual vulnerability of affective recognition is important (Orange, 2010).

Communicating this quality of affective recognition was described as witnessing by several participants. Here, not only was suffering recognised, so was 'the whole life, the personhood' (Patricia). Patricia described the importance of letting the patient know that the awfulness of their situation had 'landed' with her, that 'you're still here, it's been a life you know, you're worthy'. Witnessing is part of forming an empathic connection, and is a healing activity (Coulehan, 2012). It is a reminder of community, of relation. Frank's (1995) 'reciprocity of witnessing' (p. 143) and choice of this term over 'survivor' for people who have survived cancer, indicates the responsibility of the witness to connect with the community and tell what has happened. Doctors such as Patricia assume a responsibility to be an 'embodied witness' for the dying patient, to be one who is 'called to the nexus of this affinity' between 'witness and bodily suffering' (p. 165). This social dimension of witnessing for and with the dying is an important relational and meaning-making dimension for palliative carers.

Ruth's pause in the objective assessment of the symptoms of her patient with nausea was an acknowledgement of the intersubjective need to establish affective recognition to understand another's experience: 'if I acknowledge you as a human, then we've got some kind of human-to-human thing going on and we might be able to then address the suffering'. For Ruth, only from an established relational stance, rather than an I-It experiential stance, could she assess symptoms. This is reminiscent of Benjamin's (1995) argument that intersubjective processes enable recognition of different experiences. Martinsen (2011a) calls this a perceiving eye, rather than a recording eye, and argues that adopting this relational perspective will engender a caring ethic in medicine.

'FEELING LIKE YOU'RE ACCEPTED'

Ruth's third point, 'feeling like you're accepted', describes confirmation. It goes beyond perception, seeing and recognising, towards acceptance of the 'other'. In confirmation, one takes a 'non-judgemental stance' (Scott et al., 2009, p. 5), truly turning towards the 'other' and receiving them as a partner in dialogue (Buber, 1992). It is not the same as approval, as it acknowledges the 'potential for positive change' (Scott et al., 2009, p. 5) and so involves a degree of risk-taking. It recognises the unbounded nature of person in the sense of the continuous call to being in relation, of person as 'not an object but . . . simply, undefinably, immediately present: they are just as they are,

whatever that is' (Metcalfe, 2013, p. 46) and, in this way, is a witnessing to their becoming. The distinction between acceptance and approval and the willingness to accept risk in authentic relationship appears in Joseph's narrative of his efforts to move the priest into hospital for end-of-life care. He felt compelled to 'push' the priest towards something he did not want but that was in his best interests. Such 'pushing' is a feature of the appreciating power domain of the healing relationship model (Scott et al., 2009). This distinction between confirmation and approval speaks to the responsibility of the clinician to put the patient's best interests above all else—at times, a difficult task.

Confirmation is profoundly dialogical. It is the expression of 'welcoming the difference', the alterity of another (R. Kearney, 2006). Hospitality re-emerges as a linking concept between the tradition of hospice or palliative care and Buber's 'I' and 'Thou'. The original hospices in the Middle Ages were places that offered hospitality for travellers or care for the terminally ill (Lutz, 2011). The founder of modern hospice, Cicely Saunders, is often quoted as saying, 'You matter because you are you', evoking a sense of recognition and confirmation, followed by the response: 'and we will do all we can not only to help you die peacefully, but also to live until you die' (Monroe, 2011), in which the potential for ongoing becoming is recognised. Drawing from Buber, Stumm (2014) writes:

> Another person is not an object to be grasped, a presence to be subdued, or a thing to be mastered, but a Thou to be genuinely encountered and welcomed . . . [The ethical response to another is one of] a hospitable orientation of openness, vulnerability, and receptivity. (p. 389)

7.5 DIALOGICAL ENCOUNTER AND CULTURAL REFLECTIONS

Cultural beliefs and practices fundamentally influence how people approach the end of their lives (Murray-Parkes, Laungani, & Young, 1997). Therefore, a cross-cultural dimension, with the objective of exploring commonalities and differences across Indian and Australian palliative care. In additon, the study would add to the cultural representation in the literature (see Section 2.3).

To provide context for this discussion of cultural dimensions, a summary of the similarities and differences is first provided. Participants in Australia and India were similar in their use of an holistic approach to relieving suffering. Many participants from

both countries had trained and worked in the UK at some stage of their career. This provided standardisation of teaching about symptom control, communication skills, ethical concerns and end-of-life care. However, there was clear evidence of adaptation and interpretation of these skills and services by Indian palliative carers to suit their local setting. Adaptations included caring for patients with chronic nonmalignant illnesses, paraplegia, or cerebral palsy in contrast to Australian palliative care where there are other community services for those diagnostic groups, directly providing a greater range of social services rather than referring to different social service providers as in Australia, and high levels of community and volunteer participation particulary in Kerala, all of which have been reported (Kumar, 2013; McDermott, Selman, Wright, & Clark, 2008). Further, cultural expectations and norms influenced how serious news was communicated. For example, Vashti and Nisha described ways to negotiate disclosure to female patients, within gendered cultural norms of speaking with the male member of the household. They attempted to maintain the relationship with the whole family, while respecting the need of the patient for truthfulness, and following best practice in communication training. Their sensitivity in communication and efforts to relieve suffering echoed findings from Bangladesh, where palliative care providers' style of communication and approach to suffering distinguished their field from mainstream medical care (Dehghan, Ramakrishnan, Uddin-Ahmed, & Harding, 2012).

Palliative care is a much less well-established healthcare speciality in India compared to in Australia. Therefore, more of the Indian participants were pioneers and palliative care leaders in their state and nationally. Indian participants also had more variety of experience prior to palliative care (see Table 5) and shorter periods of training compared to the standard three years of speciality training for Australian doctors. Resources, such as opioids and other analgesics, dressings, social and healthcare services, and caregiving equipment are lacking in many parts of India. Families are responsible for providing physical care, even when patients are in hospital, and shouldering the financial burdens of treatment. Patients, especially the poor, often return home to die, with minimal access to ongoing healthcare. Two Indian participants expressed confusion and possible burnout, with a lack of self-belief in their leadership skills and capacity to make a difference to patients' suffering. For one Indian palliative care doctor, adapting the communication and holistic messages of palliative care

presented issues for her in identifying and maintaining boundaries in her relationships with patients (see Appendix 12). Both groups of participants spoke of personal practices of selfcare, but Indian participants had less opportunity for debrief or formal self-care practices in the workplace compared to the Australian participants. The small and relatively isolated workforce, heavy workload and pressing concurrent demands for service development, education and advocacy, are risk factors for burnout.

However, the strongly relational dimension of Indian society was evident in the narratives and appeared to provide considerable support for participants. Ravi's account of being taken for 'a cup of tea' by his professor and how 'everybody used to pull up' to look after each other reflects this informal system of support. All the Indian participants worked in teams and identified teamwork as important to patient and personal care. They also sought support from friends and family members; however, for Sarita, this could strain those relationships. Considering that mainstream medical practice in India turns away from suffering (Abhit), asking palliative care doctors to be sensitised to suffering without adequate support raises questions about sustainability and risks of vicarious trauma in this setting. While dialogical encounter offers the possibility for renewal and reward, measures that attend to workload and organisational contributing factors are also vitally needed for enhancing self-care and reducing burnout risk.

THE OPPORTUNITIES REVEALED BY CROSS-CULTURAL DIFFERENCES

Medical training in Australia and India draws from Western concepts of medical care, with little integration of other cultures in shaping the understanding of the clinical relationship. Attitudes towards privacy, communication, caregivers' and volunteers' roles, shared decision-making, originate from an assumed Western gold standard.

The capacity of Indian participants to be with suffering despite the many challenges of working in their settings, offers potential to expand this predominanly Western perspective. A practical example of what can be learnt is the striking adoption of the biopsychosocial model and translation of this to the local context. Indian participants described supporting families financially, arranging marriages, providing employment, funds to educate children, food and clothing if needed. General social and community services are lacking in India; palliative care services organised these for their patients.

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Another feature was the strong spiritual belief systems which Indian participants expressed simply and without embarrassment. Many expressed their own spiritual beliefs more often in their narratives than did Australian participants, drawing on these beliefs to explain the need to accept the limitations of their ability to relieve suffering, as well as to find meaning in their work. This integration of spiritual beliefs within role understanding may be easier to express in a country such as India, where religious rituals are widely practiced and accepted. The practice of religion is less prominent in Australia, making the expression of spirituality more personal and less ritualised. While palliative care originated from the Christian-inspired beliefs of Dame Saunders, and expressed this orientation of love and hospitality towards another, there continues to be disquiet in expressing this dimension, perhaps increasingly so, as pallaitive care moves to a more mainstream, secular branch of health care (Bradshaw, 1996; Kaut, 2002).

Finally, dialogical connection is independent of culture and language, and may be achieved across cultural settings (Lorié, Reinero, Phillips, Zhang and Riess, 2017). Buber (1992, 1998) saw this encounter as requiring little more than a glance, or awareness, a turning towards, the other. However, as discussed in Section 4.2, an interpersonal understanding of intersubjectivity refers to shared understandings of symbols and gestures (Blumer, 1986; Coelho & Figueiredo, 2003). Transposing culturally-determined practices from one cultural setting to a very different setting requires humility and recognition that the many cultural strands that underpin and make sense of that practice may not be present in the different setting. Gestures and language may be mis-understood. This may lead to mis-application of the practice and potential harm. Sarita spoke of her irritation with Western-originating communication skills teaching which did not resonate with her experiences with patients. For example, asking someone how they are feeling or if they are suffering, when it is obvious that they are distressed or their situation is dire. My own experience in India is that non-verbal communication is very important and this is often misunderstood by non-Indians. A simple example is the way of expressing thanks; in India, this may be communicated by head movement or facial expression alone, in contrast to the Western norm of verbal expression. Culturally-determined understandings of the role of the doctor, a hierarchical structure which facilitates authority and leadership, relational cultural norms operating within teams and in the wider family and culture,

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and strength of personhood observed in the senior Indian palliative care pioneers interviewed, all create different strands in the Indian cultural contexts compared to the Australian. Some of these features appeared to compensate for shortfalls in resources and formal supervisory supports as well as modify the doctors' behaviour and scope of their role. The narratives of the indian participants identifies that their experiences hold promise of enriching and informing medical training in end of life care, alongside the more Western view illustrated by the Australian participants.

7.6 DIALOGICAL LANGUAGE

When speaking about the response to suffering, the language of healing was not acceptable to many participants in this study. Introducing the dialogical terminology of encounter and the intersubjective moment of meeting may provide a useful alternative for several reasons.

First, the importance of forming connection to relieve suffering was well understood by participants. They implicitly understood that connecting to a person during their suffering, with the resultant restoration of the potential for relationship with self and others, is a healing act. I suggest that dialogical terminology may resonate widely with palliative care providers, given the identified qualities of this specialty group, their practice of non-hierarchical teamwork and focus on the relief of suffering (Granek & Buchman, 2019).

The ontology of the dialogical has been well developed by Buber and subsequent scholars, and provides a sound conceptual framework for dialogical practice (Scott et al. 2009). The dialogical turning towards the other in acceptance, termed confirmation, has conceptual synergy with the palliative care tenet of hospitality, welcoming the other (Friedman, 2009). Dialogical framing validates the humanity of both clinician and patient.

Contrasting this conceptual clarity, there is considerable confusion about related terms such as empathy. Here, the clinical understanding differs from that outside healthcare (Halpern, 2014; Hirshfield & Underman, 2017). Even within medical parlance, there are multiple definitions and disagreements about what the term means (Betzler, 2018). A clear conceptual understanding of the term and how to measure it is lacking (Pedersen, 2009). The dialogical term 'inclusion' is related to empathy but is

distinguished from it (Friedman, 2002). It is well defined (Brown, 2015) and has the additional advantage of not being used outside a therapeutic context.

Another advantage of dialogical terminology is that it would provide an important link between palliative care practice and psychodynamic therapeutics. Equipping palliative care providers with a deeper understanding of psychodynamic principles has clear relevance for the relief of existential suffering at the end of life.

A final point in support of introducing dialogical terminology is that, in dialogue, multiple voices are invited and valued. This speaks directly to the goal of shared decision-making and fosters the capacity for this by a fundamental respect for the perspective of both partners in the dialogue. This emphasis is consistent with the role understanding of being fellow travellers (Hawkins & Sacks, 1993; Johansen et al., 2010), described as being witnesses, friends and companions by participants in this study. This mutual journey also reflects the reality of end-of-life care, where the power differential between doctor and patient is less evident, given the empty-handedness of the doctor, unable to significantly alter the trajectory of illness towards death

Considering these advantages, a dialogical framework for palliative care practice offers an alternative to the language of healing and may help to validate the importance of the doctor–patient relationship in the relief of suffering. A dialogical framework is not limited to palliative care but can be applied to other medical and healthcare disciplines.

7.7 CONCLUSION

In this chapter, I have presented the doctor's response to suffering as a dialogical encounter between doctor and patient. Healing moments emerge in responsiveness to the other, in the realm of the 'between'. Within encounter, through inclusion, suffering is shared. This relationship is bounded by the nature of the relation: the patient seeking help from the doctor, who is at the service of the patient. The reciprocal relation of I and Thou is integral to this encounter.

In this study, palliative care doctors in the distinct settings of India and Australia similarly recognise the importance of this dialogic, healing relationship and bring their

humanity to their work with patients. The discussion concludes with the suggestion that adopting a dialogical framework has advantages for palliative care practice.

Recognising the value of and creativity within the healing relationship for both doctor and patient is sustaining for the doctor, immersed as they frequently are in suffering, often empty-handed, unable to prevent the inevitability of death or relieve many elements of existential suffering. This study supports the contention that this relatedness between doctor and patient is the foundation of care or, as Ten Have and Gordijn (2014) claim, 'medicine's point of departure' (p. 169).

Chapter 8: CONCLUSION—
BEING WITH SUFFERING AT THE END OF LIFE

In this thesis, I have explored the concept of the relief of suffering in palliative care from the perspective of doctors working in this field in Australia and India. The aim of the study was to explore how suffering is recognised by palliative care doctors, to understand what features of the patient experience would trigger an appreciation of their suffering in the doctor and how they responded. Suffering is a complex phenomenon, intensely personal and described as an experience of a loss of the integrity of personhood (Cassell, 2004). By exploring this cross-culturally, in Australia and India, I aimed to identify differences and commonalities in the understanding of suffering, its causes in the different patient populations, and in how doctors responded. Using narrative methodology facilitated the revelation of self by participants and drawing on Buber's dialogical ontology provided a conceptual lens for interpretation.

Through the interviews with participants, the recognition of suffering was found to entail a turning towards the 'other', with the deliberate intent to meet the 'other', and the effective communication of that intention and recognition. This recognition and response required engagement of the person of the doctor, leading to my argument that the intersubjective relationship underpins both the recognition of and response to suffering.

The response to suffering is dialogical, where the alterity of the 'other' is received and welcomed in the present moment. As suffering is associated with the loss of integrity of self, dialogical meeting engenders possibility for reconnection, reintegration, and a new becoming of self, leading to the relief of the suffering arising from loss of personhood. Within these I-Thou encounters, both doctor and patient become more fully self. By contrast, remaining within the I-It dimension objectifies and diminishes both parties (Abramovitch & Schwartz, 1996).

My findings demonstrate that while dialogue is mutual, within the doctor–patient relationship, this is bounded by that particular professional relationship (Cohn, 2001; Pellegrino, 2006). Managing that boundedness, maintaining shared humanness while not being overwhelmed by identification with the other, is a profound dimension of

medical clinical practice. The participants described their ongoing integration of professional and personal experiences, formative to their own personhood and capacity to be with the suffering of their patients. I argue that learning to be open to receiving from patients within the boundaries of the doctor–patient relationship is a form of self-care and affirmation for doctors.

The causes and quality of suffering differed across India and Australia, with poverty described as a defining feature of suffering in India. Palliative care was described by Indian participants as seeking to address social and financial suffering in recognition of the urgency of those unmet needs for patients. However, doctors across both countries described forming connection with, listening to, being with, being present for their patients as central to their responses. These dimensions are in the realm of spiritual care, are healing components of the clinical relationship, and, I argue, are demonstrated in this study to be part of the doctor's role.

8.1 CONTRIBUTION TO PRACTICE

Dialogical encounter, as described in this thesis and resonant with other literature (Buber, 1965; Friedman, 2009; McConnell & McConnell, 2014), is a life-giving, interhuman meeting, which makes both partners more fully human. In modern medical practice, in view of the prominence of burnout and compassion fatigue (Schwenk, 2018), I consider that enhancing doctor's capacity for dialogical encounters has the potential to improve their wellbeing and offer them a means of renewal of purpose. Recognising the importance of dialogical encounter, as demonstrated in this study, encourages both doctors and patients to trust in the value of shared humanness, even in helplessness and empty-handedness.

The focus on developing communication skills in medical training is an important recognition of the centrality of the interpersonal dimension in healthcare (Ong, de Haes, Hoos, & Lammes, 1995; Roter, 2000). Developing skills in dialogical encounter would build on this work. Dialogue, in its demand for presence, goes beyond technique and calls for genuine human meeting. As noted by Joseph, and in my personal experience of intersubjective encounter as a patient, responding to suffering is not about counselling. It is about meeting, about being seen and accepted for who one is and has the potential to be, by another human who is aware of his/her own potential for suffering. Given the resistance to the terminology of healing identified in the study,

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'dialogical encounter', 'connection' or simply 'encounter', may be acceptable terms for modern doctors to use when discussing this aspect of their role.

Dialogical encounter is not limited to doctors. Healthcare providers and therapists of all disciplines are called to relationship with the people they serve. The call to relationship arises both as a defining feature of being human, and as a core dimension of professional duty. It is hoped that the description of dialogical encounter, and its key elements of the 'between' inclusion and mutuality, offered here will contribute to understanding how to apply this to other areas of healthcare. I recognise that the purpose of the clinical relationship conditions the nature of encounter. For example, doctors usually bear the responsibility within the healthcare team to initiate therapies and management plans. With this responsibility comes a fear of failing to improve the patient's medical condition and suffering, as was spoken of by participants in this study. Other health professionals' roles likewise carry particular responsibilities. Therefore, the conditions conducive to dialogical encounter will vary by care setting.

To promote dialogical practice within healthcare, I also advocate for attention to building providers' capacity for the recognition of helplessness, self-awareness and reflective practice. This study supports the renewed efforts of educators and organisations to attend to the wellbeing of healthcare providers. In India and many developing nations, there are high demands placed on the small and sparsely distributed palliative care workforce (Knaul et al., 2017). In this situation, the need for culturally and situationally appropriate supportive supervision is even more pressing.

For the doctors in this study, sharing patient experiences was a professionally acceptable and congruent means of fostering self-awareness and reflection. I suggest that this was more widely acceptable because doctors are familiar with case discussion as a core activity of their profession. Facilitating a narrative discussion of experiences is an extension of this practice, and offers promise. My positive experience of conducting these interviews using videoconferencing technology, and the growing acceptance telehealth medicine and education, including in India (Kiss-Lane et al., 2018), suggests that widely dispersed practitioners could readily meet for narrative discussions, mentoring and support.

8.2 CONTRIBUTIONS TO KNOWLEDGE

This study is one of very few cross-cultural studies in palliative care internationally. I am aware of no other study that explores patients' suffering from the perspective of palliative care doctors working in India and Australia.

It is also one of the few studies which explores doctors' experiences of working with suffering.

It adds a new understanding of the importance of the doctor in the therapeutic relationship and an alternative to the prevailing approach to suffering advocated by protagonists of physician-assisted suicide and euthanasia, in which suffering is 'fixed' in an I and It mode of interaction. This study offers an alternative approach, that of dialogical encounter, and continuance of caring, to the relief of suffering. It therefore contributes to the granular understanding of different approaches to relieving suffering in different settings.

The study provides new understanding of the mutuality within the doctor-patient relationship in end of life care, and the potential within the experience of medical empty-handedness. Mutuality is present inthe doctor-patient relationships of both cultural groups studied. Mutuality facilitates the emergence of the between, a transformative new knowing for both doctor and patient. Such experiences are sustaining and renewing for doctors. This study applies this Buberian understanding of dialogical encounter to the realm of palliative medicine practice. To see that dialogical encounter underpins the practice of palliative care doctors in both countries, despite the differences in their particular experiences, contributes to the ontological understanding of the healing relationship and of being human. Relational being and becoming, through encounters with an 'other' (person, self, nature or 'God'), that facilitate a movement from individual to intersubjective understanding, has been identified as profoundly important in the relief of suffering. This ontological understanding of encounter offers a new perspective for palliative care practitioners on the nature of the doctor–patient relationship.

It also provides a snapshot of doctors' experiences at this particular time of palliative care development internationally. The lifeworlds of these doctors, their culturally-determined daily life and practice (Thoresen et al., 2011), are described in their

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narratives of encounters with patients at the end of life, in which they reveal something of the influences and experiences which shape them, both professionally and personally. These narratives are therefore valuable for educators, supervisors and mentors as well as other doctors in practice and in training as they describe the daily experiences of doctors in this field. The cultural variations within the narratives are powerful reminders of the importance of attuning to culture in the medical encounter. Cultural diversity is increasingly the norm in many countries and this study provides health care practitioners with insights into the cultural influences at the end of life.

A further contribution is that in an intersubjective sense, when speaking about patients' experiences of suffering, the palliative care practitioner is present in the experience and is also narrating self-experience. While this observation was made by Winnicott (1987), and Casher (2013) as noted in Chapter 7.3, there has been little examination of this in palliative medical practice. The intersubjective experience of suffering cannot be separated from the assessment of intractable suffering by the clinician. This has implications in the current environment in which there is an increasing turn toward physician-assisted suicide and euthanasia for the relief of suffering. Generally, these practices require clinicians to assess the intractability of suffering but there is little discussion about the intersubjective dynamic within these assessments.

A final observation to make concerning this study's contribution to knowledge is the application of Buber's terminology to the medical encounter described by doctors in this study. Doctors described the elements of inclusion naturally; that a person who is suffering needs to be seen, understood and accepted. With the confusion around the term 'empathy', the term 'inclusion' offers an alternative. Similar terms, such as compassionate solidarity and healing connections, also encompass this deeper sense of relationship between patient and health professional.

8.3 LIMITATIONS

There are some limitations to this thesis that need to be borne in mind. First, the dialogical encounters described here are from the perspective of the doctor, who is only one partner to the encounter. The experiences of the 'other', the patient, are as interpreted by the doctor, and subsequently the researcher. Their actual experience of encounter remains obscured from this study. While this understanding of narrative

experience as interpretation rather than fact is fully acknowledged in narrative methodology, this must not be lost sight of in interpreting the findings of the study.

Given this is an account and interpretation of only a small number of doctors from Australian and Indian palliative care, extrapolating their experiences beyond this particular context requires caution. Whether doctors working in other disciplines would have similar experiences of dialogical encounter or feel that it is of similar importance is not clear. There is a small literature to suggest that this is of importance (e.g., in general practice), but there may be fundamental differences determined by role and orientation between different areas of medicine that limit the application of these findings across all fields.

Similarly, dialogical encounter may be different for other healthcare providers in accordance with the caregiving roles of each discipline. This study has not explored this and thus recognises the need for careful consideration of role responsibilities when advocating for dialogical encounter to all healthcare providers as the foundation of the relief of suffering.

The interviews were conducted in two ways (in person and via videoconferencing), and generated two types of data (audio and video recordings). There is a potential for different methods of interviewing to affect the nature of the narrative interviews, with possible distancing and technological disturbances diminishing the capacity for encounter in the videoconference interviews. It was necessary to accept this limitation to explore the experiences of a widely dispersed workforce. This limitation sits alongside the benefit of using different approaches to obtain the narrative experiences of a wide range of practitioners within budgetary and personal resource limitations.

I consider that my role as interviewer/researcher and colleague was of an "inbetweener" stance (Milligan, 2016). I was familiar with Australian and Indian palliative care but not wholly part of one or the other. This inside knowledge of medical practice in palliative care facilitated shared experiences and co-construction of narratives, with a dialogical quality. However, the prior 'knowing' (Löyttyniemi, 2005) of the experiences being studied carries a risk of misleading assumptions. There is also the possibility of normalising or minimising the import of shared experience as a personal defence against evoked memories. I acknowledge this personal connection

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to the participants' experiences as a potential limitation in the study but also recognise that shared knowing can facilitate trust and connection (Chew-Graham et al., 2002).

Finally, the institutional ethics board required me to emphasise my duty of mandatory disclosure to the participants in the consent form and at the time of interviews. Mandatory disclosure refers to any revelations by doctors of causing harm to patients. The ethics application was submitted to a cancer centre ethics committee in Victoria, Australia, at a time of heated public debate about the legalisation of voluntary assisted dying for intractable suffering. Part of the rationale given for legalisation was that physicians were already, covertly, providing euthanasia or assisted dying. The ethics committee's emphasis on warning doctors may have been a reaction to this. Emphasising this to participants may have affected their candour in sharing difficult experiences with suffering patients.

8.4 FUTURE RESEARCH

This study suggests several areas for further exploration:

Firstly, it would be of interest to explore in greater depth the dimension of reciprocity within the doctor–patient relationship, both in palliative care and in other areas of medical practice. In particular, it would be of interest to understand better how this dimension helps to improve and maintain professional wellbeing. This would address the lack of research on how to help physicians deal with emotionally distressing situations.

Secondly, dialogical theory and practice are developing in other disciplines, such as family therapy and social work. There is scope to explore the place of dialogical therapy in medical practice, how to teach it and how to evaluate the outcomes for doctors and patients. There is also a need for greater understanding of the experiences with dialogical encounters of other types of healthcare providers in the relief of suffering.

Third, teamwork is critical to modern healthcare. The insights into the relational dimensions of healthcare, gained from relationship-centred care models of health delivery, reinforce the need to understand and appreciate the experiences of all members of a team if patient experiences are to improve.

Finally, Western principles of privacy, confidentiality and autonomy appeared to be at odds with Indian cultural understandings of relationality. This is relevant in communication training and healthcare quality evaluation. Further research on communication and relationship in non-Western settings would enrich understandings of these principles.

The data from this study will be deposited in the Lancaster University Pure depository to provide a resource for future research.

8.5 Last words

In conducting this research, my own embodied experience of a life-threatening diagnosis brought a hermeneutic, phenomenological dimension to the study, a lived experience interpreted through the lens of the conceptual framework for the study and my own reactions. The experience of healing encounter during routine care encouraged me to believe more deeply in the importance of encounter for patients in vulnerable healthcare situations.

Australian author, Richard Flanagan, wrote that Australia needs a depth story such as the Aboriginal dreaming and creation stories, to sustain, unite and direct it forwards (Flanagan, 2018). For me, the palliative care depth story is about hospitality, welcoming patients who were dying (Saunders, 2000), recognising in this 'stranger' the common condition of human suffering and responding with all the means at one's disposal, including the person and presence of the palliative care practitioner. This study revisits and emphasises this depth story.

My hope in presenting this thesis is that healthcare providers will find in dialogical encounter, a quiet place to rest, when providing care to people in suffering. In addition, I hope that the experience of empty-handedness is recognised as shared humanity rather than helplessness.

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APPENDICES

APPENDIX 1. SEARCH STRATEGIES

Data-base	Date Range		Search Strategy	Results
Medline	Jan 1960 – Aug 2019	1	exp physicians/ or exp physician-patient relations/ or exp students, medical/	218,825
		2	intern*.mp.	1,060,681
		3	1 or 2	1,254,568
		4	exp "Attitude of Health Personnel"/	151,887
		5	(experience* or impact*).mp.	1,923,216
		6	4 or 5 (1490906)	2,041,547
		7	exp palliative care/ or exp terminal care	90,922
		8	exp stress, psychological	123,927
		9	suffer*.mp.	288,399
		10	8 or 9	407,224
		11	3 and 6 and 7 and 10	372
		12	limit 11 to (English language and humans and yr="1960-current")	338
PsycINFO	Jan 1960 – July 2019	1	exp physicians/ or exp medical students	53,886
		2	(intern* or physician*).mp.	409,534
		3	1 or 2	432,000
		4	exp palliative care/ or exp terminally ill patients	15,927
		5	dying.mp.	35,583
		6	4 or 5	46,475
		7	exp suffering/	3,653
		8	3 and 6 and 7	117
		9	limit 8 to English language	111
		10	limit 9 to yr="1960-Current"	110

EMBASE	**Jan 1960 – Aug 2019**	1	(physicians or physician-patient relations or students, medical).af.	483,297
		2	intern*.af.	4,908,808
		3	1 or 2	5,265,582
		4	attitude of health personnel.af.	714
		5	(experience* or impact*).af.	2,755,809
		6	4 or 5	2,756,259
		7	(palliative care or terminal care or "end of life").af.	2,035,154
		8	stress, psychological.af.	597
		9	suffer*.af.	418,847
		10	8 or 9	419,414
		11	3 and 6 and 7 and 10	783
		12	limit 11 to yr = "1960-current"	781
		13	limit 12 to English language	744
CINAHL	**Jan 1960 – Aug 2019**	S1	(MH "Physicians+")	97,936
		S2	(MH "Physician-Patient Relations")	28,898
		S3	(MH "Students, Medical")	13,790
		S4	(MH "Interns and Residents")	6,952
		S5	S1 OR S2 OR S3 OR S4	138,283
		S6	(MH "Attitude of Health Personnel+")	84,907
		S7	experience*	365,051
		S8	impact	292,218
		S9	S6 OR S7 OR S8	676,778
		S10	(MH "Palliative Care") OR (MH "Terminal Care+")	57,433
		S11	(MH "Suffering")	2,376
		S12	suffer*	55,518
		S13	S10 OR S11	55,518
		S14	S5 AND S9 AND S10 AND S13	124

Outcome of Quality Assessment

∗ One article excluded:
  - Baverstock (2008), Mixed methods (survey, open-ended questions). Methodology of both components was not strong; interpretation of results was limited.

Qualitative Appraisal Tool: Critical Appraisal Skills Programme (2010) Checklist

1. Was there a clear statement of aims of the research?
2. Is a qualitative methodology appropriate?
3. Is it worth continuing?
4. Was the research design appropriate to the aims of the research?
5. Was recruitment strategy appropriate to the aims of the research?
6. Were the data collected in a way that addressed the research issue?
7. Has the relationship between the researcher and participants been adequately considered?
8. Have ethical issues been taken into consideration?
9. Was the data analysis sufficiently rigorous?
10. Is there a clear statement of findings?
11. How valuable is the research?

Additional Considerations:

From Cherry et al. (2014, p.154):
- Was the research guided by a clear question?
- Was the research conducted in an ethical and rigorous manner?
- Was there clear information about the methods that were used to collect and analyse the data?
- Did the research provide information that indicates the bias of the researcher?

From Spencer et al. (2003):
- Is there transparency of data collection and analysis?
- Does the research offer plausible arguments?

Quantitative Appraisal Tool: Critical Appraisal of a Survey (Centre for Evidence-Based Management, 2016)

1. Did the study address a clearly focused question/issue?
2. Is the research method (study design) appropriate for answering the research question?
3. Is the method of selection of the subjects (employees, teams, divisions, organisations) clearly described?
4. Could the way the sample was obtained introduce (selection) bias?
5. Was the sample of subjects representative with regard to the population to which the findings will be referred?
6. Was the sample size based on pre-study considerations of statistical power?
7. Was a satisfactory response rate achieved?
8. Are the measurements (questionnaires) likely to be valid and reliable?
9. Was the statistical significance assessed?
10. Are confidence intervals given for the main results?
11. Could there be confounding factors that haven't been accounted for?
12. Can the results be applied for your organisation?

\# Mixed-methods study where both components were given equal importance in analysis.
  - Jackson et al. (2005), Survey, face-to-face completion, principal components analysis to find thematic clusters (quantitative assessment included in next section).

∗ Studies with mixed methodology, where the main focus is the presentation of the qualitative findings. Quantitative elements are listed below:
  - Fanos—anxiety depression scale
  - Hegarty—online questionnaire, four participants of the 17
  - Breaden—as for Hegarty (2010)
  - Rhodes—written questionnaire, 10-point scale generating descriptive data from questionnaire
  - Papadatou—quantitative component minimal, 10 stressful conditions to order hierarchically

- Jackson et al. (2008)—oncologists, survey as used in Jackson et al. (2005), but more focus on qualitative outcomes.

Quality Assessment Table for Selected Qualitative Articles

Study	Author, Date	1	2	Y/N	3	4	5	6	7	8	9	10	11	I/E
1	Whitehead, 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
2	Fanos, 2007*	Y	Y	Y	Y	NK	Y	N	N	N	Y	Y	L	I
3	Jackson et al., 2008*	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
4	Aase et al., 2008	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
5	Zambrano & Barton, 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
6	Hegarty et al., 2010*	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
7	Breaden et al., 2012*	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	H	I
8	Beng et al., 2013,	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	M	I
9	MacLeod, 2001	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
10	Malterud & Hollnagel, 2001	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	H	I
11	Takman & Severinsson, 1999	Y	Y	Y	Y	Y	Y	Y	NK	Y	Y	Y	H	I
12	Boston & Mount, 2006	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
13	Johansen et al., 2012	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	H	I
14	Johansen et al., 2010	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	H	I
15	Mulder & Gregory, 2000	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	M	I
16	Rhodes-Kropf et al., 2005*	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
17	Papadatou et al., 2002*	Y	Y	Y	Y	Y	Y	N	N	Y	Y	Y	M	I
18	Bruce et al., 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
19	Loiselle & Sterling, 2012	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	H	I
20	Baverstock, 2008	Y	Y	Y	NK	N	Y	N	Y	N	Y	N	L	E

21	Vegni et al., 2005	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
22	Jackson et al., 2005*#	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I
23	Clay, 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	H	I

Y: Yes, **N**: No, **NK**: Not Known, **NA:** Not Applicable   Ratings: **H**: High, **M**: Medium, **L**: Low   **I**: Include, **E**: Exclude

Quality Assessment Criteria for Selected Quantitative Studies

Study	Author, Date	1	2	3	4	5	6	7	8	9	10	11	12	Rating H/M/L	I/E
24	Moore, 1984	Y	Y	Y	Y	U	N	U	U	Y	N	N	Y	M#	I
25	Moores et al., 2007	Y	Y	Y	Y	Y	N	Y	Y	Y	N	N	Y	H	I
26	Redinbaugh et al., 2003	Y	Y	Y	N	Y	Y	Y	Y	Y	N	N	Y	H	I
27	Van der Steen, 2017	Y	Y	Y	N	Y	N	Y	Y	Y	Y	N	Y	H	I
28	Smyre, 2015	Y	Y	Y	N	Y	N	Y	Y	Y	Y	N	Y	H	I
22	Jackson et al., 2005*	Y	Y	Y	N	Y	N	Y	Y	Y	N	N	Y	H	I

Y: Yes, **N**: No, **U**: Unsure   Ratings: **H**: High, **M**: Medium, **L**: Low   **I**: Include, **E**: Exclude

Moore, 1983: early study, weaker analysis, poor response rate, poor selection of invited participants, too general. However, respondents would have been interested in end-of-life care, so study provides information on their views. There was a lack of similar studies in community end-of-life care at that time, so this is a useful, early contribution to literature.

CRITICAL APPRAISAL SKILLS PROGRAMME

Paper: (Whitehead, 2014)—The lived experience of physicians dealing with patient death

SCREENING QUESTIONS

1. Was there a clear statement of the aims of the research?

Yes

Consider:

- What the goal of the research was
- Why is it important
- Its relevance.

Goal: Explore physician's experiences of dealing with patient death in order to understand how such experiences affect them and their communication with patients/Iatrogenic suffering caused by poor communication /Mutuality

2. Is a qualitative methodology appropriate?

Yes

Consider:

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants?

Seeks to build on Kuhl's 'iatrogenic suffering'

3. Is it worth continuing?

Yes

4. Was the research design appropriate to address the aims of the research?
        Yes

Consider:
- If the researcher has justified the research design (e.g., have they discussed how they decided which methods to use?)

Phenomenological qualitative method/lived experience: Not justified design but appropriate to question

4. Was the recruitment strategy appropriate to the aims of the research?

        Yes

Consider:
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g., why some people chose not to take part)

Ten doctors; 5M 5F; convenience sample through work contact, then formal letter to invite; doctors in large tertiary hospital in Canada; >3 years work, exposed to multiple deaths. Palliative care, emergency, general medical, family practice, ICU; limited discussion re recruitment. Age 35–60, Caucasian

5. Were the data collected in a way that addressed the research issue?

        Yes

Consider:
- If the setting for data collection was justified
- If it is clear how data were collected (e.g., focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews were conducted, or did they use a topic guide?)
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g., tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Semi-structured in-depth interviews x2; 10 themes. Daily experience of patient death in particular memorable deaths/ impact on lives personal, professional

6. Has the relationship between researcher and participants been adequately considered?

> ***Yes***

Consider:
- If the researcher critically examined their own role, potential bias and influence during:
    - formulation of the research questions
    - data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Little discussion of this relationship—convenience sample, informal work contact with participants. Acknowledge possible bias via self-selection of participants. Potential researcher bias not discussed

7. Have ethical issues been taken into consideration?

> ***Yes***

Consider:
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

University British Columbia ethics approval. Details of discussion with participants not discussed nor any ethical issues

8. Was the data analysis sufficiently rigorous?

> ***Yes***

Consider:
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Thematic analysis, part of a larger dissertation. Sufficient data is reported to support findings. Individual themes identified then validated through member-check in second interview. 10 themes validated by further member-check. Cross-check by independent expert. 10 themes separated into 3 categories: impact of the context surrounding the experience of patient death; immediate experience of dealing with patient death; impact of the experience on personal and professional life. This paper focuses on 5 core themes

9. Is there a clear statement of findings?

> *Yes*

Consider:
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Clear discussion of the 5 themes identified: memories below the surface; expectation and responsibility; question of competence; breakthrough experiences; action versus presence
- *'simply being present' p. 273*
- *Breakthrough experiences—how deeply these physicians were touched by the 'human part of the tragedy' p. 273*
- *Expectations and responsibilities as 'brutal' and 'inhuman' or 'impossible to fulfil' p. 272*
- *'difficult to balance the expectations of "medical responsibility" with the uncertain and unpredictable nature of patient care' p. 272*
- *Expands our understanding of 'the other side of iatrogenic suffering'*

10. How valuable is the research?

Consider:
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations, or considered other ways the research may be used

Future research ideas discussed: doctor–patient communication and education. Limitations recognised: wellbeing enhancement.
Note little support for medical students and residents who experience emotional reactions to patient suffering; repression of emotional reactions in students
Iatrogenic suffering may occur when physicians maintain the 'disconnect' of action mode at times when their patients require openness and connection of presence.
©Critical Appraisal Skills Programme (CASP) Qualitative research checklist_14.10.10

Reflection

I have included this article as it focuses on the impact on doctors of exposure to patient suffering and death. It describes the complex interplay between a professional role and personal response to suffering. The notion of 'functional disconnect' to sustain professional role but balancing this with a process of reconnection is useful. Action and presence are both needed, and physicians need to manage this balance. This article emphasises the humanity of the physician.

APPENDIX 4. DATA EXTRACTION TABLE

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Whitehead, 2014) Canada	Physicians' experiences of patients' death—impact and communication/ Tertiary care hospital/ 10 senior physicians, diverse specialties	NS/ Phenomenology SSI Thematic analysis	Complex process of managing the balance between personal and professional reactions to patient suffering and death
(Fanos, 2007) USA	1. Early experiences with illness and death in paediatrician's childhood/adolescence 2. Coping strategies to manage stress of caring for ill children/ Paediatric oncology settings 1990s/ 30 paediatric oncologists	NS/ Mixed methods - SSI - Anxiety and depression scales (Hopkins) Thematic analysis	Relapse and terminal phase most difficult aspect Women more likely to be depressed (P=0.006, 2-tailed t test). 57% had significant childhood illness. Experiences included stress on family life, repetitive dreams, efforts to achieve balance, perspective on oncology as a challenge, maintaining façade of strength, and importance of life experience to gain sensitivity rather than formal education; individual grieving; distancing
(Aase et al., 2008)	Physicians experience of and coping with existential aspects of their clinical work—effect on their professional identities/ University hospital 2006–2007/ 10 physicians, diverse specialities	Vetlesen's existential concepts/ SSI Analysis by systematic text condensation	Vulnerability linked to professional identity and responsibility; experience of meaning and being connected to patients provided balance to vulnerability; belonging to caring community of fellows also assisted with coping with loneliness and powerlessness

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Zambrano & Barton, 2011) Australia	GPs experience of the patients' death / 11 GPs	NS/ Social constructionist grounded theory SSIs, thematic analysis	Death journey metaphor featured prominently. 5-stage journey—stages have emotional reactions. Coping mechanisms, contributing factors (professional identity, training, experience, beliefs) and appraisal of situation featured.
(Hegarty et al., 2010)	Developing the capacity for sustainable practice with people with refractory suffering/ Postgraduate palliative care course/ 17 palliative care clinicians (5 doctors)	NS/ Mixed methods, exploratory SSI/online questionnaire Thematic analysis	Perceptions of capabilities required to work with refractory suffering—beyond knowledge (e.g., awareness, insight), clinical approach, self-awareness, perspective within uncertainty, engaging with suffering, supportive presence, communication skills, clinical decision-making skills
(Breaden et al., 2012) Australia	Witnessing refractory suffering/ Postgraduate palliative care course/ 17 palliative care clinicians (5 doctors)	Groundlessness (existentialism), Social constructivism/ Mixed methods, exploratory SSI/online questionnaire Thematic analysis	Overarching theme of negotiating uncertain terrain; subthemes of 'being with' rather than 'fixing'—'from heroic quest to pilgrimage' (p. 898); maintaining perspective through different dimensions of time and tempo; negotiating boundaries; living the paradoxes

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Beng et al., 2013) Malaysia	Experiences of stress of palliative care clinicians/ Tertiary hospital/ 20 palliative care clinicians (10 doctors)	Transactional model of stress and coping/ SSI Thematic analysis	9 themes: organisational challenges, ability to relieve suffering; care overload; communication challenges including exposure to suffering; differences in opinion; misperceptions and misconceptions regarding cancer and suffering; personal expectations; emotional involvement with seeing suffering; death and dying thoughts; appraisal and coping
(MacLeod, 2001) New Zealand	Doctors' experiences of learning to care for people who were dying/ All settings/ 10 doctors	Humanistic model, concept of care/ Hermeneutic phenomenological SSI Interpretive analysis	2 main themes: degree to which doctors' education prepared them for end-of-life care; 'turning points' which led to a new perspective of the notion of care, and engaging in learning to care
(Malterud & Hollnagel, 2005) Norway	Impact of doctors' vulnerability on patients/ General practice/ 9 participants (7 GPs)	NS/ Analysis of memory-text by systematic text condensation	Doctor's perception and (often spontaneous) exposure of emotions are essential to understanding patients. Recognise the distinctive relational character of general practice

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Takman & Severinsson, 1999) Sweden	Health professionals' experience of encounters/ University hospitals/ 11 participants (3 doctors)	Dialogical Phenomenographic approach/ Unstructured interviews—narrate an encounter	3 categories: 2 in which health professionals understand patients' expression of suffering by 1) gaining personal knowledge and understanding of patients' different ways of communicating experienced suffering and 2) making patients feel confident; third is not understanding patients' way of communicating their experienced suffering Health professionals may need support to understand patients' way of communicating suffering
(Boston & Mount, 2006) Canada	Spiritual/existential needs of patients and their caregivers/ University setting/ Multidisciplinary (2 doctors)	Dialogic/ Focus groups Thematic interpretation	8 themes: concepts of spirituality; creating 'openings', (counter)-transference; cumulative grief; healing connections; wounded healer; sustaining healing environment; challenges and strengths in this domain of practice
(Johansen et al., 2012) Norway	In-depth experience of being a doctor for people with advanced cancer/ General practice/ 14 GPs	Humanistic/ SSI, thematic narrative analysis focused on relational aspects	Loyalty, honesty, shared humanness Caring for the dying from a relational perspective of equal importance to curing cancer. GP learns that bodily and existential suffering are connected. Needs theoretical framework in modern medicine

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Johansen et al., 2010) Norway	GPs perception of role in healthcare for people with cancer/ 14 GPs	NS/ Purposive sampling from national GP survey Exploratory face-to-face interview; Content analysis, assisted by nVivo	Handyman; mediator; personal companion Personal aspects inspired doctors most deeply
(Mulder & Gregory, 2000) Canada	Experiences during training and what was learned from patients/ Palliative medicine training/ 1 doctor, 116 encounters	Coping mechanism theory/ Case study design/ Thematic analysis	Key themes of tensions of time, truth-telling/denial; meaning of life and death; teamwork; person-self and physician-self Healing in midst of suffering as unspoken potential in palliative care practice
(Rhodes-Kropf et al., 2005) USA	Emotional reaction to 'most memorable' patient death/ 2 medical schools/ 38 third-year medical students	NS/ Mixed methods SSI, thematic analysis	Highly emotional reactions to death when moderate to extreme suffering perceived; multiple coping strategies; perceived lack of support from team; emotions viewed as negative aspect in medicine
(Papadatou et al., 2002) Greece	Grief responses and experiences of Greek physicians and nurses/ Paediatric oncology/ 30 clinicians (14 doctors)	NS/ Mixed methods Descriptive, cultural context SSI, Grounded theory	Recognition that physicians and nurses grieve over death of a child, and of differences between them (e.g., length of relationship with dying child, ways of expressing grief, sources of satisfaction or grief)

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(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Bruce et al., 2011) **Canada**	Engaging with existential suffering at the end of life/ 22 participants (10 healthcare, inc. physicians)	Yalom's theory of existential struggle/ SSI Grounded theory	Limits of language to express existential suffering, groundlessness, 'being shaken to the core', identified as the shared experience or challenge; leads to search for stability or peace; 3 responses: engaging groundlessness, refuge in habitual, living in-between
(Loiselle & Sterling, 2012) **India**	Indian hospice workers' experiences of patient deaths and suffering/ South Indian hospice/ 25 staff (1 doctor)	NS/ SSI Thematic content analysis	Paradox of death—relief and sadness; balancing personal and collective needs and experiences; mindfulness of workplace initiatives to support staff; commitment to service
(Vegni et al., 2005) **Italy**	Physicians' internal representation of the doctor–patient relationship with the suffering patient/ Academic centre/ 151 doctors	NS/ Textual analysis Clinical interpretive narrative	Dynamic flow between biological, professional and personal perspectives within doctor–patient relationships in pain management

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Jackson et al., 2005) USA	To understand the emotional experience of physicians who care for dying patients To identify educational interventions to improve patient care and physician wellbeing/ Quaternary medical centres/ 196 physicians: - 144 in the quantitative study - 51 in the qualitative study	NS/ Mixed methods: - Focus groups to develop survey - SSI - Analysis of adjective clusters	Memorable deaths were emotionally powerful Identified 3 types: shocking death, good death, over-treated death Over-treated deaths associated with suffering; deaths early in training are emotionally powerful; junior doctors seldom sought support from consultants; consultants unaware of junior doctors' powerful emotional responses to deaths
(Jackson et al., 2008) USA	Oncologists provision of psychosocial end-of-life care; personal coping/ Oncology wards 1999–2001/ 18 oncologists	Learning theory of professional growth/ Mixed methods: - Focus groups to develop survey - SSI - Grounded theory - Statistical analysis	An understanding of clinical practice that incorporates biomedical and psychosocial aspects was associated with finding end-of-life care a satisfying aspect of clinical role

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
(Redinbaugh et al., 2003) USA	Doctors' emotional reactions to recent death/ Quaternary medical centres/ 188 doctors	NS/ Mixed methods: - Focus groups to develop survey - SSI - Grounded theory - Statistical analysis	74% reported caring for dying patient was satisfying experience. Level of training not associated with differences in emotional reactions. Longer relationships associated with stronger emotional reactions (i.e., impact (P<0.01), grief (P<0.01), disturbing (P<0.01)); 48% reported moderate or high patient suffering
(Moore, 1984) UK	Perceptions of patients' experience of suffering and dying/ General practice/ 302 GPs and 17,500 bereaved relatives	NS/ Descriptive survey	Degree of suffering differently reported by GP and relatives Agree in 52.6%; when disagreed, relatives identified more suffering than doctors (29.6% v. 17.9%), severe suffering (14.1% for both; relative 19.2% v. 5.1% doctor)
(Moores et al., 2007) UK	Reactions and coping strategies of doctors following recent memorable patient death/ Teaching hospitals, district hospital/ 188 doctors, diverse specialties	NS/ Descriptive survey with self-completed questionnaire	Most memorable was disturbing (median 7/10) but satisfying (median 8/10); more junior doctors least satisfied (P=0.019) Perceived need for training and support associated with more intense reactions; no relationship between exposure to previous training and intensity of emotional or physical responses

(Author, Year) Country	Aim of Study/Context/ Participant	Theory/Method	Results
Clay, 2015 USA	Situations and emotions evoked by clinical situations, memorable at time of graduation/ University hospital/ 300 medical students	NS/ Content analysis of letters	6 themes: sorrow for patient suffering theme in 174/300 (94.6%) letters related to death, unalleviated pain, vulnerability; isolation (alone, language, age)
Van der Steen, 2017 Netherlands	Associations with physicians' perception of suffering in last 6 hours of life with the characteristics of physicians & patients/ 103 doctors	Model of Caron 2005/ Questionnaires	Two key correlates with physician perceived suffering: 1) dying unexpectedly and 2) dying of pneumonia Other patient factors: those who did not receive palliative sedation; worse quality of care; cardiovascular death; younger patients Physician factors: less experience
Smyre, 2015 USA	Assess physician attitudes to spiritual suffering/ National database of AMA/ 1878/2016 (62%) practicing physicians, diverse specialities that care for dying patients	NS/ Survey; Questionnaires with validated criterion questions	Unresolved spiritual pain worsens physical pain (81%) Physicians should try to relieve spiritual pain (88%); those who strongly agreed with this less likely to report unacceptable suffering (27% v. 54%)

Notes: N = 27 articles. GP = General practitioner; NS = Not stated; SSI = Semi-structured in-depth interviews

Detailed analysis using Gee's (1991) linguistic approach

Part 1. Establishing relationship in diagnosis and care
Stanza 1 Particularly hard on all of us
1.   I think one was particularly hard on all of us
2.   because he was a 20 year old young man with,
3.   he had, he drove one of those little 3 wheelers,/

Stanza 2 He was the main income generator for the family
4.   and he was the main income generator for the family, /
5.   because he had 4 other siblings,/ the youngest of which was 2,
6.   and he as a 20 year old had just got married,

Stanza 3 It was actually a pathological fracture
7.   and he had an accident and had a fracture of his femur, /
8.   and that was when they discovered /that it was actually a pathological fracture,
9.   it was an osteosarcoma, /and he had a # of ,
10.   he had an amputation and then some radiotherapy.

Stanza 4 He said the doctors were very rude
11.   Then he said the doctors were very rude, /so he came back home /and refused to go back to the hospital.
12.   So when we saw him he was fairly healthy looking, /and joined our tailoring class /because
13.   he couldn't drive the 3 wheeler,
14.   and became very adept at making bags.

Part 2. Conflict in the doctor–patient relationship
Stanza 4 No, I'm not breathless
15.   But one day when he came in, /and I was sitting right there in the clinic
16.   when he appeared to be breathless,
17.   so I said are you breathless today,
18.   and he said no, I'm not breathless.

Stanza 5 But I'm pretty certain
19.   So I said well why don't I just take an x-ray, /and you can join the class and /- so he agreed to that,
20.   and I could see the mets everywhere.
21.   So I asked him to call his father /and told the father that you know, /I think this has spread /and I know it's spread,
22.   if you want you can have a CT scan, /but I'm pretty certain.
23.   So they did opt for a CT scan which confirmed it.

Stanza 6 I know I don't have cancer
24.   But when we told the patient /he said there's no way I'm going to die,
25.   I know I don't have this,/ I know I don't have cancer,

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26. and <mark>he</mark> went off to see a private practitioner /who told him, /who looked at the x-ray /and told him he has TB.
27. Put him on TB medication, /
28. and <mark>he</mark> came back /and <mark>he</mark> said oh look I'm so much better /because I'm on TB medication
29. and it's not cancer at all.

<mark>Part 3. Restitution of relationship</mark>
Stanza 7 He had a peaceful death
30. <mark>Of course</mark> within about 2 weeks <mark>he</mark> was back, /terribly breathless,
31. and <mark>he</mark> passed away in hospital in front of us.
32. <mark>He</mark> had a very peaceful death,

Stanza 8 So much suffering there
33. but it was, um, (pause) there was so much suffering there,
    <mark>because</mark> <mark>he</mark> was so sure, /<mark>he</mark> was so certain in his mind /that he wasn't going to die
34. And for the family it was their eldest son /who had just got married,/ the main wage earner.
35. <mark>So</mark> it was just, /and for us as a team it was very very difficult,
36. <mark>everyone</mark> cried of course
37. and <mark>we've</mark> never forgotten him

Gee's analysis in detail

1. <mark>line and stanza structure</mark>: the ideas and perspectives on characters, events, states, information; hierarchically related pieces of information
2. <mark>syntax and cohesion</mark>: very important as the linguistic devices that achieve cohesion and tie the language and the sense of it together (e.g., 'so', 'that'). Links lines to each other and links stanzas to each other across the whole narrative. They are indicators of the narrator's meaning-making or, as Gee puts it, the 'logic of the narrative' (Gee, 1991)p.28
3. main line/non-main line: main lines are identified by perfective aspect, simple past tense; non-subordinate, non-embedded, main clauses
4. <mark>psychological subjects</mark>: interesting how these changed in Gee's example narrative example from 'we' to 'I' to 'we' and how recognising this change in perspective helps to interpret the overall meaning of the narrative
5. focusing system: identified by pitch and stress, shows the narrator's intention, the key images or themes from which we can 'build an overall interpretation of the narrative'

Dialogic Narrative Analysis Proforma -derived from (Smith, 2016)

LAYOUT TEMPLATE FOR INDIVIDUAL STORIES

1. Stories selected with summative comment (confirmation, witness etc.)
2. How do these relate to dialogical encounter theme?
3. Mutuality
4. Culture
5. Dialogical narrative analysis questions
   a. what
   b. how told (focus on dialogic nature and co-construction)
   c. action (impact on researcher)
6. Extract
7. Full narrative

Story selected with summative comment (confirmation, witness etc)
This narrative told by Patricia tells of a distressing encounter with an acutely psychotic young Chinese woman with leukaemia. Patricia was a mature-aged medical trainee working in acute medicine. She felt isolated in her medical team in her efforts to provide palliative care for this woman and helpless to relieve her suffering.

How does this narrative relate to dialogical encounter theme?

Dialogical encounter: Junior trainee, grappling with maintaining normative limits of therapeutic relationship, feeling concerned and distressed for a young, vulnerable, isolated patient and at odds with the rest of the clinical team.

Mutuality: young, unsure of self, trainee. Compassion for the woman. Own father had died and stimulated interest in palliative care. Identified at some level with this patient. Feeling vulnerable herself in her training as a mature-aged student, as well as protective of this vulnerable patient.

Dialogical narrative analysis questions
a. caring for a young schizophrenic patient with terminal haem illness—only one who cared about her. Older trainee seen as more mature and feeling like needed to prove herself
b. there was a lot of interaction, probing by me, sharing and supporting her in her recollection of the distressing nature of this clinical encounter
c. recognise the similar experiences of feeling at odds with other members of clinical team; the vulnerability of the trainee; solidarity with the palliative care provider 'against' other medical practitioners

Culture: medical training culture, haematology culture, palliative care culture

Extracts chosen for body of thesis

1.

Stanza I'd gone beyond some kind of a – a connection
75. So yeah that was a, that was pretty/Yeah that was /and I still often think about her
76. But in the end, /and you now it took me a while afterwards to realise
77. that probably being so involved with her
78. hadn't helped me care for her well in the end.
79. Like I recognised that I'd gone beyond some kind of a – a connection
80. to one that was actually unhelpful.
81. I was so distressed by what was happening to her
82. that I couldn't actually make, couldn't actually help her anymore

Full narrative

Part 1. Training days
Stanza I'm more aware of actually pulling back
1.   Yeah, as a more junior person.
2.   I probably still recently in a way,
3.   but I'm more aware of actually pulling back from it.

Stanza The one I remember most
4.   So the one I remember most, /there's a couple,
5.   but the one I remember most was actually not, /I wasn't doing palliative care
6.   I was doing my clinician training rotations,

Part 2. The medical treating team
Stanza It was a haematology patient
7.   it was a haematology patient
8.   and she was 18 or 19, no maybe she was 21, /a little Chinese 21 year old
9.   who was schizophrenic, /severely schizophrenic,
10.   and they'd put her on Clozapine
11.   and she'd actually had a fantastic response psychiatrically,
12.   but started to develop this kind of dysplasia

Stanza Lost control of her schizophrenia
13.   and then they were doing the blood test
14.   and they thought it was the Clozapine,
15.   they stopped it, /lost control of her schizophrenia,
16.   it took them about 3 months to work out that /actually it wasn't the Clozapine,
17.   she actually didn't have aplastic anaemia, she had leukaemia,

Part 3. The patient
Stanza She was mad, mad, mad
18.   and then she was committed for treatment to our ward
19.   acutely psychotic,
20.   she was mad, mad, mad.

Stanza She was absolutely beautiful
21.   she was beautiful, she was physically beautiful,
22.   she was like – did you ever see Monkey /she was like Tripitaka /the little Chinese monkey
23.   she was absolutely beautiful,

Stanza It was a nightmare
24.   and she was often meditating and praying and doing salute to the sun every morning
25.   and then at night she was having all these horrific delusions
26.   about all the staff coming in and having sexual extravaganzas,/ and she was always being sexually assaulted
27.   and you know, she was just, it was a nightmare,

Stanza She was in there on her own

28.   she had, her family didn't speak English hardly at all,
29.   she was in there on her own
30.   she was committed /so she was there full time, she didn't go home.

Part 4. The trainee and the patient
Stanza I was quite traumatised by having to care for her

31.   I looked after her
32.   and I was quite traumatised by having to care for her.
33.   And she was going to die you know /she was clearly not going to do well,
34.   but no one talked to her about that.

Stanza I was challenged in every possible way

35.   So you know ethically, I was challenged in every possible way by her care,
36.   and then in the end, you know the psychiatrists were too scared to come near her,
37.   because they were a bit freaked out by how sick she was medically,
38.   and I thought actually she should be on a psych ward
39.   because she was so distressed, her behaviour was so difficult
40.   and you know in the end the day when I found her trying to nucleate her eye,
41.   the psychiatrist finally said yes okay, /and she died on the psych ward in the end.

Stanza I was so involved

42.   And I was having to do lumbar punctures /and you know epidural,
43.   she was having spinal chemo
44.   and it was just blah, it was just blah.
45.   It was horrible.
46.   And I was so involved you know I couldn't –
47.   you know I just thought everything about it was so awful and upsetting.

Stanza You're so close to your patients

48.   Yeah you're the most, yeah
49.   You are, you're so close to your patients,
50.   particularly someone like that who you know
51.   I perceived that she didn't have a lot of support.

Part 5. The trainee and the team
Stanza The nurses needed me

52.   The nurses on the ward were fantastic,
53.   but she challenged them.
54.   They actually needed, /the nurses needed me actually
55.   because I think I had a kind of level of maturity that, I was older than them
56.   I was junior medically /but I was older
57.   because I'd come back, I was older than my consultants quite often /I was in my 40's, early 40's.
58.   So I was often older than my consultants, often older than my registrars

Stanza I had to learn to manage that relationship
59.   Well I had to learn to manage that relationship
60.   because I was junior, you know,
61.   so it was interesting and varied, varied yeah

Stanza I found palliative care in every job I did
62.   I found palliative care in every job I did, as it came to me,
63.   I mean it's there, and the thing was the consultants used me.
64.   I think they recognised I was safe and sensible and I would do it reasonably well
65.   and I would let them know you know, /I kind of managed the medical
66.   but I particularly managed the palliative, the social and the symptom management ,
67.   and they actually appreciated it /so they let me do that generally

Part 6. The medical relationship
Stanza It's impacting on your relationship with that person
68.   I didn't find that okay, /I've always hated interventions, /I find them stressful,
69.   I'm always, I mean to me that's the distressing part of a job is,
70.   the thing where, and particularly when you think that the treatment is probably fairly futile
71.   and this person is not able to give an informed consent
72.   and it is incredibly invasive
73.   And it's impacting on your relationship with that person
74.   who's got very few people to, you know, really connect to.

Stanza I'd gone beyond some kind of a – a connection
75.   So yeah that was a, that was pretty/Yeah that was /and I still often think about her
76.   But in the end, /and you now it took me a while afterwards to realise
77.   that probably being so involved with her
78.   hadn't helped me care for her well in the end.
79.   Like I recognised that I'd gone beyond some kind of a – a connection
80.   to one that was actually unhelpful.
81.   I was so distressed by what was happening to her
82.   that I couldn't actually make, couldn't actually help her anymore

Stanza They left me to it
83.   The haematologists, not those ones
84.   Well sometimes there are but not those ones
85.   And my registrar was very blokey too.
86.   I think he could see that I was struggling a little bit
87.   but he just, but again I was older than him and probably that was part of it,
88.   they left me to it

Stanza I was a physician trainee, and you know how that goes
89.   Yeah, and I mean I wasn't struggling in the sense I was going to crash and burn,
90.   but it was hard
91.   Absolutely, I was a physician trainee, and you know how that goes.

92.   You're trying to tick all kinds of boxes
93.   I was a single mum as well

Follow-up narrative reflecting further on the encounter with this patient

Part 7. Team roles
Stanza That feeling of helplessness
1.   And that feeling of helplessness
2.   And the absolute ethical quandary of her psychiatric condition
3.   and having such I guess a, you know it's in your bones
4.   wanting people to be able to make a proper decision about things
5.   and understand what's happening to them as they're able to,
6.   and she just, you know, you couldn't.

Stanza It's not something I could ever have done, not like that
7.   I just remember one of the haematologists,
8.   and she's literally on her knees in the hallway going /you're gonna fix me, aren't you,
9.   and he's patting her on the head going yes of course dear,
10.   and I'm thinking you're a fucking idiot.
11.   But it was effortless to him,
12.   but it's not something I could ever have done, not like that

Stanza I'm happy to, rather than have them do it badly
13.   Completely, which so many clinicians do really every day of the week.
14.   They leave it to us to fill that gap.
15.   But I'm happy to. /I'm happy to, rather than have them do it badly
16.   I'm happy to do it

(ask her more about the Chinese patient)

Part 8. Communication
Stanza He didn't even tell me
17.   Not much, so my registrar used to meet with them,
18.   I didn't realise this for some time actually,/ he didn't even tell me,
19.   but he had a regular meeting with them about once a fortnight with an interpreter.
20.   They'd come onto the ward and he'd update them.

Stanza I was never there for any of those conversations
21.   But I don't know how much he was actually telling them or explaining to them,
22.   they were very, you know they were not highly educated,
23.   you know she was in such a double bind,
24.   and I was never there for any of those conversations so

Stanza He just wanted to keep it manageable
25.   It was interesting./Maybe the registrar wanted to keep me away, /I was a bit too much
26.   Yeah possibly, he just wanted to keep it manageable from his point of view
27.   Well he might not have wanted to do that.

28.   He knew all his little cells and his pathology really well
29.   but some of the communication stuff, boy

Part 9. Letting go
Stanza But you have to let go of the outcome
31.   Yeah not fixing/That's the thing you've got to be able to manage I think in palliative care isn't it?
32.   Yeah, you know obviously you fix or you facilitate,
33.   you create conditions where things can fix or not
34.   but you have to let go of the outcome.
35.   And people who can't do that can't do palliative care.
36.   You know you see that with the juniors as well,
37.   this is going to be a very hard term for you honey bun

Project 14/67L   Exploration of doctors' views about suffering Version 1.1 dated June 2014

Exploration of doctors' views about suffering
Interview Topic Guide

Phases of Interview

The narrative interview typically has a number of phases:

- pre-interview or preparation phase
- tentative or initiation phase
- main narration or immersion phase
- questioning, clarifying phase, also regarded as emergent phase
- conclusion.

Pre-Interview phase

At the beginning of the interview, the researcher will ensure that the participant is comfortable, remind them that the interview will be recorded and confirm consent to commence the interview.

The researcher will then be reminded of the legal and ethical obligations in Australia for mandatory reporting of 'notifiable conduct', in particular where 'the practitioner has placed the public at risk of harm because the practitioner has practised in a way that constitutes a significant departure from accepted professional standards'. These obligations will have been explained at the time of consent, but will be reiterated at the start of the interview. The participant will be told that **'Should you disclose information that indicates you may or have hurt others or yourself, I will need to inform my supervisor and the relevant ethics committees (Peter MacCallum and Lancaster University) and may, in certain circumstances, need to notify the AHPRA'.**

Participants will again be asked if they are willing to proceed with the interview.

Tentative Phase and Main Narration Phase

Questions to Guide Interviews

- What drew you into palliative care practice?

- Describe your practice and experience working with seriously ill patients?
- What are some of the more memorable experiences you have had in this practice?
- What are some of the most challenging aspects of your work?
- Can we talk about your experiences of suffering in your palliative care work?
- How do you understand the term suffering and respond to it in your palliative care work?

Questioning/Clarifying Phase

During this phase, both the researcher and participant can ask questions about the interview and seek clarification about any aspect of the narratives and interview in general.

Conclusion Phase

In the wrapping up phase of the interview, the researcher will determine the participant's preferences for reviewing the transcript and providing comment on it. In addition, she will confirm if the participant is willing to be called for a second interview should it be required, and remind them that she will be in touch in the next 2 days to see if the participant has experienced distress as a result of the interview and provide support. The participant will be given the contact details of counselling organisations and individuals available for support, should they wish to avail themselves of this support. The participant will also be invited to contact the researcher at any time to discuss the interview and be invited to contact the researcher if they wish to speak again one month after the interview to reflect further on this topic.

The researcher will also discuss the relationship between the researcher and participant at this time, to ensure that researcher and participant have reached a secure understanding and are comfortable with the new relationship which will have developed between them as a result of this interview. Paramount to this is that the participant feels secure that what they have shared will be treated with great respect and will be reported in ways which the participant feels are trustworthy to the intent of the narrator. Finally, all participants will be offered the

opportunity to review the transcript and to withdraw from the study up to 2 weeks after the interview.

The participants will be thanked and offered refreshments if the interview occurred in-person. All will be sent a letter of thanks following the interviews.

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Moorabbin
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Participant Information Sheet/Consent Form

Title	Exploration of Doctors' views about suffering
Project Number	14/67L
Project Sponsor	Peter MacCallum Cancer Centre
Principal Investigator	Assoc. Prof. Odette Spruyt

1 Introduction

You are being invited to take part in a research project that seeks to understand how doctors understand and respond to suffering encountered in patients approaching the end of life, and how this impacts on therapeutic choices and clinical practice. You are being invited to take part because you currently work in palliative care and look after people who are seriously ill.

This Participant Information Sheet/Consent Form tells you about the research project. Please read this information carefully. Ask questions about anything that you don't understand or want to know more about.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage before or during the interview and your data can be withdrawn up to 2 weeks after you participate in the study. Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with the principal researcher.
If you decide you want to take part in the research project, you will be asked to sign the consent section and you will be given a copy of this Participant Information and Consent Form to keep.

2 What is the purpose of this research?

The relief of suffering is a core goal of medicine. The aim of this study is to explore what doctors think of the term, "suffering", and how they recognise and respond to it in patients who are approaching the end of their lives. The study will explore what meanings are constructed by the doctors about the experiences and encounters they have with patients whose distress cannot be relieved.

The study will compare the experiences of 16 – 20 doctors practicing in Australia and India in order to identify common and different ways of making sense of these experiences, and the impact of factors such as different levels of resources, culture and settings of care. The opportunity to compare the experiences of doctors working in Australia and India came about due to my experiences of working within both countries over the past 20 years.

The study will provide narrative, qualitative data which will add to our understanding of the ways in which doctors sustain themselves in palliative care practice, through the use of powerful narratives which give life and meaning to their practice.

Currently there is a lack of formal training in how to manage existential pain or unrelieved suffering and a corresponding lack of teaching in self-care. The study aims to inform the training of doctors in end of life care and, in particular, provide insights into the potential for narrative in self-care practice.

The results of this research will be used by the researcher, Dr Odette Spruyt, to obtain a PhD Palliative Care from Lancaster University, UK.

This research has been initiated by the principal investigator and is supported by continuing medical education allowance. It has no other sponsorship or grant funding.

3. What does participation in this research involve?

A flyer advertising this study and an expression of interest form have been sent out through a number of medical associations in Australia and India. The study was also promoted at palliative care meetings. Following your expression of your interest in participating in the study, you have been selected for the study and sent this information and consent form.

The principal researcher will call you to discuss the study further with you and go over this form. If you consent to participate in this study, you will be asked to sign this form and return it to the investigator and we will make arrangements together to set up the interview.

There will be 16-20 research participants in this study, half of whom will be doctors working in Australia and half will be doctors working in India. All will be working substantially in palliative care. The PI is the sole researcher involved in this study but is supervised within her doctoral program by two senior academics of the Faculty of Health and Medicine, University of Lancaster, UK, namely Dr Amanda Bingley and Prof. Carol Thomas.

The Interview
The principal researcher will conduct the interviews. All interviews will follow a narrative interview style. Where possible, the interview will be conducted face to face in a location which is accessible and acceptable to participants. If this is not possible, a Skype video call will be arranged. Participants using Skype should be aware that the internet cannot be guaranteed to be a completely secure means of communication.

Interviews will last one to two hours. They will be conversational in style, assisted by an interview guide. With your consent, the interviews will be digitally taped, downloaded onto a password protected computer and transcribed for analysis.

Five participants will be invited to participate in a second interview, within one month of the initial interview, to add further depth of exploration on this topic. If you are asked to participate in a second interview, this will be conducted with the same care as the first interview. It will be taped, transcribed and analysed as research data. You may however, vary the mode of the interview, for example using Skype instead of conducting it in person.

All participants will be offered an opportunity to speak again one month after the interview, or to send written reflections to the researcher, after the interview, should they wish to reflect further on this topic.

Participants will be offered an opportunity to debrief at the end of the interview and given the contact details of local organisations or individuals which provide counselling to doctors.

The research interviews will be conducted between July 2014 and May 2015. The project analysis and reporting will be completed by December 2015.

This research project has been designed to ensure that the experiences of the participants is represented with integrity and fidelity to the stories told.

There are no costs associated with participating in this research project, nor will you be paid. You may however be reimbursed for any reasonable travel, parking, meals and other expenses associated with the research project visit.

On completion of the project, participants will be sent a brief summary of findings unless you express that you do not want to receive this. This will be emailed to the address given on the EOI form completed, unless an updated email has been received. It is anticipated that this summary will be completed by June, 2016.

4.   What are the possible risks and disadvantages of taking part?

This study carries two main areas of risk to participants. These are the risk of causing distress and the risk that you may disclose conduct which places you at risk of legal repercussions.

Asking questions about your experiences caring for patients who are suffering may cause you distress. You may feel that some of the questions are stressful or lead you to revisit painful experiences. If you do not wish to answer a question, you do not have to or you may stop the interview.

If you become upset or distressed as a result of your participation in the research project, the researcher will be able to arrange for counselling or other appropriate support. Any counselling or support will be provided by qualified staffs who are not involved in this research. This counselling will be provided free of charge.

All participants will be contacted by the PI one or two days following the interview, to check if there are any distressing effects from the interview. Contact details of medical counselling or support services will be provided at the time of interview.

In the course of the narrative interview, you may discuss sensitive areas of clinical practice. You need to be aware that I will need to comply with the legal and ethical obligations of disclosure in Victoria which mandate reporting to Australian Health Professionals Regulatory Authority (AHPRA) when a doctor practising in Australia has practiced unlawfully and placed the public at risk of harm. If there is discussion of practice which constitutes a significant departure from accepted professional standards, this will need to be disclosed.

5.   What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time before and during the interview and your data may be withdrawn up to two weeks after the interview. If you decide to withdraw from the project, please notify the researcher as soon as possible. .

You should be aware that data collected up to the time you withdraw will form part of the research project results. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project. Efforts will be made to extract your data. However, if your interview is more than 2 weeks previously, it will not be possible to withdraw your data from analysis.

6 What will happen to information about me?

By signing the consent form you consent to the research team collecting and using personal information about you for this research project. The personal information that the research team collect and use is information arising during narrative interviews, and demographics such as your age, gender, years worked, ethnicity and your primary medical speciality area.

The information you provide is confidential. Hard copies of any identifying documentation, such as your expression of interest and signed participant information consent form, will be stored, in a locked, research filing cabinet, at the Peter MacCallum Cancer Centre, and accessed only by the principal researcher.

There are some limits to confidentiality and if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and involve appropriate authorities and/or support services. If possible, I will tell you if I have to do this.

All electronic records of research data, including the audio files of the interviews and the typed version, will be retained on password-protected computers in databases requiring password access, either on the researcher's laptop and/or on the researcher's personal folder on the Peter MacCallum Cancer Centre main hospital server which is firewall-protected. The researcher has sole access to this folder. This data will be stored separately from the master list of names and matching codes.

The digital recording of interviews will be downloaded onto a password-protected computer, de-identified, and encrypted in folders or databases requiring password access, immediately on completion of the interview. The interviews will be typed and made anonymous by removing any identifying information, including your name in the typed version.

The interview data will be permanently archived on hard disk and CD-ROM by the researcher. Any other research data will be kept for at least 15 years and then destroyed by incineration or shredding.

The results will be summarised and reported in a dissertation. They may also be submitted for publication in an academic or professional journal and / or presented in a variety of fora. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission. Pseudonyms or exclusion of details which may identify you will be used to ensure anonymity.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

7 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of the Peter MacCallum Cancer Centre and the Lancaster University Research Ethics Committee (UREC) and Faculty of Health and Medicine Research Ethics Committee (FHMREC)

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

8   Further information and who to contact

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the researcher on +61 3 96561918 or any of the following people:

Research contact person

Name	Dr Amanda Bingley
Position	Lecturer in Health Research, Faculty of Health & Medicine, Division of Health Research, Lancaster University
Telephone	+44 (0) 1524 592718
Email	a.bingley@lancaster.ac.uk
Name	Carol Thomas
Position	Professor of Sociology, Director of Postgraduate Research Studies in Division of Health Research (DHR)
Telephone	+44 (0)1524 594092
Email	c.thomas@lancaster.ac.uk

The details of the Peter MacCallum Cancer Centre and Lancaster University complaints persons are:

Complaints contact person

Position	Patient Advocate, Peter MacCallum Cancer Centre
Telephone	(03) 9656 1870
Position	Dr Amanda Bingley, PhD supervisor, Lancaster University
Telephone	+44 (0)1524 592718
Position	Chair, Lancaster University/Faculty Health Medicine Research Ethics Committee
Telephone	+44 01524 592838

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC name	Peter MacCallum Cancer Centre Ethics Committee
HREC Executive Officer	Ethics Coordinator
Telephone	(03) 9656 1699
Email	ethics@petermac.org

Reviewing UREC/FHMREC name	Chair, Lancaster University/Faculty Health Medicine Research Ethics Committee
FHMREC Committee Secretary	Research Support Officer
Telephone	+44 01524 592838
Email	d.hopkins@lancaster.ac.uk

Consent Form

Title   Exploration of Doctors' views about suffering

Project Number   14/67 L

Project Sponsor

                                       Peter MacCallum Cancer Centre

Principal Investigator   Assoc. Prof. Odette Spruyt

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print) _____   Signature _____   Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher[†] (please print) _____   Signature _____   Date _____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

APPENDIX 9. PETER MACCALLUM CANCER CENTRE ETHICAL APPROVAL AUTHORISATION

Peter MacCallum Cancer Centre
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Locations
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Bendigo
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Moorabbin
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PETER MACCALLUM CANCER CENTRE AUTHORISATION TO CONDUCT A RESEARCH PROJECT

Peter Mac Project No: 14/67L

Project Title: Exploration of doctors' views about suffering. A qualitative study investigating the perception of and responses to suffering of doctors caring for patients who are seriously ill

Principal Investigator: Dr Odette Spruyt

Approval Date:	2 July 2014	**Approval Expiry:** 2 July 2016

I am pleased to advise that the above project has **received ethical approval and satisfies Peter Mac research governance requirements** and may now be conducted at Peter MacCallum Cancer Centre. Conduct of the project is subject to compliance with the conditions set out below.

Approved Documents:

- *Protocol version 1.1 dated 16 June 2014*
- *Interview topic guide version 1.1 dated June 2014*
- *Advertisement flyer version dated May 2014*
- *PICF version 1.1 dated 16 June 2014*

In order to comply with the National Statement on Ethical Conduct in Human Research (2007), Guidelines for Good Clinical Research Practice and local research policies and guidelines, you are required to notify the Peter MacCallum Cancer Centre Ethics Committee Secretariat of:

- Any proposed amendments to the project including any proposed changes to any of the approved documents;
- Any unexpected developments in the project with ethical implications;
- Your inability to continue as Principal Investigator and any other change in research personnel involved in the project at Peter MacCallum Cancer Centre;
- Any proposed extension to the duration of the project, past the above stated approval date;
- Any decision taken to end the project prior to the expected date of completion.

You are also required to submit to the Ethics Committee Secretariat:

- An Annual Progress Report every 12 months for the duration of the project.
  Note: Continuation of ethics approval is contingent on submission of an annual report in a timely manner; and
- A Final Report upon completion of the project.

The Peter MacCallum Cancer Centre Ethics Committee may conduct an audit of the project at any time.

Please refer to the Peter MacCallum Cancer Centre Ethics Committee Secretariat website (http://www.petermac.org/research) for access to forms, policies and guidelines and other information and news concerning research at Peter MacCallum Cancer Centre.

Patron: The Honourable Alex Chernov, AC, QC – Governor of Victoria

The Peter MacCallum Cancer Centre Ethics Committee is organised and operates according to the NHMRC National Statement on Ethical Conduct in Research Involving Humans (2007) and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and the Health Privacy Principles enumerated in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

Please be advised that the Principal Researcher and any Associate Researchers named on the application did not participate in deliberative discussions or decision-making regarding the project.

Yours sincerely,

Dr. Dianne Snowden
Ethics Coordinator
Ethics Committee Secretariat
T: 9656 1699
E: ethics@petermac.org

APPENDIX 10. APPROVAL OF AMENDMENT TO PROTOCOL

1. Peter MacCallum Cancer Centre Hospital Research Ethics Committee response to amendment application, 2018

Reply Reply All Forward ▼ · ▣ · ▣ ▣ ▣ ✕ ▣ · ⬆ ⬇

RE: Notification 14/67L v 1.3 Doctors views on suffering

Snowden Dianne on behalf of ethics department

To: Spruijt Odette

                                                                                              29 November 2018 10

Peter Mac Project No: 14/67
Study Title: Exploration of doctors' views about suffering. A qualitative study investigating the perception of and responses to suffering of doctors caring for patients who are seriously ill

Hi Odette,

This activity appears to be post study development of educational materials. The Ethics Committee does not require notification of this activity.

Appropriate consent from participants for use of their image/audio in educational material is standard institutional practice, and not a matter for the Ethics Committee.

Regards,
Dianne

Dianne Snowden
Manager, Human Research Ethics & Governance
Peter MacCallum Cancer Centre

Phone +61 3 8559 7540

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2. Lancaster University Research Ethics Committee / Faculty of Health and Medicine Research Ethics Committee approval of amendment to protocol, 2018

Lancaster University

Applicant: Odette Spruijt
Supervisors: Amanda Bingley and Sean Hughes
Department: Health Research
FHMREC Reference: FHMREC18039

06 December 2018

Dear Odette

Re: Exploration of doctors' views about suffering. A qualitative study investigating the perception of and responses to suffering of doctors caring for patients who are seriously ill

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);

- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

R·E Case

Becky Case
Research Ethics Officer, Secretary to FHMREC.

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How do you recognise suffering?	
Indian Doctors	**Australian Doctors**
Ask	
Most people suffer. So the very clear question is what is bothering you, what is the greatest element of your suffering, and who are we to decide whether their suffering is intense or genuine or unjustifiable or justifiable – that person is suffering, he is suffering So I think though we do pick up some suffering which is nonverbal, unfortunately Indians are very stoic people, so it takes a lot of effort to actually, if you ask them do you have a problem, they tell you the physical aspects You have to ask, if you don't ask they won't, they may not volunteer Ravi We wouldn't use the word suffering honestly speaking but we would possibly ask the patient what do you feel, what's troubling you, in what other aspects of your life can we help you with, it would be something like that, and we keep on asking what else, what else, you know so that, when the physical is over and he says well okay I don't have any other physical suffering, okay so what else then come to the psychological, and if we're very lucky then we come to spiritual Vashti	I'd say you seem to be worried about something, or you seem more preoccupied than normal, or that must be quite difficult, not being able to manage with X. So maybe it's a little bit more round about rather than direct John I suppose probably the starting point for me would be to not assume when a person is suffering, and so as much as possible yeah ask them if they think they're suffering Andrew But I do ask it either a) when I subconsciously or consciously remember to ask it, or b) when the conversation is clearly going down that particular line and it's contextually appropriate to ask it Andrew I might ask you know what are the main things troubling you, what are the things troubling you and those sort of things. But I think there's always, and I often ask about anxiety and worries Luke So are you suffering at the moment, I also wonder what the sensitivity would be, because you might be suffering but would people admit that they are, because it's a big admission John
Listen	
We don't recognise suffering because we don't allow the patient to verbalise what they're feeling. So I	I think in palliative care because a lot of what we do is about listening and talking and the more listening the

How do you recognise suffering?	
Indian Doctors	**Australian Doctors**
think listening to their stories, listening to their hopes, their dreams, their aspirations, some of their disappointments, and this comes with time Nisha What I teach others now is to be good listeners Nisha I think every patient comes with a whole lot of suffering, and to me the thing which we have to keep telling ourselves, and listening to the patient or listening to the family members, is just shut up and listen. Vashti	better so trying to practice listening and letting people tell me stuff and currently we go out and do a community visit and we sit for 40 minutes just listening to people telling us these long sad stories partly because they have to be able to tell, now sometimes they've told 25 different people and they just can't help themselves but often they just need to tell it and get it out there and then you can say okay so where do we go from here and I think that's important and so often I would do that on ward rounds driving the registrar nuts Elizabeth
Rapport building	
It takes a lot of rapport building before they will feel you know motivated enough to share what other suffering they have besides physical. Vashti	but I think I convince people that I'm willing to listen and I'm trustworthy and I think they get the message that message reasonably quickly Ruth
Intuition	
I can sort of see what is going through this person's mind you know, sometimes I feel weird, but that's what I mean by intuition or sixth sense Ranjani Yeah, I think probably it's intuition, I think we're attuned to that sort of thing and we're very receptive when patients are actually suffering Ranjani	It's totally intuitive and it's really difficult to explain to people and that's also part of my educational theory stuff which is the business about the expert who becomes very good at picking up something and says I think it's this Elizabeth if I pick up a sense that they're not telling me everything John

How do you recognise suffering?	
Indian Doctors	**Australian Doctors**
Non-verbal-mannerisms, facial expression	
He's not looking so satisfied, there's something on his face, or something in the way he spoke to his family or the attitude in which he is sitting, and then I feel that maybe we haven't addressed all his concerns Sarita Suffering is not very difficult to recognise, you can see it on the face of the family and the patient, you can see it in their mannerism, you can see it in their emotions and their words which they tell you. Sharma verbal and nonverbal, and I would look more at the nonverbal signs of suffering Vashti	I guess if you're reasonably aware of all the difficulties that people may face, then you should be able to pick up that they're unhappy or distressed, whether they're getting angry or complaining or withdrawn or tearful or – I guess it's an observational thing Tom I think a lot of people are suffering in their own silence, the patients, I think they don't often volunteer a lot of the different parts of suffering from their own point of view. Luke
Behaviours –including difficult, miserable, distressed, angry, withdrawn	
anger was a demonstration of their suffering Nisha So we often find that one of the major symptoms for cancer patients is depression, and this goes unrecognised even by many very well trained oncologists, and the reason is because the manifestation of depression is never direct, so there is an onset of symptomatology onset of, I mean ah, disheartening feeling from the patient, a difficulty in establishing a rapport with the patient, a difficulty in establishing a rapport with the family, which is often not perceived that this is a sign of depression, Ravi	being able to look beyond the immediate presenting sort of behaviours or whatever you want to call them, usually it's when people are you know, you think they're not being very nice or they're being quite difficult or they're angry or they're combative or they're critical, you know what I mean? Eliza it's allowed me to not panic or get anxious or feel emotionally burdened by other people's emotional responses and behaviours, so if they get angry or lash out or they're difficult or you know. But actually recognise what's behind their behaviours Eliza
Imagining what it must be like –Empathy	
Sometimes you know question, for the first time who comes you know, we may not ask this question	If you're, I think a lot of people in palliative care are actually quite profound empaths, probably more

How do you recognise suffering?	
Indian Doctors	**Australian Doctors**
whether you are suffering or not – so depending on the presentation, depending on the presentation for example you know, and depending on the age groups also you know, okay it depends, suppose a mother taking a small child to the OPD and the small child is you know, is suffering for everybody, even for the doctor also. So it is that moment you can sometimes ask you know, so this must be very difficult for you, how are you suffering so much, something like that Praveen	than they're even aware of, so they're reading and tuning into the emotional cues subliminally or consciously, you know the more skilled people do it consciously, but a lot of us are doing it kind of all the time, and also within teams, that's what we do all the time and that's our strength Patricia You get responses within yourself and it's about recognising that Eliza But yeah I could palpate his suffering, his sense of self really, and we never had an explicit discussion about faith Patricia
Obvious	
suffering is obvious, no need to ask that. Sarita	

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
Forming connection: bringing in emotional engagement; communication; human-to-human	
The other thing I would probably look at is um, what are the things that they're interested in and what are their hobbies, or what would they do, going back, or what they ate in the morning, a simple question, and then I would sort of expand that and say oh you like that specifically, so what do you like about it, you know, so that they get talking, or a particular dish Ranjani	Yes if I thought the patient has got terrible suffering trying to work out whether there was any, if I couldn't connect to them whether there was anyone else who could connect. He was absolutely tell me about who's this picture of you as a young person, what is it. So that sort of stuff, trying to connect back in to the other part of their life or you know their own trajectory or to someone else who's interacted with them who can connect Elizabeth
No, not really but maybe except to point out that I would consider a few things a basic requirement for this, like this means certainly building that relationship, which needs that I need to have respect for that person, without that I cannot build that relationship. (LONG PAUSE 5 seconds). I need to have an unconditional approach, I shouldn't be judgemental. (LONG PAUSE 5 seconds) I should certainly have empathy, but at the same time I should remember that I cannot possibly put myself in his position completely, I am handicapped by being a different person. (LONG PAUSE 5 seconds) And I should, and I not should, must, must, must not impose my personal convictions on him. So without these basic rules I suppose the person may still sit there and smile and answer my questions, but they will not connect with me Abhit	I think actually that's one of the differences between you know when you're talking to the referring doctor and they say oh look I don't know how many times I've told them their prognosis, it's not like it's anything new and you think well they got it when I said it and I think it might be because I'm a warm communicator and there are cool communicators who can do it as well but I think I do bring that emotional engagement to the conversation Ruth

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
I think giving them the chance to talk, and areas that less people talk about, and listening to them, seeing them, and genuinely listening and not just making the motions, not going through the motions, just listening to them genuinely, and I am fond of people, I'm genuinely fond of people, I'm not just praising myself, I'm fond of people Sarita	the music I think I use a lot of music in my – and so it's a roundabout way of answering the question that I think I use that kind of communication like a slower more you know less cerebral means of communicating with people just to kind of try and find a different bit of their brain that might express the suffering that's not really allowed existence in the neo cortex or something Ruth
So then I tell them no I belong to that area, they become more comfortable. So there are these small things, and I know the name of the village, I know which train goes there, or what time, which monument is there in that area, or what market is in that area, what sort of food they eat, so this is the familiarity which makes them to confide a bit more as compared to others. So they become more open and tell things a bit details Sharma	But I mean I don't think there's any doubt that there's some, there's people who can actually you know be in a very subtle and skillful way tease out what's bugging people and what's making them suffer or unhappy, and find ways of helping them. Whether it's you know whatever dimension we're talking about, in terms of expectations you know their beliefs, the information they have that may be misguided or incorrect, their worries about things you know and all these holistic dimensions, I think – and I think doctors make mistakes when they think they're just there to do their job, and a lot of patients actually want a sort of personal connection with, and feel that the doctor is a human being and shows their human side and their vulnerability to an extent Tom

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
So I've noticed that the moment you smile and have a light conversation, immediately they just loosen up you know, and they become light and they say yes doctor like what do I do, I've been suffering and none of you seem to be helping me, then their tone completely changes. You know so there is some amount of relief in their suffering as well I feel, so I think humour is a very good tool to probe as well to kind of bring them out a little bit from suffering Ranjani	
Listening	
I think giving them the chance to talk, and areas that less people talk about, and listening to them, seeing them, and genuinely listening and not just making the motions, not going through the motions, just listening to them genuinely Sarita	I think that's how I try and engage with the suffering is just to sort of take it sort of seriously and slowly and leave massive gaps in the conversation to the point where the poor registrars feel they need to jump in and you know damp the eyes of the patient with a tissue and pat them on the back and say there, there it's alright. look what M's done she hasn't said any words she's just kind of made a noise and sighed or something and I think I do a lot of that you know just kind of like oh you know Ruth

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
so it sometimes makes sense to move the family out of the room and say I would like to examine the patient, but put the patient on the couch, don't examine the patient immediately, ask them about their many other issues which suddenly crop up. So you may actually hear a whole new story from the patient of what the logistic problem, what was the problem in coming to the hospital, what's happening at home, why wasn't she brought, why wasn't she brought earlier or later and things like that Ravi	Well that's one of the reasons I think why it's easier when you're older because you've done some being with a bit of luck and you've worked out who you are and how you are and how you work and things so I think that probably helps and it's trying to get them to realise that they have to sit down, they have to listen, they have to just be and let this stuff happen and let people tell you stuff about their worries, about what's going on, about what they think might be happening or might not be happening and trying to help them by yes the opiates and yes making sure that they're not vomiting all the time but also that the stuff that they're worried about underneath is being heard and even if you can't fix it, because their daughter's run away with someone they really don't like and they think is awful, that you're valuing this as a really important part of who they are and what bothers them. Yeah the therapeutic, the person as the therapist, probably more as a communication tool, the communication as the therapy and I think in palliative care because a lot of what we do is about listening and talking and the more listening the better so trying to practice listening and letting people tell me stuff Elizabeth

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
We don't talk much, we just hold them and they pour out, they cry maybe 1 or 2 minutes they ventilate, and then they say certain things, they want to meet people or maybe they open up saying that maybe I was not good – it's what they do, we just have to be there and acknowledge what they're going through, and then we say, if she says that I feel very bad, you can ask what do you feel bad about, we never tell no, its not like that, you should feel, no no no, not like that. This is just listen most of the time and go along with the conversation, make small small gestures that's it Joseph	Not that you have to fix everyone's problems for them, you can't you know, but at least if you listen and support, then people will be able to – I mean they say that most people can actually find their own solutions to their difficulties Tom
but yes I will listen to them for a long time and I'll allow them to speak and I'll see how it goes, I mean whether I may not be able to help as an intention directly. Sarita	
Holistic care	
I learned a lot from that, that we learned how to manage some of the social problems. For example, because I felt that the suffering was mainly due to poverty, and not just income poverty, but poverty of opportunity, lack of opportunity yeah. So we built in very large awareness meetings, and so went into villages and schools trying to tell them about palliative care, and also tell them about how to prevent the most common cancers, like oral cancer, or self-examination of the breast. So we went into preventative care, got 1 or 2 dentists involved who could do early detection. So most of our men had head and neck cancer Nisha	but you want to tell me how proud you are of some aspect of your life and I'm not going to find out about the vomiting until I see you as a human, so if I acknowledge you as a human then we've got some kind of human-to-human thing going on and we might be able to then address the suffering. Ruth
Seeing the suffering being willing to see it	

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
I suppose it was by being brave and not turning your backs to that suffering I do believe that as a medical student or as a young doctor, what we learned from our seniors and peers, they really did run away from the suffering, turn our backs to the suffering and just look at the diseases. I suppose that's the way most people somehow live with our medical and nursing practice, 'there's too much suffering, if you try to see it, you are in trouble. Just build a wall, let the therapeutic distance grow to 2 miles, look at only the disease with that telescope and treat it'. Abhit	I think we do just get, I think we attune to it and sometimes we just get very good at choosing who we. Ruth I think we attune to it and sometimes we just get very good at choosing who we – because I think the surgeons hear that stuff too but they hear it with, and some of them are fabulous, but they hear it with a lens of oh well if I go down that path it's going to take me 5 minutes longer so it's not that they're any less attuned, because they are they know where not to go Ruth
I think approach in palliative medicine is totally different, that is there, because we spend a lot of time with patients and we actually look at the suffering that they go through, Ranjani	– I think the first thing you know, the authentic response is actually is to respond to it. It's like oh my God you know that's awful, or I mean it's not a form of words but that's the authentic thing is to actually [PAUSE] to let the person know that that's landed, that you've got it, that you can really see them and their situation and that you can, you're aware of that, fully aware of it Patricia

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
I mean I think I see it now I didn't think that there was much difference earlier, but your junior person might just see the wound, and may not see the effect that wound has on the whole quality of life and the whole day and the suffering, they might just see the wound and give metrogel dressing and dressing for the maggots and counsel the family about how to heal the wound – but what it's doing to her? Sarita	maybe the obvious things such as the patients and what's going on, to other deeper things such as the staff responses to what they're seeing, I'm still not sure that I understand it all fully, but whether it is this you know, it's like the western, dare I say it oncologist response, who becomes either immune or burnt out to what's going on, and you know they operate just on the, at the level of prescribing the next lot of chemotherapy, and I'm not sure that I fully understand it all but I do – I suppose I've tried to remain open minded or accepting of whatever they might be going through… Andrew
Being there, being with, accompanying, witnessing	
so it's imperative that you can't bring every patient into the hospice, it is not possible, you can't be present in every patient's house, so you need to recruit their help and teach them how to do things, and you need to have your mobile phone on all the time so that they can call you whenever, more than one mobile phone on, so that they can call you for any assistance which they may need to take care of breakthrough pain, take care of troublesome symptoms from morphine. So those are pretty important to understand, so you need to keep yourself open. And most importantly unless you take the family into confidence, the whole scheme doesn't work, it falls apart Ravi	There would be both, there would definitely be both, and the you know, and we're always debriefing on cases where we feel that we didn't help, and it's about learning to recognise where you did actually help and actually just sticking with it, because many teams don't, you know whereas we hang in there and we remain present and I think that that, and often you get those feedback later when you realise the value of that, you might get feedback from relatives. And you know, just I suppose not so, people who feel that life is just you know, you're just being present and not running away from the awfulness of it I think can, I hope is a comfort to people Eliza

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
	And you're saying I'm not scary, I'm kind, I'm nice. And so there's complexity there in that, but we do some of the accepting for them, that's what I feel like we do, without confronting them with it or without forcing them forward, just to help them be in that place, they can't avoid being there anyway. To keep them a bit of company yeah because mostly Patricia So its not just witnessing suffering, it's witnessing the whole life and the personhood that's come there Patricia
	Oh no it's like bearing witness isn't it you know you bear witness to people and that's part of it you know having somebody to – you know I think a lot of suffering is about being understood or having your condition understood and so feeling that you're being understood by somebody like a doctor is quite important to people and particularly if that helps you know in other ways, you know just that in itself can help suffering feeling like you're seen, feeling like you're understood, feeling like you're accepted. Ruth
Healer	
You can, the idea comes back to you when after the death of the patient you ask to come for a memorial, by the time, that means you have healed. So this is a sort of thanking the caregiver, thanking the physicians, the nurses, the team which attended on the patient, so we thank you for having been there to take care of our patient, and we hold no animosity to you and we are happy that she passed away or he passed away	Yeah I mean I think there's things that I feel responsible for but there's also lots of things that I realise I can't. So I suppose I've really, I think I've changed on a journey from this idea of a Hippocratic or you know, a medically involved external model of fixing things, to more of a, this idea of a healing model of trying to you know, allowing people to make their own decisions and allowing people to decide what they want. And I certainly think now, I

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
peacefully. So it's a healing process, that means everybody in that family could lay to rest their suffering Ravi And so suddenly the patient will burst into tears in front of you and may want to make many other things, so once that emotional outburst is there and they start crying, that means that is the beginning of healing emotionally. You bottle up your emotions you put a very stoic face, that means you are actually ready to burst like a volcano – so those are the people who are pretty depressed, pretty emotionally uptight and they do very badly. I feel those patients who actually come down once in 3 weeks, once in 3 months to cry on your shoulder, they do better, they live longer Ravi	think as a doctor now I'm much more, I much more have an approach that I suggest things to people but I realise that for many people who want control, they won't do what you say they should do first up, you let them have time to decide whether they want to do that or not, and if they choose to do something completely different, that's okay with me as well in the whole setting and you know, that's their choice along the way I think. Luke I guess that is the not so much healer because we're not going to be able to heal them but perhaps healing their soul or helping them work out where they're going by allowing them to reflect on where they've been and what's happened and so that you're sort of connecting the arc and you're not just saying oh we've got you here and this is what you're going to do Elizabeth And they're looking for care, which I guess are similar, but in fact healing isn't a bad concept to use, because even if you can't fix the problems, you can actually allow people to achieve some sort of peace, and if you want to say healing Tom
Mending relationships	
I think suffering is a total imbalance in what a person would consider as their normal life, their normal activities, so anything that disturbs that balance would be suffering. It doesn't necessarily have to be a physical symptom, but something that is a disturbance even in relationships	Another one I remember who I would describe as suffering was a 50's English woman with a son who had been 30's perhaps … it seemed to be just the two of them and she didn't want to die and she didn't want to talk to anyone about anything and was impossible to talk to Elizabeth

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
within the families when they're sick Nisha We had one patient with a very large wound a buccal mucosa cancer and very large wound, and his wife was adamant, she said there is no way I'm going to look after him and it took almost 6 months for us, and I have a beautiful picture of her holding him just before he died Nisha we also reconciled her with the neighbours, we had an awareness meeting in the village, we said that this is, she is not well, but it is not a contagious disease, and she's in a lot of pain because nobody is visiting her, she is very lonely. So the neighbours got together and at Devali, they whitewashed her house and there was a little Devali function in her home, just before she died Nisha	
Helplessness	
And I totally feel helpless, totally feel helpless and I'm sometimes, not sometimes, most often I wonder what am I doing here, you know, what is our role. Even with that, of course when they have a problem they turn to us and they call us and they ask us and things like that. But even with that, how much suffering are we actually relieving I have no idea Odette, you know so it really troubles and what are we trying to do here is a big question mark. Ranjani	
Recognising limits and boundaries, the unfixable, learning to work with that, links to healing	

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
you and I and our colleagues have chosen not to do that, but to see the suffering, remove what we can, and then live with the rest. Abhit	You can observe, you can witness, you can respond authentically, but it's actually not your life story, it's theirs, and some people's lives are just very hard you know. And it's not just the people we see it just happens. So to me to be effective you actually need to have that boundary and the boundary is not one that says I'm not going to be present for that person, it's actually just acknowledging that it is isn't fixable, and when you do that then you can actually still be there. But if you're trying to fix it or you're feeling responsible for it, then you actually get, you get drawn in and it can be very destructive so Patricia
sometimes A, my colleague, says it's not your job to get so friendly, it's not your job to get so friendly, because you're a doctor and you can't maintain that relationship Sarita Sometimes I think he's right because there has to be some boundary, surely, between your professional thing, and I shouldn't get so pally with them that they can, I don't know where you draw the line. You're talking about palliative care and talking about exploring the family concerns and social support and who's an important care giver, and then you say that – I mean you can't tickbox form, family, 3 children, that sort tickbox. I mean, you talk to them, they're genuine, they're people and you're trying to get to know. But then where do you draw the line between being the professional care giver and I don't mean friend, but yes you want to be considered – I mean I don't know, because a lot of my friends that you're getting too close to	And that the person themselves can only, they're the only ones that can heal themselves and you're there to help them on the journey and some people will be healed, die healed and some people won't die healed and it's not really whether they died healed or don't die healed, it's really about how well you're giving them the opportunity to do that. And you know, what I would see as a big role for us is to try and help physical symptoms to help with their ability to heal, because it's very difficult I think to heal in a broader holistic sense if you're physically in a lot of discomfort. And then while you're dealing with that I think it's also important to deal with holistic other things, like you know the psychological stuff, the social stuff, the cultural things, the spiritual things, I think they're all really important to try and help in the healing sense. And I actually, that's what I try and teach my trainees and talk to them about this idea of healing where it's not your responsibility to fix everything, it's your responsibility to allow the

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How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
them, one of my surgeon colleagues whom I'm fond of and I respect, he said it's not your job to get so close to patients, it's not in the job description to be so friendly and to get to know the dog's name, you shouldn't get that friendly, I don't know Sarita	opportunity to happen, you have to let it happen and not happen. Luke that's the whole point of the suffering is that it's not fixable Luke
Developing skills to be present without being overwhelmed	
the moment you shift to the other bed, you may not have, here's another one, we don't remember, so detachments I feel it's over the years that's happened yeah Joseph	You're not letting go in the sense that you're abandoning the person. I think that's the, maybe that's the mental thing you have to do, by not carrying this person's pain away with me in my own body, and you know in my own mental world, I'm not abandoning them. You can be completely with someone, you can completely take on board their situation, you can be completely open to whatever they want to tell you, or whatever you can [PAUSE] learn of their situation through all the inputs that happen when you sit on someone's bed or you visit them, and then respond you know with your whole professional and human kind of capacity, you know give them the best that you possibly can, and then you can walk away and discuss it with someone else in the hallway, and that doesn't mean that you weren't there for that person 5 minutes ago' Patricia

How do you respond to suffering?		
Indian Doctors		**Australian Doctors**
Physical relief		
	Ensuring supply of morphine Ravi More so if the patient has say something like cervical cancer which is eating into the lumobosacral plexus, the patient has got spinal metastasis and is bedridden, you can't ask them to bring the patient to the hospital. So even if the family member comes with the outpatient card and for the morphine prescription we'll renew it, so we will still honour it' Ravi	she had a gynaecological malignancy, a vulval cancer and yeah she was just paralysed by severe pain and was just rigid standing up, …and so it was lovely to see that morphine can relieve physical pain Andrew
	Umm, most unfortunately morphine as I said is not freely available, but it's still available in liquid form in India, so ah, the liquid form is actually quite cheap, so you can actually supply it and get the supply through the WHO free supply, so that you can give it through the nasogastric tube so that they can relieve of at least pain. Once you relieve them of the pain then you gain their confidence, that now they're looking forward to good nutrition, keeping their mouth healthy, preventing super infection and preventing the sloughing of the tumour and leading to a catastrophic bleeding. (interrupts) And if you control the pain then actually offer some form of metronomic chemotherapy, sometimes it works, sometimes it doesn't Ravi	

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
Detailed and meticulous assessment	
I think you know being very meticulous and detailed, sometimes when you are doing the same thing over and over again, it becomes like filling out the medical records, and that's the end of that. But to continue to have that passion, to delve into areas that maybe uncomfortable but might be causing suffering. So it could be physical, but really thinking of all 4 dimensions that are described in palliative care, not forgetting the spiritual aspect depending on the faith of that person, and not forgetting the social part of it which sometimes you know people I've seen here in India say well the social part is beyond us, we can't help with that. But we can help with this RSVY scheme, we can help with the widow's pension, we can help people illiterate people fill out forms, so being very meticulous in all 4 areas. So I insist on that, and I think if you're very detailed and very meticulous in doing that for every single patient, I think we can relieve a large proportion of the suffering Nisha	
We separate out the psychological suffering, the social suffering, the spiritual suffering, also – so all of us kind of try to spend time in breaking up these aspects of suffering, because otherwise we get lost in the physical and we don't go beyond that Vashti	

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
Clinical expertise and team work	
with a combination of things when you don't have an opioid, with a combination of medication, you can keep the patient very comfortable, which is what we have found in our 5 services that don't have morphine. Nisha But to continue to have that passion, to delve into areas that maybe uncomfortable but might be causing suffering. So it could be physical, but really thinking of all 4 dimensions that are described in palliative care, not forgetting the spiritual aspect depending on the faith of that person, and not forgetting the social part of it which sometimes you know people I've seen here in India say well the social part is beyond us, we can't help with that. But we can help with this RSVY scheme, we can help with the widow's pension, we can help people illiterate people fill out forms, so being very meticulous in all 4 areas. So I insist on that, and I think if you're very detailed and very meticulous in doing that for every single patient, I think we can relieve a large proportion of the suffering Nisha	And then there's all that stuff in – that sort of supervision, debriefing, the in-house lectures we have on, our pyscho-oncology service is brilliant so we are very lucky really that we – this is an area that they are constantly reminding us of, when we are saying "oh this was awful I found it really difficult" Eliza
That's why we use the volunteers to rapport build initially, and then the social workers also look at the social side of it, and spiritual I think all of us try and you know all of us try and find out where does that existential suffering of the patient, and the family also Vashti	there are some team issues in this department that I won't go into, because it's possibly not relevant, but I mean I think all teams have the potential to have issues, and people going off on their own you know. And everyone's quite busy, very busy at times Tom

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
Social care	
and I suppose though we did not put that into words at that time, we recognised that pain and suffering was not only a physical problem and therefore the solution had to come from the society at large Abhit	
So yes I do feel that if we are not really providing holistic care unless we are individualising the problems of each family, not just the patient, but the family as well. For example facilitating or expediting a marriage, so very often a woman who is dying will tell us I really want to see my son married, and since the arranged marriage system works here so well, you can arrange a marriage quite quickly Nisha We sort of talk to the family and talk about you know the caste system and okay where would you find a bride and could you do them a wedding early But we fortunately have many donations of clothes, so we can provide the family with quite nice clothing for a wedding so that they don't have to spend on that, yeah Nisha	
Narrative interview	

How do you respond to suffering?	
Indian Doctors	**Australian Doctors**
I mean the person coming out with what his life story, his story, which has now got broken now with the disease. That is a sense I think, without that you cannot possibly do a spiritual assessment, and support. So it's the same thing. I totally understand you and I am sure that without doing that, psycho social spiritual support is not possible. But how much we are able to do is variable, and very clearly it is a very expensive treatment modality' Abhit	
Dignity	
But then, we we need to have some dignity towards life, so what my personal viewpoint is, that you must provide that dignity for that dying person, to say, yes I have lived my life, yes there are people who care about me in this life, there'll be people who think about me, I'll be in the hearts of people even after I leave this physical world, that's fine Ravi	