

**MEDICAL CONCEPTS OF DEPRESSION IN THE
PALLIATIVE CARE SETTING: PERSPECTIVES FROM
PALLIATIVE MEDICINE SPECIALISTS AND
PSYCHIATRISTS**

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This thesis is dedicated to my grandmother, Miranda Ko, whose relentlessly persistent attitude to learning has always been an inspiration to me.

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ABSTRACT

Depression is one of the focus areas within the scope of palliative care, but its conceptual ambiguity poses many challenges for clinicians. This ambiguity is arguably more pronounced in the palliative care setting, given the confluence of advanced illness and potential psychosocial, existential and spiritual ramifications at the end-of-life. The existing literature indicates that clinicians hold various notions about depression, which could impact on the diagnosis and treatment of depression. Similarly, conceptual diversity is evident in the palliative care research literature on depression and precludes meaningful meta-synthesis of their findings. This core problem of concept forms the topic of this thesis, which reports on research that explored medical concepts of depression in the palliative care setting.

This thesis is comprised of three studies and is presented in publication format. Study 1 was an exploratory study and a prelude to the other studies. Through the use of a questionnaire, it explored broad concepts of depression that were held by medical practitioners practising in palliative care. In addition to demonstrating conceptual variations, it identified some areas of conceptual differences specific to depression in the palliative care setting, which contributed to the design of Studies 2 and 3. These two studies sought to understand and characterise the conceptualisations of depression from the respective perspectives of palliative medicine specialists and psychiatrists working in the Australian palliative care setting. These medical specialist groups were chosen for their recognised expertise and authority on end-of-life medical care and depression. The two qualitative studies used purposive sampling, a semi-structured, in-depth interviewing technique, and the theoretical framework of Kleinman's Explanatory Model. Thematic analysis was performed on verbatim transcripts.

The findings of the three studies are presented in the form of five papers. Paper 1 reports on the questionnaire study, while the other four papers report on selected aspects of Studies 2 and 3, as determined by the chief thematic domains that were identified through data analysis. The contents are organised in the following manner: Paper 2 focuses on palliative medicine specialists' concepts of depression; Paper 3 on palliative medicine specialists' causal explanations for depression; Paper 4 on palliative medicine specialists' treatment approaches for depression; and Paper 5 on psychiatrists' concepts of depression.

In this thesis, it is demonstrated that depression was not a unitary concept among medical practitioners in the studies, but varied within and between medical disciplines. For palliative medicine specialists, depression involved divergent ontological perspectives that called for an absolute judgement on normality versus pathology on the one hand, and contextual understanding on the other. These perspectives were difficult to unite and gave rise to anxiety over diagnostic boundaries and errors. In comparison, psychiatrists more overtly articulated the heterogeneity of depression and accommodated its multifarious natures using different conceptual models. Specific challenges were highlighted for depression in the palliative care setting, relating to its conceptualisation, diagnosis and treatment. A direct link was also supported between the concept of depression, its causal explanation and treatment approach.

The findings of this thesis have implications for future research on depression in the area of palliative care, developments in treatment guidelines for depression in this area, medical education and professional development for palliative care clinicians, service models for the interfacing of palliative care and psychiatry, and developments in psychiatric nosology and causal explanation frameworks. Furthermore, the central relevance of conceptualisation to clinical practice is illustrated.

THESIS DECLARATION

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in my name, in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission in my name, for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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Felicity Ng (PhD Candidate)

Date

CHAPTER 1 INTRODUCTION

1.1 Overview of thesis

Depression is widely regarded as a commonly encountered clinical problem in palliative care, but is also a nebulous concept that lends itself to various interpretations. The boundary between depression and emotional suffering has been an enduring subject for contemplation, debate and research in philosophy and in health disciplines. In the palliative care setting, the demarcation is even more obscure, given the potential afflictions and emotions that may emerge at the end-of-life (EOL). The EOL milieu can amplify the ambiguity of depression as a notion, and therefore the diversity in conceptualisation for both clinicians and patients. Diverse understandings can lead to inconsistent clinical approaches to depression, with implications for detection, intervention and patient outcomes. This ambiguity, when paralleled in research, generates confusion in the interpretation of the literature.

This thesis focuses on research that examined the ways in which medical practitioners think about depression as a concept in the palliative care setting. The research firstly set out to explore, through the conduct of a questionnaire in Study 1, broad concepts of depression at the EOL as held by medical practitioners practising in palliative care. It then set out to encapsulate the contemporary understandings of depression that were held by palliative medicine specialists (in Study 2) and psychiatrists (in Study 3), using a qualitative, in-depth interviewing methodology. These two target stake-holding groups were chosen on the basis of the relevance of their recognised expertise to the topic under study.

This thesis is undertaken in publication format, that is, the format of a portfolio of papers that have been published and/or submitted for publication and/or are written in publication style. There are a total of five papers in this thesis, with one reporting

results from the questionnaire, three reporting on key aspects of interviews with palliative medicine specialists, and one reporting on interviews with psychiatrists. Each paper forms a chapter in this thesis. At the time of writing this thesis, the papers were either published or under review with peer-reviewed journals, and their publication status are stated at the start of the respective chapters. The published papers are included in the Appendices (Appendices H, I and J), and presentations I have given during my PhD candidature are listed in Appendix K. This introductory chapter contextualises the research topic and outlines the research questions and methods. The concluding chapter integrates and discusses the main findings and research methodologies of this thesis.

1.2 Terminology

Some key terms that are used in this thesis need to be qualified at the outset.

Depression

The term “depression” in this thesis refers to the clinical usage of the word in medicine. It is not assumed that “depression” corresponds to any specific diagnostic label or represents set manifestations or subjective experiences. This broad definition of the term is necessary in order to explore the variety of concepts that medical practitioners apply to depression, which is the crux of this thesis. This matter will be further elaborated when epistemological assumptions are discussed in Section 1.7.2.

Palliative care

There is currently a lack of international standardisation of the terminology used to describe non-curative medical care, with overlapping terms such as “palliative care”, “hospice care”, “terminal care”, “end-of-life care”, “comfort care”, “supportive care”, “supportive and palliative care” and “pain and palliative care” being variously used to refer to this field.[1-3] This profusion of terms partly arises from the evolution of

palliative care in its scope and specialty status over the past several decades, but also reflects the substantial regional variation in the use of terminology.[1-4] The term “palliative care” was introduced by Balfour Mount in 1973,[4] and has since received multiple organisational definitions.[2] The most widely applied definition of palliative care is from the World Health Organisation (WHO),[2] which states that “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”[5] Inherent in this definition is the notion of a holistic approach to the care of those who are facing life-limiting illness, and a focus on symptomatic relief and optimising quality of life. Whereas palliative care historically commenced at the end of curative treatments at advanced stages of life-limiting illness, the current practice standard aims for its earlier introduction in conjunction with treatments that are given to prolong life.[5] In this thesis, the term “palliative care” is used to refer to the clinical setting where patients are receiving an approach of care for life-limiting illness as defined by WHO,[5] and does not imply that this care is provided by any specific health professionals or in any particular place such as hospices, hospitals or in the community.

Palliative medicine

The term “palliative medicine” is not synonymous with palliative care. Whilst the latter refers to an approach to care provision, palliative medicine refers to the medical specialty that is devoted to expert medical knowledge and skills in palliative care. The definition of palliative medicine that is used by the medical professional training bodies in the United Kingdom and in Australia is “the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life.”[6,7] In Australia,

medical practitioners must be accepted into the palliative medicine training programme and complete stipulated training requirements before they can be professionally recognised as palliative medicine specialists (also referred to as palliative medicine physicians). However, medical practitioners can work in palliative care services as non-specialists, for example, in the capacity of pre-vocational junior medical officers, trainees in palliative medicine, career medical officers who have not undergone specialised training, and general practitioners. In this thesis, the terms “medical practitioners in palliative care” and “palliative medicine practitioners” refer to both specialist and non-specialist medical practitioners who work in any palliative care setting.

Primary care palliative care providers and specialist palliative care providers

Palliative care is provided in both primary care and specialist settings. Primary care palliative care providers are “health services and staff that have a primary or ‘first contact’ relationship with the patient with a life-limiting illness”,^[8] and are commonly the main providers of palliative care. Specialist palliative care providers are accredited health services and professionals who provide “consultative or ongoing care for patients with a life-limiting illness” where a higher level of expertise is sought for patients with complex needs.^[8]

End-of-life

The term “end-of-life” (EOL) does not have a universally agreed definition and can be used to describe different periods in a person’s life, ranging from a narrow interval of the hours or days preceding death, to a broad interval between entry into old age and death. In one study that examined terminology within the palliative oncology research literature, no definition of EOL was offered by any of the 386 articles that was identified to use the term.^[2] According to the U.S. National Institutes of Health’s State-of-the-Science statement, EOL is marked by the presence of a chronic

disease, persistent symptoms or functional impairments that require care and can lead to death.[9] The definition that is offered by Palliative Care Australia, the peak national organisation which represents the field of palliative care, is “that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.”[10] This is the sense in which the term is used in this thesis, and is sometimes used as an alternative phrase to describe the period of time during which patients receive palliative care.

1.3 Background

1.3.1 The fundamental dilemma of depression in palliative care

Depression is widely recognised to be a common clinical issue in the palliative care setting,[11-14] although its prevalence has been difficult to estimate due to the diverse definitions and methodologies used in the research literature. The first extensive systematic review published in 2002 found a prevalence range of 5.6% to 32% for all depressive disorders in the palliative care population, based on studies that assessed depression using diagnostic criteria and/or diagnostic interview. The prevalence range reduced to 5% to 26% (median rate of 15%) when the diagnosis was restricted to Major Depressive Disorder (MDD) as defined by the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), and moderate or severe depressive episode as defined by the *International Classification of Disease* (ICD).[15] More recently in 2011, a meta-analysis of psychiatric interview-based studies in the palliative care setting reported prevalence rates of 24.6% for “any depression” (consisting of DSM-defined major depression, minor depression or dysthymia), and 16.5% for “syndromal depression” (consisting of DSM-defined major depression or ICD-defined major depressive episode).[16] Regardless of the individual diagnostic labels and their prevalence figures, the literature suggests that depression commonly occurs among patients who are in the palliative phase of care.

Depression has been linked to various undesirable clinical features and outcomes. In the palliative care setting, it has been associated with somatic symptoms such as pain,[17,18] fatigue,[17,19] poor sleep[20] and mobility.[17] It has also been associated with lowered functionality,[18,21] reduced quality of life,[17] lengthier hospitalisation and hospice care,[12] and earlier death.[22] Among patients with terminal cancer, depression and hopelessness have been identified as the strongest predictors for a desire for hastened death,[23,24] but an association between depression and request for euthanasia is not established.[25] Although these associations do not indicate causality, they intimate the potential extent of the adverse impact of depression not only for patients at the end of their lives, but also for their families, health care providers and systems.

Despite the clinical significance of depression in the palliative care setting, it is often raised as a problem that has not been adequately addressed.[12,26-30] This was highlighted by an Expert Working Group report from the European Association of Palliative Care in 2001, which emphasised the under-detection and under-treatment of depression as a major shortcoming, and made recommendations for improvements in detection, training and treatment of depression in this setting.[29] Subsequent to this report, depression became one of the three focus areas of the European Palliative Care Research Collaborative, alongside pain and fatigue. This initiative was formed in 2006 and aims to improve the classification, assessment and management of depression through the implementation of evidence-based clinical guidelines.[31] The first set of guidelines was published in 2011, and although comprehensive, also highlighted a paucity of evidence in the areas of prevention, detection and treatment of depression in the palliative care population.[32]

A number of general obstacles have been proposed to hinder research in palliative care. These include ethical concerns about consent, vulnerability of patients and

subjecting them to additional burden, and logistical issues such as access to patients via “gatekeepers”, mental competence, life expectancy restrictions, and high attrition rates.[32-35] For research on depression in the palliative care setting, an additional obstacle is the lack of consensus on definition. There are at least two concurrent paradigms for conceptualising depression in clinical practice, namely, as a phenomenon of depressive symptoms and as specific depressive disorders that are defined by diagnostic criteria.[29,36] This mixed conceptualisation is reflected in the palliative care research literature, where diverse definitions of depression have been used.[15] In fact, a systematic review of the literature from 1970 to 2007 identified a total of 106 different assessment methods used in 202 published studies, which included single- and two-item screening questions, general health screening questionnaires, depression inventories, clinical interviews, unstructured and structured diagnostic interviews. Many studies did not define depression, and where case definitions existed, these were mostly based on cut-off scores for various general health questionnaires and depression inventories. Diagnostic criteria such as the DSM classifications were less frequently employed, and when they were employed, were often modified or incompletely applied.[36] This assortment of definitions makes findings in the literature difficult to compare and interpret as a whole.

Prior to the research undertaken for this thesis, there had been no published research that primarily focused on the definition of depression in the clinical palliative care setting, although a few studies had investigated how medical practitioners diagnosed depression in palliative care patients and suggested that definition was also variable in clinical practice. A questionnaire study conducted in the United Kingdom showed that palliative medicine physicians approached the assessment of depression in different ways. They placed different weightings on symptoms that they considered to be most useful in assessing depression in palliative care, but anhedonia was notably omitted.[37] A similar questionnaire study conducted a decade later in Australia and

New Zealand found that its sample of palliative medicine practitioners overwhelmingly favoured clinical interview for the diagnosis of depression and, compared with the UK study, emphasised different symptoms that were considered most useful in diagnosis. Of significance, a substantial portion (42.8%) of the respondents did not consider DSM-IV diagnostic criteria to be useful.[38] The respondents from both questionnaire studies relied on non-somatic symptoms in the diagnosis of depression.[37,38] In a study from the Netherlands, focus groups were conducted with family physicians to explore their opinions regarding the assessment and management of depression in palliative care patients. The family physicians described a diagnostic process that involved clinical judgement and “gut feeling”, based on interpreting symptoms and signs against the patient’s personal background. They did not rely on screening tools for depression, and viewed the DSM-IV definition of major depression to be incompatible with the palliative care context.[39]

With such diversity in the conceptualisation and definition of depression, the ambiguity of depression as a concept is a fundamental problem that compromises efforts to promote consistency in the clinical approach to depression in palliative care and to further knowledge through research. However, this conceptual ambiguity is not unique to palliative care, as depression has never been a stable concept throughout the course of medical history.

1.3.2. Shifting concepts of depression in medical history

As a diagnosis, depression is a relatively recent phenomenon from a historical perspective. Despite the semantic association, the concept of melancholia in classical antiquity was not the predecessor of depression, and was instead a form of insanity that was unconnected with affect, understandable only within the framework of the humoral theory, and has no contemporary correlate.[40-42] In the 19th Century, however, the concept of melancholia underwent major changes in the context of the

prevailing philosophical, epistemological and social milieus, and emerged as an illness primarily characterised by inhibited emotions.[40-43] Other diagnoses, such as “neurasthenia” and “mopishness”, also emerged to describe emotional or nervous exhaustion.[44] The term “depression”, with its physiological connotation of a lowering of mental energy, was borrowed from cardiology and was initially used to convey a lowering of spirits that was ideationally distinct from melancholia, although the two terms eventually became synonymous by the early 20th Century.[40,43-45] Since then, depression has become the dominant term to describe disorders of low mood, as other terms devolved.[44]

Depression has been classified in many ways according to proposed causality (e.g. exogenous and endogenous depressions), temporal course (e.g. post-natal depression, dysthymia), phenomenology (e.g. atypical and psychotic depressions), symptomatic severity (e.g. major and minor depressions), treatment response (e.g. treatment-resistant depression), and relationship to other affective syndromes (e.g. unipolar and bipolar depressions).[46-48] Throughout the history of psychiatry, there has been no stable consensus on how depression should be classified.[47,49]

The contemporary concept of major depression, which came into existence with DSM-III in 1980,[50] has become the most widely used and influential diagnostic term for depression in the modern era.[48] Arising from the initiative to provide psychiatry with reliable diagnoses and an empirical grounding,[51] major depression is a syndromal diagnosis based on the presence of certain symptoms that cover the emotional, behavioural, somatic and cognitive domains. Melancholic depression became subsumed as one of its subtypes, and is characterised by prominent anhedonia, loss of affective reactivity, psychomotor and vegetative disturbances.[52] Notwithstanding its dominance in clinical practice and in the research literature, the concept of major depression has been widely criticised.[43,45,53-61] The most

fervent criticism has been of its philosophical foundation. Being atheoretical, the DSM is solely syndromal in organisation and does not intend to consider theoretical causality in its diagnostic classification. Therefore, the creation of the DSM-defined diagnosis of major depression abolishes the distinction made by previous generations of psychiatrists between depressions with predominantly biological versus predominantly psychosocial determinants, a conceptual shift that has been noted to be a historical anomaly.[45,51] Some have pointed out that, contrary to its claims, the DSM is in fact highly theory-bound in its positivist stance that rejects psychoanalytic perspectives,[53] its in-built hierarchical structure (such as the precedence of major depression over adjustment disorder and dysthymia), and its retention of diagnoses such as adjustment disorders and secondary depressions that assume direct causality.[58] Aside from these internal inconsistencies, the categorical nature of major depression has raised concerns about an artificial separation of pathology from normality, with the delineation based on arbitrary criteria rather than empirical evidence.[59] It has been pointed out that the diagnostic criteria for major depression can be satisfied by 227 different combinations of symptoms, and is thus a highly heterogeneous syndrome.[62] Research using the concept of major depression has generated limited success, in that no clear biological markers for major depression have been identified, and clinical trials have found mixed results and high placebo response rates.[58,63-65] Together with its high spontaneous remission rates,[58,66,67] these observations support the concern that the heterogeneity of major depression may prove detrimental to its usefulness and validity as a concept.[51,58,60,68] Furthermore, the cross-sectional and decontextualised concept of major depression has led to consternation over the medicalisation of human misery or distress.[43,55,58,61] Complicating the concept of depression further, context or triggering life events do not appear to be uniformly pertinent in depression.[69]

The shifting concepts and classifications of depression over time partly reflect the developmental course of psychiatry as a profession. Operating as a specialty in medicine, psychiatry has placed a strong focus on diagnosis, which serves a central organising function in defining the boundaries of the medical profession.[70] In contrast to the diagnostic classifications in other areas of medicine, which over the last two centuries have been increasingly based on underlying pathology, psychiatry has been challenged by being primarily concerned with illnesses for which pathology cannot be clearly identified.[48] In the absence of biomedical markers of pathology, psychiatry has relied on theoretical frameworks to make sense of mental disorders including depression. Numerous theories, ranging from the psychoanalytic and behavioural to the biological, have arisen in the context of the prevailing ideas and local practices,[41,43] which in turn have been influenced by wider medical and societal determinants. Psychiatric nosology has therefore varied in parallel with the dominant scientific and social paradigms of the time.

From an anthropological perspective, illness is understood as a social construct, shaped by culturally-determined perception, experience, evaluation, explanation and behavioural response to discomfort in the person.[71] As such, the concept of depression in the clinical sense is underpinned by the values and expectations of society. For example, stigma associated with mental illness has often been cited as a deterrent to conceptualising symptoms as depression.[72,73] On the other hand, societal values such as individualism and self-actualisation have been proposed to foster a culture that is less tolerant of distress, which, further enabled by the influence of contemporary psychiatric nosology and the pharmaceutical industry, may have broadened the modern concept of depression.[68,74] Both the conceptualisations of depression and its classifications are anticipated to evolve as society and psychiatric models change.

1.3.3 Diagnostic difficulties of depression in palliative care

The instability and diversity of depression as a concept is not merely of historical interest. The shifting and multitudinous notions of depression complicate the concept of depression for clinicians, and lay a precarious foundation for diagnosis. There are a number of other factors that may also contribute to the clinical challenges of diagnosing depression. At the outset, depression deals with phenomena that are inextricably connected to emotional and mental experiences, which are communicated through the patient's narrative and behaviours, and require interpretation by the clinician. The diagnostic process is therefore reliant on use of language and metaphors and on ideological representations, all of which are subject to inter-individual variations.[75] The lexicon of emotions and their ideological representations vary within cultures as well as between them,[44] and terms such as "melancholia" and "depression" are imprecise and used to convey different ideas.[40] Furthermore, the patients' constructions of their experiences and the interpretation of these by clinicians are underpinned by psychological and sociocultural determinants,[71,76] including the training background of the latter. In particular, there is an extensive body of literature that substantiates the differences between lay and professional concepts of sickness.[44,71,77,78] Having no corporeal diagnostic markers, the diagnosis of depression is therefore contingent on these vicissitudes and ultimately on the clinician's individual notion of depression.

There is no agreement on what constitutes depression. Depression is variously recognised as a symptom, a syndrome, a disease, a disorder, and/or normal or abnormal reaction to stressors.[29,51] There is no consensus on its core features, with influential theoretical proponents bestowing primacy on different aspects,[44] for example, mood,[79] psychomotor disturbances[80] and cognitive distortions.[81] In contrast, the DSM-defined concept of major depression avoids emphasising specific clinical features and, except for stipulating the presence of either

depressed/irritable mood or decreased interest/pleasure in most activities, places equal weighting on a range of symptoms.[52] In addition, a profusion of theories are applied in an attempt to explain depression, including those rooted in biomedical, psychodynamic, behavioural, cognitive and social frameworks, which can at times seem incompatible with one another.[77] The variability of depression as a concept is so great that the term “depression” has been cynically compared in specificity and meaningfulness to terms like “vapours”, “nervousness” and “madness”.[45]

The palliative care setting presents unique issues that further obscure the concept of depression. The EOL is emotionally evocative and is often emotionally charged. A complex interplay of psychological processes may occur, and may involve aspects such as grief relating to myriad losses (e.g. loss of bodily integrity, personhood, independence, dignity, future and relationships), anxiety and fear in the face of uncertainties, suffering, guilt, and existential and spiritual crises that may come to the fore. Given this backdrop, the diagnosis of depression requires distinction from context-appropriate psychological processes, and is a challenging task that again hinges on conceptual boundaries and individual views about the emotions associated with death and dying. Polarity in views is suggested by the critique, on the one hand, that depression is under-detected in part because health professionals assume depression to be inevitable in the terminally ill,[29,82] and the critique, on the other hand, that misery and sadness are increasingly medicalised into a diagnosis of depression.[55,61] Furthermore, depression is often difficult to distinguish from conditions such as advanced disease, delirium, the physical process of dying, and neuro-suppressive medication effects, all of which commonly occur in the palliative care setting.[29,83,84]

In an illustrative study, Chochinov et al.[85] highlighted the subjective vulnerability of diagnosing depression in patients receiving palliative care. By applying two subtly

different severity thresholds for two symptoms (dysphoric mood and pervasive loss of interest or pleasure in activities) of DSM-III defined major depression, this study found that the lower symptomatic severity thresholds led to a doubling of the diagnostic rate for depression compared with the use of the higher thresholds. In comparison, applying these two severity thresholds to the Endicott criteria, which substitute somatic symptoms with non-somatic alternatives in order to reduce the symptomatic overlap between depression and somatic disease, resulted in a lower diagnostic rate than the DSM-III major depression criteria only when the lower symptomatic severity thresholds were used, while the use of the higher symptomatic severity thresholds resulted in the same prevalence rates. In other words, although the much-debated issue of somatic symptomatic confounding appears to affect the diagnosis of depression, its influence may in fact be slight in comparison with the impact of using subtly different severity thresholds for individual symptoms, the consistency of which is more difficult to achieve among clinicians.

1.3.4 Medical conceptualisations of depression at the end-of-life

The conceptual multiplicity of depression and its obscure boundaries with disease and psychological phenomena likely foster variability in medical conceptualisations in the palliative care setting. This variability is important given the centrality of conceptualisation to assessment and treatment approaches. It is therefore pertinent that medical concepts of depression be explored and discussed. Greater clarity of the different concepts of depression may also facilitate more nuanced research and yield findings that can provide clinically meaningful guidance.

Currently, there is very little literature on how depression is conceptualised in the palliative care setting. Prior to the research undertaken for this thesis, there were studies that had explored causal attributions,[86-88] illness perceptions,[89] and attributed meanings[90-92] of cancers and chronic diseases from the perspectives of

terminally ill patients. Some studies had examined the association between attributions or perceptions of terminal illness and psychological adjustment including depression.[89,93] However, there were no published empirical studies that investigated how patients or clinicians conceptualised depression in the setting of terminal illness.

Depression as a concept in terminally ill patients can at present only be understood indirectly by considering the different applications of the term in the palliative care literature. As previously mentioned, depression is most commonly used to indicate either the presence of depressive symptoms or specific depressive disorders as defined by certain diagnostic criteria.[29,36] Neither of these meanings, however, conveys a rich or cogent characterisation of depression as a notion, with respect to elements such as its causality, boundaries with normality and illness, course, treatment or prognosis. A third sense in which the term depression is used in the literature is in the context of grief theories, where it is considered to be either a stage in normative grief[94,95] or a complication resulting from pathological grief processes.[96,97] There has also been contention over the boundary between grief and major depression, which in recent times has come to the fore with the removal of the bereavement exclusion from the criteria for major depression in DSM-5.[98-100] The duality of considering depression as a normative component of grief, which is essentially an adaptive process, and a psychiatric disorder in the context of grief and loss complicates the concept of depression in palliative care, where grief and loss are commonplace occurrences. This confusion may contribute to the widely reported difficulty that health professionals, including family physicians, palliative medicine specialists and nurses, have in distinguishing between sadness and depression.[26,37-39,101]

An indication of how depression in the terminally ill is considered may also be gleaned from research in other settings. The conceptualisation of depression by medical practitioners has been most frequently studied in the primary care setting, where dissonant concepts have been reported. A qualitative study on general practitioners demonstrated conflict in their clinical descriptions of depression, arising from applying a biomedical model of understanding depression and recognising the social contexts of depression in clinical practice.[102] Similarly, in a systematic review of qualitative studies that investigated general practitioners' concepts of depression, their description of depression as a medical disorder was observed to be inconsistent with their understanding of depression as primarily a reaction to overwhelming circumstances.[103] Of particular relevance to the palliative care setting, a qualitative study examining the views of primary care practitioners (general practitioners, practice nurses, district and community nurses) found that they saw depression as justifiable in old age and therapeutic nihilism was a feature of all interviews with these health professionals.[104] Another qualitative study of general practitioners, primary care nurses and counsellors also found a predominantly psychosocial model of explanation for depression in old age, and concerns about medicalising loneliness and grief was a theme, which were reflected in the expressed ambivalence about treating depression in the elderly.[105]

There is little empirical guidance on how specialist medical practitioners consider depression as a concept. Within the psychiatric literature, pluralistic and often seemingly contradictory models of conceptualising psychiatric disorders have been described.[77,106] The complexity of these disorders has led to the current movement towards pluralistic and integrationist paradigms of illness conceptualisation.[107,108] As these are different models of conceptualisation from those extracted from the primary care literature, this suggests that psychiatrists'

conceptualisation of depression may differ from general practitioners, and, by extension, also possibly from other non-psychiatric medical practitioners.

Significantly, discordant conceptualisations of depression between patients and medical practitioners have been reported.[78,109,110] A qualitative study of patients and their general practitioners illustrated a conceptual divide. Patients were found to describe depression as a deeply subjective experience, borne out of difficult personal circumstances that injured their sense of self, for which they had limited expectations of concrete help from their general practitioners. In contrast, general practitioners, although cognizant of personal circumstances, were focused on the pathology of depression, which was approached as a medical problem.[78] In a study of older adult patients with moderate depression, participants felt that their understanding of depression differed from that of medical practitioners. Whilst they expressed appreciation that medical practitioners could identify their symptoms and integrate these into a diagnosis, they felt that the medical concept of depression was inadequate in that it omitted consideration of cause, embodied experience and social context.[110] A similar dissonance was reported by an Australian study in primary care patients' accounts of being diagnosed with depression. On the one hand, these patients embraced certain aspects of medical discourse, such as being in an abnormal state and having the right to access treatment, and incorporated a diagnosis of depression into their narrative. On the other hand, they resisted the medical concept of depression by emphasising the social context of their experience, challenged the role of antidepressants, and considered that they sought the help of their general practitioners for non-medical reasons.[111]

1.3.5 Theoretical frameworks for studying illness conceptualisations and the Explanatory Model

Several theoretical frameworks have been used in the literature to study illness conceptualisations, each with its distinct focus. The Common Sense Model of Illness Representation[112,113] from the health psychology literature has been extensively applied in physical and mental health research. It proposes that cognitive and emotional responses to health threat information are integrated into lay illness representations that guide coping and appraisal of illness outcomes. It is comprised of the five cognitive dimensions of identity, consequences, cause, timeline, cure or control.[112,113] This model was derived to understand lay illness representations and behaviours, and is generally not applied to professional concepts of illness, which is the focus of this thesis. Attribution theory has also been widely used in health research, but to a lesser extent in mental health research. It focuses on the perception of causation and the consequences of such perceptions, and can be applied to a broad range of events, including illness.[114] As illness attribution is only one of many dimensions[115] of illness conceptualisation, this theory has a narrow scope when used to study conceptualisation of illness and is not optimal for this thesis. The Health Belief Model[116,117] is another established theory relating to health concepts that has been used in depression research. It is a social psychological theoretical framework that focuses on individual attitudes and beliefs, but its main intent is to explain and predict health behaviours, which has led to its main application in public health research.

The Explanatory Model of illness is a widely utilised framework for exploring illness conceptualisations, and is the theoretical framework used in this thesis. It is derived from medical anthropology and was introduced in the 1970s by Kleinman, a psychiatrist and anthropologist. An explanatory model is defined as “the notions about an episode of sickness and its treatment that are employed by all those engaged

in the clinical process”.^[118] The fact that patients and their families or carers, as well as clinicians, bring to the clinical encounter beliefs about an illness and its treatment is highlighted in this definition. Regardless of whether they are lay or professional, explanatory models share commonality in addressing, to varying extents, five areas relating to illness, which are: (1) aetiology, (2) time and mode of onset of symptoms, (3) pathophysiology, (4) course of sickness, and (5) treatment.^[71,118] Where open-ended enquiry of patients’ explanatory models is unproductive, Kleinman suggested a series of questions to facilitate the process. These questions are:

1. What do you call your problem? What name does it have?
2. What do you think has caused your problem?
3. Why do you think it started when it did?
4. What does your sickness do to you? How does it work?
5. How severe is it? Will it have a short or long course?
6. What do you fear most about your sickness?
7. What are the chief problems your sickness has caused for you?
8. What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?^[118]

Lay explanatory models have been described as characteristically vague, mutable, and tend to involve multiplicity of meanings and symbolic connections, in contrast to professional explanatory models which tend to be more fully articulated and follow single causal trains of scientific logic.^[118] Beliefs forming explanatory models are shaped by many factors, including socioeconomic status, culture, education, occupation, religious affiliation, past experience with illness and health care.^[71,118] Despite the inter-individual variability, similarities in explanatory models of illness are found on cultural and subcultural levels. Explanatory models are also fluid concepts, often internally inconsistent and capable of evolution over time and with experiences, which led to the suggestion that “exploratory maps” may be a more

suitable term to capture the mutability and uncertainty of health beliefs.[119,120] In his original intent, Kleinman advocated for eliciting the patient's explanatory model of illness in clinical practice, in order to improve understanding of the patient's experience, therapeutic alliance and clinical outcomes.[71,115] However, the elicitation of explanatory models from patients is not routinely practised, and is often not practised with the spirit of therapeutic pursuit.[115,121]

The Explanatory Model has been widely applied as a framework for research in mental health, including depression.[109,119,122-129] Methodologies have varied, from quantitative tools such as self-report questionnaires[109,125], research schedules that bridge quantitative and qualitative methodologies such as the Explanatory Interview Catalogue (EMIC)[130] and the Short Explanatory Model Interview (SEMI),[131] to qualitative interviews and focus groups.[115] Kleinman's original approach, however, was to elicit explanatory models through open exploratory qualitative enquiry,[71,115] which is the method adopted in the research undertaken for this thesis.

1.4 Rationale for this thesis

The preceding discussion has highlighted the fact that depression is a common clinical problem in palliative care, and is one that poses many difficulties with diagnosis and treatment. The nebulousness of depression as a concept lies at the core of these challenges, especially in the palliative care setting where depressive features may be attributed to different processes. This ambiguity generates conceptual variability in clinical practice, which has widespread implications for all aspects of the clinical pathway from diagnosis to treatment outcomes, as well as for consistency of clinical practice within the medical profession. Conceptual variability in research compromises the interpretability and comparability of research findings, which threatens the viability and progress of depression research in palliative care. The

complexity and instability of depression as a concept must be acknowledged to allow nuanced clinical approaches and meaningful research. The ways in which depression is considered by medical practitioners in the palliative care setting need to be explored, in order for the current clinical approaches taken by different medical disciplines to be understood and compared.

In this regard, there were two major gaps in the extant literature at the time when this research was conducted. Firstly, there had been no published empirical studies on the conceptualisation of depression in the palliative care setting. Although there were studies that had explored how depression in general settings was viewed by patients and clinicians, the somatically and psycho-socio-spiritually intricate nature of terminal illness introduces additional complexity to thinking about depression in this context, which demands specific investigation in this population. The second gap was the scarce literature that examined and compared the conceptualisation of depression among different groups of clinical stakeholders. Where this had been done, the comparison had tended to be between patients and medical practitioners, most frequently general practitioners. However, in modern medicine where increasing specialisation and multi-disciplinary collaboration operate, it is important to understand and compare the conceptualisation of different medical disciplines.

In consideration of the above, the present research therefore set out to explore the conceptualisation of depression in the palliative care setting, from the perspectives of two groups of medical stakeholders. Medical concepts of depression are important to understand given that diagnosis and treatment are generally tasks that fall within the medical domain. In addition, medical concepts of depression form a dominant influence on how this problem is perceived and addressed in society, extending from the promotion of public awareness, to the development of clinical practice guidelines, service provision, and funding in healthcare and research. In palliative care, the

medical practitioners who attend to depression are commonly general practitioners and palliative medicine specialists, and psychiatrists on a consultative basis. In this research, palliative medicine specialists and psychiatrists were selected to represent two distinct medical specialist groups that are respectively considered to have expertise in terminal illness and depression.

The Explanatory Model[118] was chosen as the theoretical framework to guide the exploration of depression conceptualisation for several reasons. Its derivation from medical anthropology and its established application in mental health research give the Explanatory Model particular aptness for the present research. Compared with alternative theoretical frameworks, the Explanatory Model is also comprehensive in its domains, and is applicable to all clinical stakeholders.

1.5 Statement of aims and objectives

The aim of this thesis was to investigate the medical conceptualisations of depression in the palliative care setting.

The objectives were:

- To explore the concepts of depression that are held by medical practitioners practising in palliative care.
- To ascertain the conceptualisations of depression that are held by two medical specialist stake-holding groups, namely palliative medicine specialists and psychiatrists working in palliative care.
- To compare the conceptualisations of depression between these two specialist groups.
- To specify and describe the areas of conceptual difficulties in relation to depression in the palliative care setting, and to understand the reasons behind them.

1.6 Potential significance of the present research

The present research, by characterising and comparing the conceptualisations of depression between two medical specialist groups, can contribute towards addressing the two aforementioned gaps in the literature. Despite the magnitude of depression in palliative care and the growing body of literature on the subject, there has been little research devoted to exploring issues of conceptualisation, which is fundamental to all clinical and research endeavours. Therefore, this research complements the existing literature and may further the contemplation and discussion of conceptual dilemmas. In research, this may play a part in the ongoing efforts to refine depression definitions and classifications and thereby increase the meaningfulness of findings. By promoting awareness of the foundational ambiguity of depression and its applied concepts in the palliative care setting, this research may also be valuable to medical education by encouraging more sophisticated understandings of the varieties of depression, which may ultimately contribute to more individualised and nuanced approaches to managing depression in this setting.

Although this research is specifically focused on the palliative care context, its findings may also be relevant to other clinical settings. There are commonalities in the clinical issues between palliative care and medical settings such as oncology, geriatrics and general medicine, where patients frequently have chronic illnesses that, although not considered to be terminal, are enduring and result in substantial impairments and disabilities. In these contexts, the psycho-socio-spiritual and somatic issues share similarities with those in palliative care. In more general terms, increasing awareness and understanding of the conceptual difficulties of depression may also hold relevance to the area of mental health and to medicine in both primary and specialist settings.

1.7 Research design

1.7.1 Design overview and rationale

This thesis is comprised of three studies on conceptualisations of depression in the palliative care setting, using Kleinman's Explanatory Model[118] as the guiding theoretical framework.

The first study (Study 1) was a preliminary exploration of depression as a concept among medical practitioners working in palliative care, using a questionnaire developed for this purpose. The intent was to gauge the range of conceptual variability, and to canvas the potential areas of conceptual difficulties, which could then inform the content of the interview guides in the subsequent qualitative studies. A questionnaire was selected as a means to obtain broad information from a larger sample, which was desirable for this pilot investigation.

The other two studies involved semi-structured, in-depth interviews, each with a different medical specialist group, namely, palliative medicine specialists (Study 2) and psychiatrists (Study 3). The aim of each study was to understand the explanatory models of depression in the palliative care setting that were held by the respective group. Semi-structured interviews were chosen as a means of allowing in-depth exploration of areas that were pre-determined by the framework of the Explanatory Model, while at the same time allowing flexibility in exploring emergent areas. A qualitative approach of enquiry was considered particularly suited to the socio-anthropological framework of Explanatory Model, which is traditionally elicited through an open exploratory process.[115] The respective research questions for the studies were as follows:

Study 2: What are the explanatory models of depression in the palliative care setting, as held by palliative medicine specialists?

Study 3: What are the explanatory models of depression in the palliative care setting, as held by psychiatrists who work in palliative care?

Methodological details of the three studies are provided in subsequent sections. As the methodology for the two qualitative studies share considerable similarities, they will be described together. Abbreviated methodological descriptions of the three studies are also included in each of the five papers presented in this thesis.

1.7.2 Ontological and epistemological assumptions

In this thesis, the concept of depression is approached from a relativist perspective. As an ontological stance, relativism considers reality to be subjectively constructed through socially and experientially developed understandings. Hence, reality is fluid and exists in multiple versions, although shared elements are often found among individuals and across cultures.[132,133] Depression in this thesis is therefore assumed to be a construct that could be understood in different forms, and the purpose of the present research was to explore the variety of ways in which depression was considered in the clinical context.

In order to allow participants to freely explain their concepts, the term “depression” was used during this research without further elaboration or specification. Where participants sought further clarification of the term in interviews, the only additional specification provided was that depression referred to the clinical usage of the word. In the pre-existing literature on conceptualisation of depression, studies had usually defined depression according to DSM-classified syndromes such as major depression,[124,134-136] or in terms of depression screening instrument cut-offs.[137-139] As these are more akin to realist concepts that define depression in single objective terms, such approaches are incompatible with the ontological

assumptions of this thesis. The term “depression” was therefore deliberately kept undefined.

Within the relativist-interpretive paradigm, it is also assumed that the researcher and the object of research are inextricably linked, and the researcher’s values are thus inherent throughout the research process.[132,133] In the context of this subjectivist assumption, reflexive considerations of my values and potential influence on the research process will be discussed in the subsequent section on reflexivity (Section 1.8).

1.7.3 Study 1: Questionnaire on palliative medicine practitioners’ views on depression in the palliative care setting

Participants

The target population was registrants for a palliative medicine conference that was held in Australia in 2010. The conference theme was centred on the art of palliative care, and registrants were primarily Australian and New Zealand medical practitioners who worked in palliative medicine. This population was chosen because of its high level of relevance to the study and convenience arising from the concentrated opportunity for recruitment in the conference setting.

Instrument

A questionnaire was specifically developed for this study. It comprised the following main content areas: (1) demographic data; (2) the participant’s level of clinical involvement with palliative medicine and with depression in this setting; (3) concept of depression; and (4) free-text comments on the participants’ experiences of depression in the palliative care setting. Questions relating to the concept of depression were expressed as a series of 25 statements, for which participants were

asked to indicate their level of endorsement on a 5-point Likert scale that ranged from “1 = Strongly Disagree” through “3 = Neutral” to “5 = Strongly Agree”. These statements related to the distinction of depression as a concept, its prevalence, symptomatic consistency, causality, treatment and outcome. The statements were informed by the literature relating to depression at the EOL and studies of explanatory models of depression, and supplemented by my clinical experience as a psychiatrist. A small pilot was conducted (n=7) to assess the comprehensibility and clarity of the questionnaire, and to obtain an estimate of the time required to complete it. The pilot participants were selected as they either had research or clinical backgrounds or both in the areas of palliative care and/or psychiatry of old age, and were not part of the study’s target population. Minor wording and formatting modifications were made in response to feedback from these pilot participants. The questionnaire is included in this thesis as Appendix A.

Procedure

Permission was obtained from the conference organising committee to distribute the questionnaire and its accompanying introductory letter (Appendix B) to all registrants. Distribution of these items occurred in two ways, firstly with a paper version that was included in all registration packages, and secondly with an electronic version that was included in a reminder email that was sent by the conference organisers to all registrants one week after the conference ended. A verbal announcement and visual reminders in the form of a poster display and collection boxes were used at the conference as recruitment strategies. Responses were anonymous, and return of the completed questionnaire indicated consent.

Data analysis

Descriptive statistics were used to summarise the characteristics of the participants and their responses to the statements relating to the concept of depression. Non-parametric statistics (Mann-Whitney U test and Kruskal-Wallis 1-way ANOVA) were used to compare participant responses according to their characteristics because of the non-parametric data distribution. Significance was set at $p < 0.05$ (2-tailed). All quantitative analyses were performed with the assistance of the PASW, version 18 program.[140]

All free-text responses were collated using the NVivo9 software,[141] and were independently examined for themes by me and my principal supervisor, with the goal of describing the data set to its fullest. Themes, as discussed further in the following section, were understood to be patterns of meaning residing in a data set.[142] The results of these analyses were then compared and themes revised until consensus was reached.

1.7.4 Studies 2 and 3: In-depth interviews on depression in the palliative care setting with palliative medicine specialists and psychiatrists

Participants and recruitment

In Studies 2 and 3, palliative medicine specialists and psychiatrists were respectively sought to participate in in-depth interviews. In the latter group, only psychiatrists with a clinical role in palliative care were included, in order to capture psychiatric conceptualisations that had the highest impact on the palliative care patient population. Since there were relatively few palliative medicine specialists in South Australia, and even fewer psychiatrists who worked in palliative care, local recruitment posed difficulties in terms of anonymity and neutrality in relation to me as the researcher. Therefore, recruitment took place nationwide in Australia.

Specialists with whom I had a close working or personal relationship were not included.

Palliative medicine specialists were recruited through an annual conference of the Australian and New Zealand Society of Palliative Medicine (ANZSPM), the sole medical society in these two countries that facilitates professional development and promotes the practice of palliative medicine.[143] Its members are medical practitioners from various medical specialties, who provide care for those with life-limiting illness. An introductory letter and flyer was distributed to all registrants of the 2010 conference in the registration pack, with the inclusion of a reply slip and reply paid envelopes for interested individuals. The introductory letter, flyer and reply slip are shown in Appendices B and C. Further information about the study was sent to those indicating an interest to participate (Appendix D). A second means of recruitment was through individual professional contacts.

Psychiatrists were recruited through the Royal Australian and New Zealand College of Psychiatrists (RANZCP), the binational organisation that provides accreditation and representation for the medical specialty of psychiatry.[144] Members of the RANZCP Section of Consultation-Liaison Psychiatry were identified as the target population because psychiatrists who work in the Consultation-Liaison setting were expected to be most likely to have clinical involvement in palliative care. Having obtained approval from the Chair of the Section of Consultation-Liaison Psychiatry, a recruitment email was sent via the RANZCP to the members of the Section, with participant information included as an attachment (Appendix E). Additionally, a recruitment notice was also placed in the February 2011 edition of the *Psych-e Bulletin* that was published by the College and distributed to all its members in Australia and New Zealand (Appendix F). Participant information, consent form, and

the contacts and complaints form for psychiatrist participants were the same as that for palliative medicine specialist participants (Appendix D).

For palliative medicine specialists and psychiatrists, demographic characteristics such as gender, level of experience (as determined by duration of clinical experience), and geographical location (state, city or regional setting) were taken into account in purposive sampling, in order to achieve the maximal variation for these demographics. These demographic characteristics were considered to have the potential to influence conceptualisation of depression, as differences might be associated with gender, local education or training effects, and level of clinical experience. The questionnaire study (Study 1) had identified duration of clinical practice as a factor that differentiated results among the respondents, which provided some evidence for the purposeful selection of participants with diverse duration of clinical experience.

Procedure

I contacted individuals who indicated an interest in participating in this research to establish their understanding of participation, respond to any queries, confirm that the inclusion and exclusion criteria were satisfied, and arrange for a time and venue for the interview. Palliative medicine specialists and psychiatrists were interviewed in person if they were located locally in Adelaide, and telephone interviews were conducted for specialists who were located interstate.

At the commencement of the interview, the participant's comprehension of the purpose of the interview was confirmed and consent was obtained. All participants indicated an understanding that withdrawal of consent was permissible at any stage of the research until the publication of the findings. Consent was documented in

written or verbal forms. The latter was recorded on audiotape with the participant's permission. All participants consented to their interviews being audiotaped.

I conducted all interviews, which were predominantly open-ended in approach, with guidance provided on the content areas. In order to avoid a prematurely restrictive focus, participants were initially invited to comment on emotional aspects during the palliative phase of treatment, and how their concepts of depression were placed within this broad focus. The interview subsequently honed in on the participant's conceptualisation of depression and explored the boundaries between depression, normative dying process and other phenomena. Participants were also asked to reflect on any differences between depression occurring in the palliative care and other settings. The contents of each interview were used to inform and modify subsequent interviews, in accordance with the practice of qualitative semi-structured interviewing.[145] The interview guides were informed by the domains of the Explanatory Model and the questions to facilitate its elicitation, as proposed by Kleinman, and also by the results of Study 1. The interview guides with example questions are shown in Appendix G.

Beside withdrawal of consent, participation could also be withdrawn due to participant distress as a result of taking part in the interview, as determined by either the participant or me as the researcher. This eventuality did not occur.

In both studies, interim analysis of the interviews occurred alongside recruitment and data collection. The latter was deemed complete when data saturation was reached. Data saturation is defined as the point in qualitative data collection when no new themes in relation to the research questions were elicited.[146,147] During data collection with each group of participants, I performed interim analysis after each interview at two time points: immediately at the end of each interview, and on

inspecting each interview transcript as soon as it was completed. All transcripts were done sequentially and close to the time of the interviews, thus allowing timely interim analysis to be performed in order to inform subsequent interviews. In interim analysis, I noted each participant's content themes under each of the eight questions for eliciting the Explanatory Model as proposed by Kleinman.[118] Data saturation was determined to have been reached when further interviews with the participant group did not yield new interim themes under each of the eight questions at a semantic level of organisation. By this, I refer to the saturation of ideas for each interim theme. As an example, participants described different analogies for explaining depression in terms of neurochemical imbalance, which I organised under the theme of "depression is caused by neurotransmitter depletion". When further analogies and variations on this theme were not considered to add to the understanding of this theme, this theme was considered to be saturated. My notes for interim analysis were recorded in an audit trail, and served dual purposes of detecting new content areas to incorporate into subsequent interviews and facilitating the processes of constant comparison and identification of data saturation. The audit trail was also used to assist in recording my observations in the process of continuous reflexivity.

I transcribed all interviews verbatim and simultaneously de-identified them. The relevant transcripts were sent to participants who had agreed to be involved in participant validation. Only minor changes resulted from this process, involving clarification of the participants' meanings or the editing of potentially identifying material.

Data analysis

Thematic analysis was used in Studies 2 and 3.

Thematic analysis is an established qualitative method for identifying, analysing and reporting themes within data, with themes referring to both the explicit (semantic or manifest) and implicit (interpretative or latent) patterns of meaning in a data set.[142,148-150] Thematic analysis was specifically chosen as the analytic method for Studies 2 and 3 in this thesis for several reasons. Its freedom from specific epistemological orientations, in contrast to other qualitative methods such as grounded theory, discourse analysis and interpretive phenomenological analysis, makes thematic analysis widely applicable,[142,148,150] to the extent that some have considered it to be a basis for most qualitative methods.[148] It has also been described as one of the most systematic and transparent qualitative analytic methods,[148] and is especially suited to research where data consist of rich verbal or textual material such as in-depth interviews.[148,151] Besides these merits, the flexibility that thematic analysis affords the researcher by allowing dual deductive and inductive approaches[142,148-150] is particularly desirable for this thesis. A deductive approach is led by a priori theories that guide the foci of analysis, and is therefore strongly theory-driven.[142,148,149] In this approach, the researcher tends to perform detailed analysis of specific areas of data rather than attempts to describe the full data set.[142] On the other hand, in an inductive approach, themes are not predetermined by theoretically derived coding frames and may bear little relationship to the research questions.[142,148,149] However, it has been pointed out that researchers cannot analyse data in a theoretical vacuum and inductivity is thus a relative concept.[142] For this thesis, analysis of data was structured around the theoretical framework of the Explanatory Model domains, although it also sought to draw on additional themes from the raw data. The form of thematic analysis used is therefore a dual deductive and inductive approach.

It has often been noted that, despite the wide usage of thematic analysis, there have only been a handful of published guidelines on its methodological

techniques.[142,148,149,151] For this thesis, the analytic procedure followed the guidelines as set out by Braun and Clarke in their authoritative paper on the subject.[142] These guidelines were chosen for their systematic and detailed description of the thematic analytic process, and for the high standards that are expected within the process. In their approach, Braun and Clarke outline six iterative steps, which include: 1) Data familiarisation, 2) Initial coding generation, 3) Search for themes based on initial coding, 4) Review of themes, 5) Theme definition and labelling, and 6) Report writing.[142]

The content of all interview transcripts were coded and thematically analysed by me, using the previously outlined framework of the eight Explanatory Model questions, as proposed by Kleinman,[118] which cover the domains of aetiology, time and mode of onset of symptoms, pathophysiology, course of sickness, and treatment.[71,118] The codes for the first full transcript in Study 2 were independently reviewed against the raw data by two supervisors (ACH and GBC) to verify trustworthiness. In order to verify that the themes could be traced to the original data, ACH also independently reviewed the final themes against all transcripts in Study 2, and both ACH and GBC independently reviewed the final themes against all transcripts in Study 3. The three researchers involved in data analysis all have different disciplinary backgrounds, with me being a psychiatrist, ACH a psychologist and GBC a palliative medicine specialist. The NVivo9 software[141] was used to facilitate data organisation.

Rigour

Rigour in qualitative research “is about fidelity to the spirit of the qualitative work”.[152] Although many sets of criteria for rigour have been proposed,[153-158] evaluative criteria are often bound to their respective qualitative traditions and cannot be universally applied to all qualitative research.[132] In view of this array of criteria, Tracy proposed a set of eight “big tent” criteria for high quality qualitative

research, as a means of providing a parsimonious, universal quality framework that accommodates the diversity of qualitative research. These hallmark criteria consist of a worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics, and meaningful coherence.[159] These criteria accord with the idea of holistic rigour that others have recommended, referring to rigour that is reflected in all aspects of the research including its theoretical underpinning, methodological rationale, ethical considerations, data collection, analysis and interpretation, and reflexivity.[160,161] The big tent criteria are used as the framework for discussing quality in this thesis.

1. Worthy topic

Tracy characterised worthy topics as relevant, timely, significant and interesting.[159] The relevance and significance of understanding the conceptualisations of depression in the palliative care setting have already been explicated in earlier sections of this chapter. This topic is timely given the expanding research literature into depression in this particular context, which has generated confusion with its assorted definitions of depression. By examining depression from a relativist perspective, the current research has the potential to elucidate the foundational conceptual complexities of depression in the palliative care setting, and thereby stimulate debates and thinking around these core issues. It is this kind of critical potential of research that is considered by Tracy to be interesting.[159]

2. Rich rigour

This criterion refers to the richness or abundance of theoretical constructs that inform the research methodology, and of the data that is obtained and analysed. I have previously outlined the context, theoretical underpinning and rationale for the research questions and methodology of this thesis. Several techniques were applied

to facilitate the gathering of rich data and their subsequent usage in analysis and presentation. Purposive sampling was used to ensure the appropriateness of the participants for the research, because it offers a degree of control against inherent selection bias and allows the researcher to include deviant cases.[160,162] Semi-structured, in-depth interviews were considered to be the most appropriate means of obtaining descriptive data relevant to the research questions, and data collection continued until the point of data saturation, as identified by interim analysis. All interviews were transcribed verbatim, thematically analysed on a line-by-line basis, and findings were presented as descriptions illustrated with quotes.

3. Sincerity

Sincerity encompasses the notions of authenticity and genuineness, and can be facilitated by the practices of reflexivity and transparency.[159] Reflexivity is separately discussed in Section 1.8, and has been an integral practice throughout this research from its inception to completion. A record of reflexive thoughts has been kept in an audit trail. Clear documentation of the motivation for this research, its methodology, findings, deficiencies and limitations is provided in this thesis, in order for this research to be transparent to its readers.

4. Credibility

One of the hallmarks of rigour in qualitative research, credibility was proposed as one of four criteria of trustworthiness by Lincoln and Guba, alongside dependability, confirmability and transferability.[153,163] Credibility refers to the verisimilitude or truthfulness of research findings. Techniques used in this research to enhance credibility include thick description, multivocality, triangulation and respondent validation.

Thick description entails detailed illustrated accounts of phenomena that allow readers to draw conclusions about the interpretation of the data, while multivocality involves the use of multiple and varied voices of participants in both analysis and presentation of findings.[159] Triangulation is the combining of different data sources, methods or analytic approaches, in order to enhance the richness and comprehensiveness of qualitative research.[132,160] This thesis used three types of triangulation: (1) data triangulation, by using two specialist groups as data sources to enhance the capacity to understand the medical concepts of depression in the palliative care setting; (2) methods triangulation, by combining a questionnaire study with in-depth interviews; and (3) investigator triangulation, by using at least two researchers from different disciplines to independently analyse the data.[160] Respondent validation (or member checking) is a controversial technique, where transcripts or results of data analysis are shown to research participants.[160] Benefits of respondent validation include assisting the accurate portrayal of participant accounts, providing an opportunity for clarification of data, and testing the comprehensibility of results to readers.[132,159,160] On the other hand, respondent validation has been criticised for assuming that there is one accurate version of reality, which can be confirmed by participants, and which generates philosophical incongruity with interpretive or constructivist research paradigms. Other critiques include the different agendas, perspectives and goals between participants and researchers, and the dilemmatic complication of analysis where participants disagree with the analysis results.[132,160,164]. In consideration of these advantages and criticisms, the qualitative studies in this thesis only sought participant validation of the transcripts from those who were consenting to do so, with the intention being to validate the accuracy of the raw data. Participant validation of the results of analysis was not sought.

5. Resonance

Resonance is the quality by which a piece of research is able to reverberate with its readers, and can be facilitated by aesthetic merit and transferability.[159] Aesthetic merit refers to writing that is vivid, engaging and evocative,[159] while transferability is the applicability of the research findings to other contexts.[159,163] The degree of resonance of a piece of research work is gauged by its readers.[159,163] However, to facilitate the development of resonance of the present research, the sample characteristics and settings are described, thick description is utilised, and the findings are contextualised within the existing literature, such that readers are in a position to determine the transferability of the findings.

6. Significant contribution

The significance of this research, as outlined in Section 1.6, includes the theoretical, heuristic and practical domains of significance that were discussed by Tracy.[159] The potential to broaden and critique the concept of depression in the palliative care setting may contribute to theoretical knowledge, while the potential to promote further contemplation of and research into conceptual dilemmas may hold heuristic significance. Practically, furthering the conceptual understanding of depression can play a role in medical education and influence clinical approach to this problem.

7. Ethical

High quality qualitative research should demonstrate a pervasive ethical approach throughout the research. In addition to respecting the universal ethical standards that are required from institutional ethical committees, consideration should also be given to the specific ethical issues arising from the research's particular context, the interaction between the researcher and participants, and the handling of the data and findings.[159] In this thesis, the ethical considerations arising from research in the

area of palliative care are separately discussed in Section 1.7.6, and relational and data handling issues are recorded in the audit trail and reported in the reflexivity and discussion sections.

8. Meaningful coherence

This marker of quality is represented by research that achieves its purpose, utilises methods that are appropriate to its aims, and conveys a coherent thread that connects the literature, rationale and research questions, methodology, findings and their interpretations.[159] These connections are made explicit as much as possible in this thesis to facilitate the achievement of meaningful coherence.

In their practical guidelines on the approach to thematic analysis, Braun and Clarke also proposed a set of 15 criteria that demarcate high quality thematic analysis. These criteria extend across the processes of transcription, coding, analysis, and report writing,[142] and promote a thorough, comprehensive, systematic and transparent approach. These criteria have guided the thematic analysis process in this research. The details of these criteria have already been discussed in relation to rigour and methodology, and will not be reiterated here.

1.7.5 Data storage

All data including the questionnaires and their compiled data, signed consent forms, audio recordings, de-identified transcripts and analyses have been securely stored in either locked filing cabinets or electronically in password-protected computing systems. I have had sole access to the identities of the participants, as my supervisors were given de-identified data only. All data will be retained for at least 5 years after publication, in accordance with the Australian Code for the Responsible Conduct of Research.[165]

1.7.6 Ethical considerations

All three studies received approval from the Human Research Ethics Committee at The University of Adelaide (H-086-2010).

Ethical considerations relevant to this thesis include the balance of potential benefits and risks, informed consent, conflict of interest and confidentiality.

Balance of potential benefits and risks

This research was considered to pose low-level risks to its participants, in the form of time requirements and potential psychological discomfort associated with being interviewed. According to the National Statement on Ethical Conduct in Human Research, these constitute “inconvenience” and “discomfort”, respectively.[165] Participants might also be exposed to “psychological harm”[165] if they experienced emotional distress during interviewing, for example, in relation to contemplating or discussing difficult clinical or personal experiences that might be evoked by the research topic.

A considered approach was taken in the recruitment and interview processes to minimise any inconvenience, discomfort and psychological harm. As far as feasible, interviews were conducted at convenient times and venues for participants, who were interviewed at their workplace if they were located in Adelaide, but were otherwise interviewed by telephone. The use of open-ended questions and the option to view and edit transcripts allowed participants to retain control over their intellectual contribution to the research. I was vigilant for signs of emotional distress in the participants during interviews, and was prepared to check their ability to continue if such signs were observed, or to terminate the interview if participants became unduly distressed. Such occasions did not arise.

On balance, the low-level risks anticipated for this research were considered to be outweighed by the potential learnings that could be gleaned from these studies, as already outlined in Sections 1.4 (rationale) and 1.6 (potential significance of the present research).

Informed consent

All participants were given both verbal and written explanations of the studies. For the questionnaire study, completion and return of the questionnaire was stated as the conferral of consent to participation. For the qualitative interview studies, participants' understanding of the research, including its nature, purpose and potential risks, were established and any questions were answered during the process of obtaining informed consent. A record of having obtained informed consent was kept, either by the participant signing a copy of the written consent form or by audiotaping, with the participant's permission, verbal confirmation of understanding and consent to participate. Participants were reminded at the start of the interview that they could terminate the interview at any stage without needing to provide explanations. No payments, either direct or in kind, were made to participants in this research.

Conflict of interest

Given my clinical work as a psychiatrist with a focus in palliative care, conflict of interest arising from having dual roles as a clinical colleague and researcher was avoided by excluding specialists with whom I had working or personal relationships, in an effort to avoid undue influence on consent and interview processes.

Confidentiality

The participants' identity and personal details were protected during the course of this research. Having conducted all interviews and performed all transcription myself, I was the only researcher who was aware of the identity of the participants. Identifying details were removed from the transcripts prior to their examination by my supervisors and use for analysis. Participants who were willing to review their own transcripts had further opportunity to ensure that no identifying material remained. All research records containing the participants' identity and contact details were kept either in a locked filing cabinet or in password protected electronic files. All materials used in publications were de-identified, although participants were alerted to the potential that despite ensuring confidentiality, anonymity could not be guaranteed given the general description of participant demographics and the use of quotes in qualitative research reports.

1.8 Reflexivity

Reflexivity is the explicit, self-aware analysis of the impact of the researcher's own personal characteristics, training and beliefs on the research process, including the development of research questions, data collection, data analysis and presentation of the ensuing results.[160,166] It is regarded as a marker of quality and integrity across various qualitative research methodologies,[160] as the declaration of the researcher's background, perspective, beliefs and values allows readers to interpret research findings where the researcher assumes the role of a "human research instrument".[132] According to Tracy, the reflexivity process facilitates "honesty and authenticity with one's self, one's research, and one's audience." [159] The following discussion sets out the reflexive considerations that have arisen in the course of this research, which I have recorded in a journal as part of the audit trail. The main issues in this analysis have related to my professional role and personal perspective on the topic of depression, and the potential influence of these on the research process.

1.8.1 Background to the development of the research topic

The research topic of this thesis came about from my clinical work as a psychiatrist with a particular interest in psychiatric issues within the palliative care context. When I initially became involved in a consultation-liaison role with a palliative care team in 2009, I observed that depression was commonly discussed in day-to-day clinical work, but seemed to represent different ideas among members of the team, for example, being variously used to refer to sadness, distress due to illness symptoms, and psychiatric illness. When members of the palliative care team discussed with me patients with “depression”, I often found either on further elicitation of historical or mental state descriptions or on assessing the patients myself, that I had initially misunderstood the nature or severity of the patients’ conditions, which I would have used different terminologies to describe, such as grief, sadness, distress, demoralisation or fatigue. Yet, it seemed to me that the approach to treatment for these different circumstances became quite narrow once the label of “depression” was used, as though the act of labelling obliterated the context of the phenomenon. In particular, the need for prescribing antidepressants was often raised when patients were considered to be depressed. It also struck me, as it had done in other consultation settings, how differently I viewed depression as a psychiatrist compared with other medical practitioners and patients. This notion was strengthened by the discrepancy between the high prevalence rates of depression as reported in the palliative care literature and the much lower frequency of depression, as I considered it, that I was encountering in patients under the palliative care service. Although less conspicuous, I had noted over time that there were also differences in concepts of depression among psychiatrists.

These observations formed the context for my interest in the conceptualisation of depression, particularly in the palliative care setting because of the complex somatic,

psychosocial, cultural, existential and spiritual issues at the EOL. In addition to concerns about clinical miscommunication based on the different ideological representations of the term “depression”, I had also become increasingly concerned, over the course of my psychiatric career, that research on depression was predominantly based on unitary definitions of depression. This was also true for recommendations and guidelines for managing depression, which were generally developed by the psychiatric community and might not be applicable where alternative concepts of depression were applied. These were the chief motivations that led to the research questions in this thesis, which I hoped would articulate the various concepts of depression and heighten the awareness of these in the palliative care and psychiatric communities.

1.8.2 My conceptualisation of depression

Throughout this research, I was mindful of my own perspective on depression and how this could have influenced the processes of research development, conduct, analysis and synthesis of data. My conceptualisation of depression has been shaped by two main influences: my professional background and personal views of the world.

Despite my Asian ethnic heritage (Hong Kong Chinese), I was brought up in a family that practised Western Medicine and regarded this as the only valid model of understanding illness. I undertook Medicine as an undergraduate at the age of 17, directly after leaving school. My views of illness have therefore always been indoctrinated in the Western models. Not having had close experience with depression in my childhood and adolescence, my first exposure to depression as a psychiatric illness was in my fourth year of studies, as part of the Psychiatry rotation. After qualifying as a medical practitioner, I spent part of my internship year and part of my residency year working in psychiatric placements, where I developed familiarity with the medical presentations of depression. Throughout this early

undergraduate and prevocational training, I understood depression to be Major Depressive Disorder as defined by the DSM-IV-TR (the then current edition), a clinical disorder with multifactorial aetiology along the bio-psycho-social dimensions. Although not fully satisfied that this understanding was an adequate explanatory framework for depression, I found this syndromal diagnosis reassuring in its superficially clear delineation between normality and pathology, which gave me a justifiable reference point in my clinical assessments. Subsequently, in my specialist training to become a psychiatrist, I became increasingly aware of the limitations of Major Depressive Disorder as a concept, including the ambiguity of its diagnostic criteria, its lack of explanatory power, heterogeneity and poor guidance on treatments. As a consultant psychiatrist in the past 8 years, I have studied the historical changes in mood disorder classifications and other models of conceptualising depression, in order to broaden my perspective on the concepts of depression. I have also read about the philosophical underpinnings of the different models of conceptualisation, which has become a professional area of interest for me.

Through the years, I have formed a clearer personal concept of depression, one that is comprised of qualitatively different types of depressive presentations, which reflect a spectrum of overlapping aetiologies representing the situational, characterological and biological. However, I distinguish melancholic depression as a primarily biological form of depression, which I regard as a psychiatric illness. The other varieties of depressive presentations, to my mind, vary in their relative biopsychosocial aetiological contributions, and may best be represented either as psychiatric illness, a psychological response or process, or a characterological phenomenon. My experience with patients has taught me that these presentations have different qualities and require different management approaches. In essence, my personal concept of depression approximates the hierarchical model, as proposed by Parker, which encompasses different subtypes of depression that are variously

understood as categorical or spectral in nature.[167] My understanding of depression has also been influenced by various psychoanalytic, behavioural, cognitive and neurobiological theories. I arrived at my conceptualisation insidiously through the years of clinical experience, training, private study and reflections, and not as a result of immediate attachment to any single model. I also primarily use an integrative model of understanding depression, or more specifically, understanding the various causal explanations within an overarching neurobiological framework. Furthermore, I have a constructivist perspective of depression and understand that other clinicians develop their own concepts of depression, which are likely different from mine, in reflection of their personal and professional experiences.

My world views have also undoubtedly influenced my conceptualisations of depression and illness. Reflection on personal world views is particularly relevant in psychiatry, where the assessment for illness and disorders hinge on the interpretation of symptoms in the individual and sociocultural contexts, to determine whether symptoms are pathological, that is, excessive in degree or inappropriate in quality. This process is inherently subjective and requires the clinician to elicit an understanding of the patient's personal and sociocultural contexts. It is also a process that inextricably involves the clinician's own personal and sociocultural norms, which serve as a reference for interpretation.

For me, adversities are a natural part of life and necessarily evoke a range of emotions and psychological processes, the nature of which depend on individual circumstances. Whilst I believe that life adversities can in some situations partly contribute to the development of a psychiatric disorder, I think most depressive responses to life adversities fall within the spectrum of normal psychology and are best understood and managed as such. I have been struck by the trend towards an increasingly autonomous and externalising mindset in our society, and have been

concerned that this has undermined individuals' ability to accept life adversities and has led to greater investment in external solutions such as medical or psychiatric treatments to alleviate natural distress. Although the medical profession can and should assist in alleviating distress as part of care, I firmly believe that solutions to human misery are not best provided within the realms of medicine, but need to be addressed in the social and existential domains. I am therefore highly cautious of pathologising and medicalising human conditions, and do not conceptualise or label these as "depression".

In relation to death and dying, I have had the privilege of talking to many patients about the various aspects of their experiences at the end of their lives through my work with palliative care services and consultation-liaison psychiatry. I have also witnessed death and dying in my personal life and have experienced different qualities and processes of grief associated with these. These clinical and personal experiences have given me insights into the multifarious responses to losses and expressions of grief, and have strengthened my belief that dying and grief are primarily determined by individual characteristics rather than follow set stages or processes. Although I think sadness is common at the EOL, I have generally not found depression to be more common in this setting compared with others in the course of life.

1.8.3 Potential influence on research

Because of the proximity of this research to my own professional interests, I have been mindful of potential influences in the development, conduct and reporting of the studies. In particular, the main issues have been my own views on depression, my use of terminologies in relation to this subject, and my profession as a psychiatrist. In this regard, my own reflexivity and the oversight of my supervisors have been useful in managing such potential influences.

At the start of my candidature, I had the idea of researching on the concepts of depression in the palliative care setting and of using a qualitative interview method. I was comfortable with the Explanatory Model as a theoretical guiding framework, as suggested by my principal supervisor, in part because of its similarity to the medical domains of understanding illness, which was familiar to me and aligned with my conceptualisation of illness. In the process of further developing the methods of the studies, I was aware that my specific concept of depression and professional practice caused me slight discomfort in using broad terminologies such as “depression” and “emotions” without additional qualifications, and it required conscious effort to deliberately use those broader terms. To assist with this, I conducted practice interviews with different people, including my principal supervisor, a university colleague experienced in qualitative interviewing and psycho-oncology, and several PhD students. I sought their feedback on my language use and neutrality during the practice interviews, and incorporated into the interview guides their feedback on language use and guidance of contents. In particular, this process helped me to fine tune my level of awareness and comfort with guiding participants to address specific foci of content, as I had initially left practice interviews too unstructured for fear of exerting undue influence.

A stronger challenge was the avoidance of influencing the interview process through unwittingly imposing my constructs of depression. Because I had invested much time and thought on this subject matter, I had formed definite opinions, which I had been accustomed to putting forth in my roles as a practising and academic psychiatrist. I was especially aware of my own frustrations with the concept of major depression and its widespread dominance in clinical practice. Furthermore, my role as a psychiatrist complicated my relationship with the participating palliative medicine specialists and psychiatrists, making me a medical colleague as well as a student

researcher. I was aware that this could influence both parties in the interviewing process. For participants, being interviewed by a colleague could heighten self-consciousness and anxiety, thereby restricting freedom in expressing their ideas. Participants, especially palliative medicine specialists, could also refrain from criticising psychiatric models out of consideration of my profession as a psychiatrist. For both participants and me, a collegial rapport could also lead to an assumption of shared knowledge or understanding, which could compromise a fuller exploration of concepts.

To address the potential influences during interviewing, I was vigilant of the use of language including the participants' and mine, and used their language as much as possible as well as exploring their meanings without judgement. Additionally, I transcribed all interviews as they took place, and these were read by my supervisors, who did not raise any concerns about overt signs of undue interviewer influence on the material. I was aware that some (but far from all) participants appeared slightly uneasy during interviews, and one even remarked that the interview was "like a viva". I acknowledged that a degree of self-consciousness and discomfort was part of research interviews, and attempted to put participants at ease by emphasising my role as a student researcher, the fact that there were no right or wrong perspectives on the subject matter, and that my goal was to understand their thoughts. For most participants who had been somewhat anxious, they seemed more at ease as the interviews progressed and as their focus became occupied by the development of their own ideas. I was somewhat unprepared when one participant clearly related to me as a psychiatrist rather than a researcher and asked me questions about depression diagnosis and treatment. In response, I evaded the questions in the interest of keeping my views separate from the interview. However, having considered this matter further, I would in future research endeavour to plan for a more elegant response that acknowledges the relevance of such questions but gently

re-orientes the participant to the boundaries of my role in research interviews. I was also aware that as an “insider” and being familiar with psychiatric models of conceptualising depression, I at times did not ask psychiatrist participants to explain terms and concepts in as much details as I would have for the palliative medicine specialist group. This experience will inform my future research practice in enhancing my level of self-awareness.

In data analysis, I was mindful of the fact that some participants and I shared ideas on the subject matter, and as such, I was careful that these ideas were not over-emphasised. During the whole process of thematic analysis, I constantly checked the authenticity of my codes and themes against the raw data. My supervisors assisted in enhancing the trustworthiness of the findings by independently coding one full transcript and comparing these with my codes. They also examined the final themes of my analysis in conjunction with the transcripts to verify their authenticity.

Over the course of my candidature, my appreciation of the reflexivity process in qualitative research has deepened. Whereas I had understood the theory and importance of reflexivity from the outset, through active experience, I have developed greater comfort in engaging in this self-analysing process and in reporting my observations and thoughts. Beyond reasons of transparency and methodological rigour, reflexivity is a tool in my continuing development as a qualitative researcher.

CHAPTER 2 PALLIATIVE MEDICINE PRACTITIONERS' VIEWS ON THE CONCEPT OF DEPRESSION IN THE PALLIATIVE CARE

SETTING

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2.1 Statement of author contributions

Statement of Authorship

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Author Contributions

By signing the Statement of Authorship, each author certifies that their stated contribution to the publication is accurate and that permission is granted for the publication to be included in the candidate's thesis.

Name of Principal Author (Candidate)	Felicity Ng		
Contribution to the Paper	Performed background literature review, designed and conducted the study (including recruitment, data collection and data entry), performed data analysis, interpreted the data, wrote the manuscript and revised this in response to comments from supervisors, acted as corresponding author for the submission of to journals and revised the manuscript during the submission process in consultation with co-authors.		
Signature		Date	26/11/14

Name of Co-Author	Gregory B. Crawford		
Contribution to the Paper	Supervised the development of this study, reviewed and assisted in the editing of the manuscript.		
Signature		Date	26/11/14

Name of Co-Author	Anna Chur-Hansen		
Contribution to the Paper	Supervised the development of the study, performed independent analysis of qualitative data as a measure of rigour, reviewed and assisted in the editing of the manuscript.		
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CHAPTER 3 HOW DO PALLIATIVE MEDICINE SPECIALISTS CONCEPTUALISE DEPRESSION? FINDINGS FROM A QUALITATIVE IN-DEPTH INTERVIEW STUDY

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Contribution to the Paper	Performed background literature review, designed and conducted the study (including recruitment, data collection, transcription), performed data analysis, interpreted the data, wrote the manuscript and revised this in response to comments from supervisors, acted as corresponding author for the submission to the journal and revised the manuscript during the submission process in consultation with co-authors.		
Signature		Date	26/11/14

Name of Co-Author	Gregory B. Crawford		
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**CHAPTER 4 PALLIATIVE MEDICINE SPECIALISTS' CAUSAL
EXPLANATIONS FOR DEPRESSION IN THE PALLIATIVE CARE
SETTING: A QUALITATIVE IN-DEPTH INTERVIEW STUDY**

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4.2 Abstract

Objective: Medical practitioners have different causal explanations for depression, and may have greater difficulty in explaining causality of depression in the palliative care setting. The objective of this study was to investigate and describe the causal explanations of depression in the palliative care setting, from the perspective of palliative medicine specialists.

Methods: Palliative medicine specialists practising in Australia were recruited and purposively sampled. Individual semi-structured, in-depth interviews were conducted to explore their explanatory models of depression, including a focus on causal explanations. Nine participants were interviewed to reach data saturation. Interview transcripts were analysed for themes.

Results: Six themes for causal explanations of depression were identified: (1) Depression is inexplicable; (2) Biological explanations – primarily neurotransmitter depletion; (3) Psychological explanations – including reaction to circumstances, inability to accept illness and dying, diminished self, and coping mechanisms; (4) Social explanations – including inadequate social support, and contribution from modern medicine and societal norms; (5) Interrelationships between causal factors – mainly multifactoriality; (6) Different explanation for *de novo* and pre-existing depressions. Participants also articulated a link between causal explanations and clinical interventions.

Conclusions: Palliative medicine specialists hold causal explanations of depression that align with the biopsychosocial and vulnerability-stress models. They use multiple individual explanations with diverse theoretical underpinnings, and largely view depression as multifactorial in causality. Given that causal explanations are linked to clinical interventions, these findings have implications for clinical practice and medical education.

4.3 Introduction

Aetiology and pathogenesis are keystones to understanding illnesses, and are central determinants for prevention and management. Although depression is widely established to be common in the palliative care setting,[15,16] it remains poorly understood in many respects, including its causality and pathogenetic mechanisms. This situation is similar outside the palliative care setting, where depression is generally thought to result from complex interrelations between multiple causal and influencing factors across the lifespan, of a biological, psychological and/or sociocultural nature.[107,183] Within this framework, risk factors rather than causes have been identified, and pathogenetic mechanisms remain largely propositional.

There have been different paradigms over time for studying the causality and mechanisms of depression. These have placed varied emphases on biological versus psychosocial factors,[45,48] with competing paradigms being almost incommensurable with one another in their theoretical and philosophical assumptions.[107] The biopsychosocial model,[184,185] which was originally proposed as an alternative to the reductionistic biomedical model of illness, has tempered to an extent such divisions by providing a broader and more holistic framework, and has arguably become the prevailing framework for explaining psychiatric disorders.[106]

Studies of medical practitioners have identified biomedical and psychosocial causal explanations as two distinct ways of understanding depression, which often generate dissonance and conflict in being reconciled to inform management.[102-105] Little is known about medical practitioners' causal explanations for depression in the palliative care setting. Previous research shows that medical practitioners consider depression to be different in this compared with other settings.[177,186] In view of this, it is relevant to examine the causal explanations held by medical practitioners in

this specific setting. In one study, almost half of the sample of palliative medicine practitioners was ambivalent about whether depression had identifiable causes, and respondents primarily attributed causality to psychological and existential/spiritual factors over biological factors, in similar proportions to their preference for psychological intervention over pharmacotherapy.[177]

The present study aimed to investigate and characterise palliative medicine specialists' causal explanations for depression in the palliative care setting. The research question is: "What are palliative medicine specialists' explanatory models of depression?"

4.4 Methods

As the methodology has already been described elsewhere,[186] readers are referred to the earlier source for details on recruitment, data collection and analysis. A summary is provided below.

Palliative medicine specialists practising in Australia were recruited through a local palliative medicine conference, and participants were selected using purposive sampling that considered gender and geographical location. Participants underwent individual, semi-structured, in-depth interviews. An interview guide was used, which included key content areas of the concepts of depression, its causality and pathogenetic mechanisms, timing and onset of symptoms, course and treatment. Participants were given freedom to speak on these areas as well as other emergent areas relevant to the topic. As different understandings of depression were assumed, the term "depression" was used in interviews with the only specification being the clinical usage of the term. The first author, a psychiatrist with an interest in palliative care, conducted all interviews. Nine participants were interviewed to reach data saturation, which was identified through a process of constant comparison using an

audit trail. The demographic characteristics of the sample were described in the earlier paper.[186] The mean duration of the interviews was 60.2 minutes (range 46-76 minutes).

The interview transcripts were analysed for themes by the first author, using thematic analysis as outlined by Braun and Clarke.[142] To enhance trustworthiness of the findings, both co-authors (ACH and GBC) verified the codes generated from the first fully coded transcript against the raw data, and one co-author (ACH) also verified the final themes against the raw data in all transcripts. Differences arising from this process were discussed among all authors to reach consensus. NVivo9 software[141] was used to assist with data organisation.

This study received institutional approval from the University of Adelaide Human Research Ethics Committee (H-086-2010).

4.5 Results

Six themes were identified in relation to participants' causal explanations of depression: Depression is inexplicable; biological explanations; psychological explanations; social explanations; interrelationships between causal factors; and, different explanation for *de novo* and pre-existing depressions. Participants applied multiple causal explanations, but gave different primacy of focus in their explanations, such that individual participants ranged from holding primarily biological or psychosocial explanations, to holding a combination of these in equal weighting. Data extracts are given in tables to illustrate the subthemes.

4.5.1 Depression is inexplicable

Depression was considered to be inexplicable in the sense of being random in its occurrence, capable of affecting any individual at any time, and reflecting "bad luck".

Its inexplicability was also underpinned by having causality that is difficult to pin down, which left participants with an uncertain explanatory framework (Table 1). Participants felt that existing causal explanations are inadequate as a means of understanding pathogenesis. For example, a participant compared explaining depression as a chemical imbalance to explaining headaches as an aspirin deficiency. In a similar vein, participants also reflected on the inexplicability of resilience, or in other words, why more individuals do not become depressed in the end-of-life (EOL) setting, given the frequent presence of depressogenic factors.

Table 1. Illustrative data extracts for the theme: Depression is inexplicable

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Depression strikes randomly	<i>“I think it just reflects that depression can hit, you know, the general population, and because of the organic factors that happen in palliative care, it hits with more frequency, but I think it’s sort of semi-random who gets it and who doesn’t.” (Participant #3)</i>
Causality of depression is hard to pin down	<i>“I think it’s hard to pin down to one cause, or even say what the contribution is...there’s possibly a bias from other members of the team to look for psycho-socio-spiritual issues in terms of causing the patient’s mental distress and depressive symptoms, rather than thinking there’s a disease that requires physical treatment...I don’t think it’s one or the other.” (Participant #1)</i>

4.5.2 Biological explanations

The majority of participants considered depression to be caused by neurotransmitter depletion (Table 2). For some participants, depression was pathologically defined in terms of neurotransmitter depletion, and a “true depression” was equivalent to a “biological depression” that is marked by brain neurochemical changes. Contributing factors such as a fragile neurotransmitter system and physical illness were integrated into this model to provide an intrinsically coherent explanation for the link between vulnerability factors and the occurrence of depression. The neurotransmitter depletion model equipped participants with a framework for explaining depression to patients and to assist in engaging them in treatment. Participants described

employing variations on the theme that included analogies of supply and demand, replacement of depletion, and readjustment of balance. This model also indicated a clear role for medication as treatment, and placed pharmacotherapy as the “thrust” of treatment. Non-biological interventions were given secondary status and were conceptualised in terms of helping to readjust neurochemical balance.

Within this model, participants organised their understanding of how the neurotransmitter imbalance arises in terms of predilection and triggers (Table 2). Biological propensity to depression was considered to involve genetics, brain development, brain structural changes, ageing and illness. Patients with a history of depression were also seen to be biologically vulnerable to depression recurrence when further neurochemical insults occur. Resilience was explained in this framework as particular ways in which neurotransmitters are bound, as a result of genetics and development. Biological triggers of depression in the palliative care setting were either seen as direct illness factors, such as metabolic illness effects, cancer-related bioactive peptides or immunological markers, and a failing body, or as indirect illness factors that included poor symptomatic control, insomnia and chemotherapy. Dying itself was not considered to be a causative factor of depression.

Table 2. Illustrative data extracts for the theme: Biological explanations of depression

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Neurotransmitter depletion causes depression	<i>“I’m certain that of course there’s a depletion of neurotransmitter amines in the CNS (Central Nervous System), which is how pathologically, you can define depressed states sometimes, and that’s how medication is supposed to work, in interfering with metabolism of neurotransmitter amines.” (Participant #4)</i>
Biological propensity to developing depression	<i>“I think it’s a nasty disease that probably has some chemical and perhaps even some structural elements to it in the brain, definitely chemical elements...For a lot of people, it’s an inherited risk.” (Participant #9)</i>
Direct illness causative factors	<i>“I think physical illness has profound metabolic effects, which affect every part of our body – our muscles waste, our appetite goes down, we lose weight, we lose</i>

	<i>strength, we get profound fatigue. I think in the same way, these metabolic changes can affect the brain, 'cause our brain isn't separate from our body."</i> (Participant #3)
Indirect illness causative factors	<i>"I guess insomnia itself can alter people's moods...and if patients have (poorly-controlled) symptoms, that would alter their mood."</i> (Participant #1)

4.5.3 Psychological explanations

Another dominant theme in the participants' causal explanations for depression was psychological causality. There were diverse explanations, although most related to illness and dying (Table 3).

Table 3. Illustrative data extracts for the theme: Psychological explanations of depression

<i>Subthemes</i>	<i>Illustrative data extracts</i>
A reaction to circumstances	<i>"Obviously, you know, seriously depressing life situations can cause people to become depressed."</i> (Participant #9)
Inability to accept illness and dying	<i>"...there's a distinct group of people who...continue to ruminate about why me and how can I cope with this, I never wanted to live like that, what sort of a life is this? I wish it was all over, I'd be better off dead. It's very important for us not to collude with that."</i> (Participant #3)
Diminished self	<i>"...if someone who also lives very much in their physical body about being able to move and to be independent, the whole idea of, I guess, loss of function, loss of independence, loss of ability, resonate to make sense about low mood."</i> (Participant #5)
Coping mechanisms are modulating factors	<i>"I think, again, it depends on the premorbid personality as to how people react emotionally, and so, depending on a person's coping skills and the mechanisms they've used throughout their lives, so they react and so they respond."</i> (Participant #4)

First, depression was thought to be a reaction to life circumstances. Receiving bad news such as disease progression and transitioning into palliative care were considered to be triggers that accounted for increased incidence of depression at those times in the illness trajectory. Another subtheme was that inability to accept

illness and dying leads to depression. Non-acceptance was thought to arise from unresolved grief, externalised anger over personal predicament, and discrepancy between expectations and reality. In line with this understanding, assisting patients to reach a state of acceptance regarding illness and dying was seen to be an effective therapeutic intervention. Consequences of illness and dying on the self formed a third way of explaining depression in psychological terms. In this subtheme, the self becomes diminished through losing control and independence, and being disempowered, resulting in loss of confidence and a sense of being useless, hopeless, and a failure.

The last subtheme was that coping mechanisms mediate the development of depression. These coping mechanisms were understood as part of personality, often formed through learnt life experiences, and were consistent over time between the “premorbid” period and when faced with a life-limiting illness. Certain personality traits, such as being pessimistic, action-oriented or being less contemplative or spiritual-minded, were considered to place individuals in a vulnerable position to developing depression. In contrast, past life experiences were understood to strengthen individuals’ coping and thus explain their resilience to succumbing to depression during terminal illness.

4.5.4 Social explanations

Depression was considered to be more common among those who are inadequately supported, socially isolated and lonely (Table 4). Social support was seen to protect patients by allowing them to address their sadness, a process which, if thwarted, would lead to depression.

Another subtheme was the role of modern medicine in causing depression (Table 4). Two mechanisms were described. The first was treating patients with a

disempowering and isolating approach. Consistent with this understanding, journeying with patients and keeping patients informed of their disease status were regarded to prevent and ameliorate depression. The second mechanism was trauma from treatment. An example given was the use of multiple lines of chemotherapy, which can cause harm by subjecting patients to repeated cycles of hope and disappointment, and this was compared to a form of torture.

Societal norms were also thought to contribute to the development of depression by exerting pressure on patients to maintain positivity to the extent that their reality of dying is denied (Table 4). The devaluing by society of those who are old, ill, debilitated and dying was also considered to contribute to depression in terminally ill patients.

Table 4. Illustrative data extracts for the theme: Social explanations of depression

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Inadequate social support	<i>"...the patients that come to mind (as more vulnerable to depression) are often the patients who are more isolated, so patients who live on their own,...people who are estranged from families...it seems to be more of a problem for those people who are socially isolated and alone." (Participant #5)</i>
Modern medicine creates depression	<i>"I think anxiety and depression are linked together, and I think that comes partly from people feeling disempowered and lack of control, and I think that modern medicine tends to make that worse as well, because people get plugged into a system which tells them what they've got to do all the time." (Participant #2)</i>
Societal norms contribute to depression	<i>"...there's such pressure on people to maintain hope and be positive, that it almost denies them the opportunity to think about the negatives, and by not acknowledging that, I think that generates a lot of anxiety and fear and uncertainty, which again might be interpreted as depression." (Participant #2)</i>

4.5.5 Interrelationships between causal factors

Participants articulated multiple causal explanations for depression, and how individual explanations were understood in relation with one another took three

forms (Table 5). One form was in terms of a continuum, spanning from psychosocial factors at one end to organic factors at the other, giving rise to various types of depression. However, the most common form by far was multifactoriality, where depression was considered to have multiple concurrent, parallel causal explanations, which were all accepted as important. The biopsychosocial model was regarded as standard in this approach of explanation, and there was no articulation of how individual explanations interact with one another to generate depression. The third way of relating causal threads was integrative. In this approach, an overarching theoretical framework connected the different causal explanations, in contrast to the unlinked, parallel explanations in multifactoriality. Integrative explanations were scantily articulated among the participants, but an example is given in Table 5 that links life experiences with brain development, with brain dysfunction as the overarching explanatory framework for depression. Another participant explained the concept of resilience in terms of the impact of upbringing on neurotransmitter binding, thus connecting developmental and neurobiological aspects.

Table 5. Illustrative data extracts for the theme: Interrelationships between causal factors

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Continuum of explanations	<i>"...what I'm trying to say is that there is a continuum between the type of anxiety and depression...it's situational...and there's more chance of psychotherapy or psychological counselling to assist that person. But on the other end of the spectrum, it's not just the situation, it's organic effects." (Participant #3)</i>
Multifactoriality	<i>"I think it's part of a biopsychosocial response...with people who have got cancer, it's because of illness. Others see it as a major challenge to their personal integrity as a person, and there is a lot of stress, physically, psychologically, emotionally, spiritually on the body, and I guess depression comes about as an abnormal delay in response to everything that's happened." (Participant #8)</i>
Integrative explanations	<i>"Obviously, there's some biochemistry involved in there, and I guess that biochemistry and genetics are involved in there somewhere, and...learnt experiences of life as well, which I guess becomes reflected in the development of their brain." (Participant #2)</i>

4.5.6 Different explanations for de novo and pre-existing depressions

Participants conveyed the notion of different causality for depression that occurs for the first time in the context of life-limiting illness, compared with depression that has precedence before the illness (Table 6). Those with previously diagnosed depression were seen to be vulnerable to becoming depressed again, especially when faced with added stressors such as terminal illness and its implications, which were considered to play a triggering role. For this group, terminal illness or dying was sometimes considered to play no causative role at all in the recurrence of depression. In comparison, the causality of *de novo* depression was predominantly attributed to illness (primarily malignancy) and its biological effects on the brain.

Table 6. Illustrative data extracts for the theme: Different explanations for *de novo* and pre-existing depressions

Subthemes	Illustrative data extracts
Propensity for depression in pre-existing depression	<i>"...(the) group who've had episodes in the past, I sort of explain it that your brain has this propensity or vulnerability to dip in the hormones that make you feel more up than down, but I'm not surprised that this disease has triggered it." (Participant #6)</i>
<i>De novo</i> depression has different mechanism	<i>"Someone who has never had a depression in the past, I wonder if what's happening in the brain is the same sort of neurochemistry as happening in someone who's had depression in the past, who has now a major illness and it's happening again. Or whether it's a different physical change put on by the whole stress of the cancer on the body...as part of the cancer-related syndrome." (Participant #8)</i>

4.6 Discussion

This study demonstrates that palliative medicine specialists have a variety of causal explanations for depression in the palliative care setting. These largely follow the three constituent domains of the biopsychosocial model.[184] Within this framework, participants identified vulnerability and triggering factors, suggesting that their causal explanations also follow the vulnerability-stress model.[187]

Explaining causality along these dual dimensions of the biopsychosocial and vulnerability-stress models is widely adopted in psychiatry, and forms a common framework for psychiatric formulation.[188] Thus, our findings support that palliative medicine specialists generally have a holistic approach to understanding depression, and use an explanatory framework that is structurally comparable to that used in psychiatry.

Two further observations of our findings can be made: First, participants differed individually in their causal explanations; secondly, participants rationalised their interventions and engaged patients in treatment through their causal explanations, which support a direct relationship between attributed causality and treatment. The various causal explanations reflect diverse theoretical underpinnings. Neurotransmitter depletion is situated in the monoamine hypothesis of depression.[189] Among the psychological explanations, depression as a reaction to circumstances is reminiscent of the Meyerian concept that depression is a psychobiological reaction to stress;[106,190] inability to accept illness and dying as an explanation is rooted in theories of grief, which place depression as either a part of normative grief or a pathological form of grief;[94-97] the idea of diminished self is similar to demoralisation, with its manifestations of subjective incompetence, loss of control, diminished self-esteem, helplessness and hopelessness;[191,192] and the mediating role of coping mechanisms is aligned with coping and personality theories.[193,194] The social support emphasis evokes a number of social support theories that consider how social support protects people from stress and promotes coping, self-esteem, emotional self-regulation and a sense of identity.[195] The idea that society denies terminally ill patients their reality of dying is comparable to the concept of disenfranchised grief,[196] while iatrogenic causation relates to notions of demoralisation,[191,192] dignity,[197] and psychological trauma.[198]

Biological and psychological causality were prominent themes in this study, and the overall causal explanations of the participants are positioned between the primarily biological[102] or primarily psychosocial[103-105] causality that have been reported in the depression literature. Neurotransmitter depletion was dominant as an explanation among participants, which is notable in view of previous research that suggested a predominantly psychological and existential/spiritual causal attribution in the palliative care setting.[177] A primarily neurochemical causal explanation was similarly reported among primary care medical practitioners, and depression with non-psychosocial origin was likewise equated with “true depression”.[102] In contrast, other studies have reported a primarily social attribution of depression among primary care practitioners,[103-105] including two that focussed on depression in the elderly,[104,105] which has relevance for the palliative care setting. The prominence of terminal disease in the palliative care context may reinforce the relevance of biological contributions to depression, but the reasons for the dominance of the neurotransmitter depletion explanation in this study are not entirely clear. The monoamine hypothesis of depression has been influential in depression research and treatment for over 50 years, but is increasingly recognised as a simplistic model of explaining depression that has largely resulted in research stagnation.[170,199] Despite this, it appears to remain influential in medical practitioners’ causal explanations, which may reflect delay in paradigmatic shifts from research to practice, or may indicate the tenacity of a theory that harmonises with the biomedical framework, which is familiar to medical practitioners.

The variety of causal explanations described by the participants suggests that they could flexibly accommodate individualised explanations within the biopsychosocial framework. However, participants applied multiple causal explanations within this framework, each with its distinct theoretical underpinning, and all were sometimes seen as equally important. When used in this way, biopsychosocial causal

explanations have limited cohesive explanatory power. The deficiencies of the biopsychosocial model as a causal explanatory framework have been argued,[106,200,201] including the claim that it provides eclectic candidate risk factors that retrospectively justify the occurrence of psychiatric disorders, rather than predictively explain how they arise,[201] a situation that has been analogously compared to having a list of ingredients without a recipe.[106,202] Such a multifactorial biopsychosocial model, although holistic in schema, lacks specificity when used to guide management. This is particularly problematic at the EOL, where limited time and resources make specific targeted interventions desirable, instead of a blanket or a trial-and-error approach, both of which may inefficiently utilise resources and increase the interventional burden for patients. A strong causal explanation model should also explain the absence of illness as well as its presence. The biopsychosocial model has little capacity to explain why people do not develop depression given the presence of risk factors, other than providing a list of resilience factors. In fact, some participants reflected on this very point, in wonderment of the resilience of most patients in not succumbing to depression under the circumstances of terminal illness. The limited specificity and explanatory power of this causal explanation model possibly account for why some participants describe depression as inexplicable and random, and as reported elsewhere, uncertain about whether depression has identifiable causes.[177]

The theme of *de novo* depression being different from recurring or pre-existing depression reverberates with previous findings,[177,186] and is a hypothesis that deserves further investigation as it has implications for refining treatment. This theme also raises the issue of the extent to which causal explanations hinge on the perspectives of medical practitioners. Palliative medicine specialists may have a confined view of a patient's depression within the spotlight area defined by the palliative phase of care, without the advantage of witnessing the patient's experiences

over a whole life perspective. This is true of any specialised medical setting, and caution is therefore necessary when making assumptions of causality based on a previous history of depression. It may be more useful to differentiate depression according to its qualities or phenomenology,[54] rather than past history alone.

As discussed elsewhere,[186] the first author's status as a psychiatrist might have inadvertently influenced interviews, but any influence on data analysis was minimised by having the co-authors (a palliative medicine specialist [GBC] and a psychologist [ACH]) verify codes and the final themes against the raw data. The findings of this study should be transferable to settings where palliative medical training, practice and culture are similar to Australia, but may still be of interest to those that differ.

In conclusion, this study demonstrates that understanding causal explanations is important, because medical practitioners consider interventions in reference to causality and employ causal explanations to engage patients in treatment. It also describes the variety of causal explanations for depression in the palliative care setting, and how multiple causal explanations are conceptualised in relation to one another by palliative medicine specialists. Conceptually, it is important to promote the examination and active discussion of the causality models that underpin the clinical approach to depression. Although causality of depression is complex and unlikely to be explainable by single causal mechanisms, this difficult situation should be emphasised in medical education, as the appeal of reductionistic explanations can generate confusion and misguide clinical intervention. As paradigms evolve in relation to depression research and clinical practice, close collaboration will be necessary between psychiatry, palliative medicine, psychology, and the biological and social sciences, in order to enrich and further both knowledge and skills in approaching depression at the EOL.

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**CHAPTER 5 TREATMENT APPROACHES OF PALLIATIVE
MEDICINE SPECIALISTS FOR DEPRESSION IN THE PALLIATIVE
CARE SETTING: FINDINGS FROM A QUALITATIVE, IN-DEPTH
INTERVIEW STUDY**

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Contribution to the Paper	Performed background literature review, designed and conducted the study (including recruitment, data collection, transcription), performed data analysis, interpreted the data, wrote the manuscript and revised this in response to comments from supervisors, acted as corresponding author for the submission to the journal and revised the manuscript during the submission process in consultation with co-authors.		
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5.2 Abstract

Background: Treatment of depression in the palliative care setting is complicated by varied treatment preferences, a small body of research, and unique challenges associated with the end-of-life. Little is known about the treatment practices of medical practitioners in this setting.

Objective: This study aimed to investigate and characterise the treatment approaches of palliative medicine specialists for depression.

Design: Semi-structured, in-depth interviews were conducted to explore explanatory models of depression from palliative medicine specialists, including a focus on treatment. Verbatim interview transcripts were analysed for themes.

Setting/Participants: Palliative medicine specialists practising in Australia were recruited and purposively sampled. Nine participants were interviewed to reach data saturation.

Results: Five themes were identified in relation to treatment of depression: (1) Guiding principles of treatment; (2) treatment approaches; (3) factors underpinning treatment decisions; (4) difficulties arising in treatment; and (5) inter-disciplinary roles. Participants described five distinct treatment approaches, consisting of biological orientation, psychosocial orientation, combination approach, undifferentiated approach, and ambivalence. Treatment decisions were contingent on patient, depression, clinician and sociocultural factors. Difficulties included discomfort with treating depression, being inadequately equipped, and confronting therapeutic limitations. Treating depression was considered to require multi-disciplinary team effort.

Conclusions: Palliative medicine specialists' treatment approaches are linked to their concepts of and causal explanations for depression. Future treatment guidelines could aim to consider specific varieties of depression, be more differentiated in treatment modality and type, and consider decision-shaping factors. Continuing

mental health education and the incorporation of psychiatry and psychology into palliative care services may have enduring benefits.

5.3 Introduction

Medical practitioners have different treatment preferences for depression in the palliative care setting in terms of treatment modalities and the selection of specific pharmacotherapy, psychotherapy or complementary and alternative medicine.[37,39] Varied opinions on treatment have also been reported among recognised experts in the field.[172] Although expert recommendations and guidelines are available for the treatment of depression in the palliative care setting,[32,203-205] insufficient evidence has restricted their specificity.[32,206,207] Treatment is further challenged by considerations within the palliative care setting, such as short life expectancy, fear of interfering with emotional adaptation to the end-of-life (EOL), multiple priorities that compete for limited clinical time, and the relative inaccessibility of mental health specialists.[37,39,101,208]

Given the variability in treatment preferences and complexities presented by the palliative care setting, investigating the treatment approaches of medical practitioners could clarify how treatment decisions for depression are made, and identify foci for further research and debate. Few studies have explored this area, although the available literature suggests that medical practitioners in palliative care have a clear preference for psychological interventions over pharmacotherapy.[39,177]

This study asked the research question: What are the treatment approaches of palliative medicine specialists for depression in the palliative care setting?

5.4 Methods

Readers are referred to an earlier paper for details on recruitment, participant characteristics, data collection and analysis.[186]

In brief, palliative medicine specialists practising in Australia were recruited through a local palliative medicine conference and purposively sampled with consideration given to gender and geographical location. The first author, a psychiatrist with an interest in palliative care psychiatry, conducted all interviews. Individual, semi-structured, in-depth interviews were conducted with the aid of an interview guide. As different understandings of depression was assumed, the term “depression” was used in interviews with no specification of diagnostic terminologies other than the clinical usage of the term. Nine participants were interviewed to reach data saturation, which was identified through a process of constant comparison using an audit trail.

Interview transcripts were analysed for themes using the thematic analysis method outlined by Braun and Clarke.[142] The co-authors, a psychologist (ACH) and a palliative medicine specialist (GBC), verified the initial codes from one full transcript. ACH also verified the final themes against the entire dataset. Discrepancies were discussed among all authors until consensus was reached. NVivo9 software[141] was used to assist with data organisation.

This study received institutional approval from the University of Adelaide Human Research Ethics Committee (H-086-2010).

5.5 Results

Five themes were identified: Guiding principles of treatment; approach to treatment; factors underpinning treatment decisions; difficulties arising in treatment; and interdisciplinary roles.

5.5.1 Guiding principles of treatment

Three principles underlay the participants' approach to managing depression (Table 1). Firstly, treating depression was considered a remit of palliative care. Participants related this to palliative care goals of being holistic, caring for the person, and alleviating suffering. They viewed the management of depression and physical symptoms as intertwined, and valued accompanying patients through the terminal phase of illness. These factors contributed to their sense of responsibility for treating depression.

Secondly, treatment was the default position, with some participants indicating that they would always intervene in some way. This was linked to the idea that suffering required intervention. Uncertainty about the diagnosis of depression was not regarded as a reason for not implementing treatment, which was justified by potential therapeutic benefits and the risk of missing an opportunity to alleviate suffering.

The third principle was that treatment should be individualised, in the sense of accommodating individual circumstances, such as degree of frailty and quality of existing social support. Personal context was also important, and referred to respecting the patient's way of approaching the EOL, and understanding the life experiences that had shaped this.

Table 1. Illustrative data extracts for the theme: Guiding principles of treatment

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Treating depression is a remit of palliative care	<i>"I think you can't address emotional things in isolation...it goes without saying that we rigorously address the obtrusive physical symptoms, and are obliged then to follow up their emotional pain and their spiritual pain...I think holistic care means that we look at the whole person...to see if we can relieve their distress in other parts of who they are, and that may mean then that we need to address a depressed</i>

The default is to treat	<i>state.” (Participant #4)</i> <i>“...it’s that business of just...how much of it is depression and how much of it is an appropriate reaction to a horrible situation. And often, I guess, we treat it as depression because if we can make them a bit better, it’s a good thing.” (Participant #9)</i>
Treatment should be individualised	<i>“...the complexity of their lives is a unique and individual thing...if you recognise that and approach it as that, and then take each person on their own merits...rather than trying to categorise them...in some people you might use some antidepressants, but in all of them, you need to look at the context in which they are approaching the end of their life, and their experiences and what’s shaped them the way that they are.” (Participant #2)</i>

5.5.2 Approach to treatment

Participants’ treatment of depression can be described by five distinct approaches (Table 2). Those with a biological orientation considered pharmacotherapy, primarily antidepressants, to be core treatment, which was generally acceptable to patients and could benefit other problems such as insomnia, anorexia and nausea. Depression was thought to be, by definition, non-amenable to social intervention, and non-pharmacological therapies could only serve an adjunctive role, for instance, as a temporary diversion. Pharmacotherapy was considered to be a role of medical practitioners, and required expertise in combining pharmacological knowledge, clinical experience and skills. Electroconvulsive therapy (ECT) was regarded as an effective treatment, especially in the elderly, but was often contraindicated in terminally ill patients.

In contrast, participants with a psychosocial orientation considered depression in palliative care to be more amenable to interpersonal support, and viewed psychosocial interventions as key and always necessary, even when patients were close to death. Pharmacotherapy was considered ineffective and was infrequently used. Restricting treatment to pharmacotherapy was considered problematic.

Psychosocial interventions involved various foci: Establishing a relationship characterised by genuine regard, human connection, accompaniment and validation; communication and listening to patients' inner experiences; existential exploration such as the meaning of illness, accepting death and dying, life review, and redefining hope; restoring a sense of selfhood and autonomy; promoting healing; assisting with practical issues; providing an environment and professional structure that instilled a sense of security; and supportive care for the family.

For participants who described a combination orientation, treatment involved pharmacotherapy and psychosocial interventions, which were both seen as integral and jointly attended to the mind and body aspects of the individual.

In the undifferentiated approach, participants did not have a clear preference for treatment. Different interventions were discussed in interchangeable terms, for example, treatment with either pharmacotherapy or psychotherapy was seen to be equally appropriate, or different forms of therapies were non-selectively offered.

Some participants conveyed ambivalence in the treatment that they offered. This ambivalence originated from doubts about the effectiveness of treatment, or a sense that the offered treatment was a compromise. For example, prescribing antidepressants was described as a concession in situations where psychological therapy was preferred but unavailable.

Table 2. Illustrative data extracts for the theme: Approach to treatment

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Biological orientation	<i>“If I think it’s true depression, ...I would normally use an anti-depressant...(…)...I mean, all of (non-pharmacological interventions) will sometimes help the patients to get out of themselves for the period of time that they’re doing whatever they’re doing. So I think as a diversionary thing, they’re sometimes very helpful...” (Participant #9)</i>

Psychosocial orientation	<i>“...if in the context of life-ending illness, (depression) is more amenable to...social and supportive and human therapy, than it is to drug therapy....(...)...If the person can accept (dying) as an unfortunate reality for them,...and if we can help people to arrive at that state, then that’s the kind of therapeutic intervention that for me is most effective.” (Participant #2)</i>
Combination orientation	<i>“In lots of ways, the treatment of depression is a mind and body sort of process, so you can deal with the chemical side of things with the antidepressants, and you can deal with some of the mind sort of processes through acknowledging distress, but there is a lot of support that you need to give people in terms of reassurance that they’re not going to be left alone and isolated, and there is a mechanism for support for them and for their families as well, which I think is as much a part of managing the patient as is giving the prescription for the drugs.” (Participant #7)</i>
Undifferentiated approach	<i>“Well, if I think someone has a depressed mood or they’ve got sadness or spiritual distress, and they’re sort of fall in the criteria, I always ask every therapist that we have available to see the patient, to see if they can connect or help with the patient.” (Participant #8)</i>
Ambivalence	<i>“ ...my sense is that I end up prescribing antidepressants for a number of patients who I would feel much more comfortable if I could organise for them to see a psychologist, ...to actually dedicate more time for them, but...those services are just not available to people.” (Participant #5)</i>

5.5.3 Factors underpinning treatment decisions

Treatment decisions were underpinned by four groups of factors relating to the patient, depression, clinician and sociocultural environment (Table 3). Patient factors included illness considerations such as the level of disability and prognosticated survival. Frailty associated with advanced disease was seen as a barrier to psychological interventions that required the stamina to sustain conversations, and could also render patients incapable of taking oral medication. Anticipated survival was a deciding factor for treatment, especially in relation to pharmacotherapy, which was not prescribed when insufficient survival time was prognosticated. A prior history of depression was considered significant, because of the idea that antidepressants work better for recurrent depression but poorly for *de novo*

depression. Patients' receptiveness to treatment also determined treatment decisions, as treatment could not be forcefully imposed.

Depression considerations included attributed causality, diagnosis, severity and symptomatology. Depression attributed to situational causes was thought to be more amenable to psychotherapy than depression attributed to "organic" causes. Diagnosis was relevant, as exemplified by notions that Adjustment Disorder did not require pharmacotherapy, or that clinical depression could not be treated with supportive measures. Less severe depression was considered to respond to human connection, while severe cases might require ECT. Symptomatology referred to the symptom profile of depression, which formed a basis for the choice of antidepressant as well as psychosocial intervention, for example, talking about worries was thought to be unhelpful for patients who had ruminations.

Participants' prior work experience influenced treatment recommendations, as exemplified by one participant who readily considered ECT because of prior psychogeriatric work.

Sociocultural factors involved considerations of treatment accessibility and local treatment practice. Accessibility referred to constraints imposed by the patient's financial capacity to afford the recommended treatment, and the availability of treatment options. Antidepressants were commonly prescribed because they were readily available, whereas psychotherapy was often precluded by the difficulties in accessing psychologists or psychiatrists. Local treatment practices were recognised to vary, in terms of treatment approach and the ambient level of mental health expertise.

Table 3. Illustrative data extracts for the theme: Factors underpinning treatment decisions

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Patient factors	<i>“I think people who are very sick and weak and frail, are not easily able to embark on hour-long sessions of talking, so you have to fit your therapy to the patient and to the stage of their illness...(...)...There’s not a lot of use prescribing antidepressants to somebody who’s only got three days to live, you know, that’s nonsense.” (Participant #4)</i>
Depression factors	<i>“...depending on what the symptoms are, whether they’re anxious and agitated, or whether it’s more of a hypoactive kind of depression, then I’ll decide, you know, on an antidepressant.” (Participant #6)</i>
Clinician experience	<i>“I’m probably more likely to suggest ECT than anyone else, and that’s I guess ‘cause I’ve worked in an aged care psychiatry unit and I used to work in geriatrics, and for older people, ECT can in fact be really good and very helpful, so I’m a little bit more likely to suggest it.” (Participant #9)</i>
Sociocultural factors	<i>“...you often wonder, if this same patient is being cared for in a different state or a different country, would they be offered a very different therapy, or are they missing out?” (Participant #5)</i>

5.5.4 Difficulties arising in treatment

Participants described four difficulties they faced in treating depression (Table 4).

Table 4. Illustrative data extracts for the theme: Difficulties arising in treatment

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Discomfort with treatment	<i>“...discussions that seem to happen in palliative care teams are often around either not wanting to be nihilistic and say, ...they’ve got cancer, they’re dying, of course they’re sad, let’s not do anything. But swinging the other way, which is everyone is sad, we’ll just prescribe an antidepressant because they’re bound to feel better and that will make us feel better because we’ve done something.” (Participant #5)</i>
Inadequacy	<i>“I don’t, to be honest, I never come to more detail (about non-pharmacological intervention). Partly because it’s time, partly because I’m not familiar enough with the behavioural therapies. I just don’t know enough about them. So I sort of pass the buck to the people who do.” (Participant #6)</i>
Therapeutic limitations	<i>“One of the saddest and probably depressed men I’ve ever met...was a man whose wife had dementia and...he’d promised that he’d look after her. He was dying...and his despair was about the fact that he wasn’t gonna be able to fulfil his promise to his wife,...so that’s</i>

what made him despondent...I don't think there's an answer to that...we couldn't fix that issue." (Participant #2)

Risk of trying to treat multiple problems

"...mirtazapine is becoming incredibly widely prescribed, but probably more in sort of doses that help people sleep and may have some anti-emetic effect, than is necessarily a good antidepressant dose. So I think sometimes we get ourselves bogged down in terms of trying to treat multiple symptoms and then risking not treating any of them properly." (Participant #5)

Some participants described discomfort with treatment stemming from the difficulty in distinguishing between sadness and depression, and therefore uncertainty about the role of pharmacotherapy. Associated with this uncertainty were concerns about medicalising normative processes of emotional adjustment, adopting a simplistic model of addressing complex issues, and initiating treatment for their own benefit of overcoming a sense of powerlessness. Discomfort also arose from dissonance between their action and inclination, for example, when feeling pressured into treating depression by patients, families or staff, or when feeling that they were offering a compromised treatment that was inadequate or inappropriate.

Another difficulty was a sense of being inadequately equipped to treat depression. This related to inadequacies in the field, such as the paucity of evidence and consensus guideline recommendations in the palliative care literature, and to personal inadequacies. The latter involved feeling insufficiently equipped with time, expertise and skills, and insufficiently supported by access to specialist services.

Participants described difficulties in accepting the limitations of treatment for depression. Therapeutic limitations were seen as either the inability to provide efficacious treatment because of contraindications in terminally ill patients, or the lack of solutions to the problems causing depression. Working with such therapeutic limitations invoked a sense of helplessness, which was considered particularly

challenging for palliative care workers who aspired to relieve suffering and defined their worth in terms of their ability to achieve this.

Treatment could also be made difficult by endeavours to treat multiple problems simultaneously using the same treatment, which posed the risk of not addressing any problems adequately.

5.5.5 Inter-disciplinary roles

Participants regarded treating depression to be a multi-disciplinary team effort (Table 5). Inter-disciplinary members were noted to have different perspectives, and were considered to complement one another to provide multi-faceted care for patients.

Within the multi-disciplinary team, roles could be either segregated or transferable. Segregated roles referred to the assignment of specific tasks to different disciplines, which assumed specialised roles within the team. For example, social workers and pastoral care workers were charged with the tasks of selecting and delivering psychosocial interventions for depression. In contrast, some roles, such as being a support figure for the patient, were bestowed on an individual case basis and were thus transferable between team members.

Participants described both a sense of self-sufficiency and a need for external specialist support in treating depression. In most cases, they felt confident in treating depression and made few referrals to psychiatrists, whose involvement was seen to rarely add to the patient's treatment and was most useful to the team in an educational role. A reason for not involving psychiatrists and psychologists was the reservation that they were not generally inculcated with expertise in EOL care. On the other hand, having psychiatric back-up was thought to be desirable, primarily to

advise on pharmacotherapy, provide a second opinion where diagnosis is in question, and assist in difficult cases or when patients do not respond to initial treatments. A wish for increased access to psychotherapeutic skills was reported.

Table 5. Illustrative data extracts for the theme: Inter-disciplinary roles

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Treatment is a team effort	<i>“There is obviously...a difference in the way in which various disciplines respond to depression,...I suspect that the social workers from their perspective more look at the way in which people interact and their environment, and the nurses look at how they can actually provide support and care, and to prevent bad things from happening to people, and medical staff are probably in more of that diagnostic doing-stuff mode...One of the benefits of having a team, is that each of those three aspects can actually be brought to bear on the patient, hopefully constructively.” (Participant #7)</i>
Segregated roles	<i>“...in terms of non-pharmacological treatment...we have a social worker, a pastoral care worker, and we also have a mental health nurse on our multi-disciplinary team...and they, between them, will help me and the palliative care medical team decide about psychological therapy.” (Participant #6)</i>
Transferable roles	<i>“...it’s not always the doctor who’s the best person to support them, it’s the person who they connect to best. And I know, in palliative care units, where people have said, sometimes the best person is the cleaner who’s established a relationship with that person, providing the personal support, or any of the nursing staff.” (Participant #2)</i>
Self-sufficiency	<i>“...when it comes to depression, sometimes (psychiatrists) are just confirming what we already think. But we don’t call them in every time, because if it’s clear that the person is depressed, then we’ll get on and manage it.” (Participant #3)</i>
Specialist support	<i>“...we would do better if I think we knew that particularly for a group of patients who we felt that we were struggling with, that we could actually ask for some more help, so if we could actually have a psychiatrist, for example, who could go out and do a home visit on some of these patients and look at some better strategies, or even to say to us, yeah...I do agree with you, I think this person is depressed, or no, I don’t. That second opinion is really quite powerful.” (Participant #5)</i>

5.6 Discussion

In alignment with the holistic scope of palliative care and its focus on relieving suffering,[5,209] palliative medicine specialists in this study considered treatment of

depression to be part of their role, and were proactive in intervention. However, they differed in their treatment approaches, which notably include the diametrically opposite biological and psychosocial orientations. Both orientations have previously been described in relation to the treatment of depression in the palliative care setting.[37,39,177] At the core of these contrasting orientations are fundamentally conflicting notions of depression: being by definition non-amenable to social intervention and being responsive to interpersonal support. These reflect separate concepts of depression as pathological and as an emotional experience, and causal attributions relating to biological versus psychosocial explanations. These concepts and causal explanations have previously been published.[186,210] Of relevance, participants confirmed that causal attribution was a factor underlying their treatment decisions.

Combination and undifferentiated treatment approaches may be linked to a causal explanation of inexplicability, or to a multifactorial causal framework, where multiple parallel causality are considered aetiologically important.[210] In the face of causal uncertainty, different treatment modalities may be regarded as interchangeable, or combining them may be viewed as necessary to comprehensively address potential causes and safeguard effectiveness. Combination and undifferentiated approaches arguably correspond to current treatment guideline recommendations, which advocate for antidepressants and psychological therapies as mainstay treatments, but avoid guiding the choice between them[29,205] or emphasise the insufficiency of evidence to favour one over the other.[32,204] They offer similarly little guidance on the selection of antidepressant or type of psychotherapy. Although some guidelines communicate an implicit hierarchy by recommending the use of psychological interventions for mild depression and combining these with antidepressants for moderate to severe depression, they also give the impression of equipotence between pharmacological and psychological therapies.[32,204]

Some factors that participants identified as influencing their treatment decisions, such as life expectancy, depression severity and accessibility of specialist services, have previously been reported.[29,32,37] Others, such as diagnosis, attributed causality, symptomatology, prior clinical experience and local treatment practice, have received lesser attention. Together, these decision-shaping factors highlight considerations unique to the palliative care setting, and also convey the complexities of clinical treatment decision-making. Diagnostic terminologies appear to influence treatment, with supportive measures, for example, being seen as unsuitable for treating clinical depression. Specifying treatment according to diagnosis is not established in relation to depression, in contrast to many areas of medicine, and this discrepancy may cause excessive investment in some treatments.

Participants expressed uneasiness about the treatment of depression, as reflected by the subthemes of ambivalence in treatment approach, discomfort with treatment, being inadequately equipped and confronted by therapeutic limitations. There are three sources of uneasiness: Firstly, the conceptual distinction between sadness and depression generates concerns about diagnostic error and medicalising nature; secondly, inadequacies in skills or resources result in perceived compromise in the offered treatment; thirdly, lack of confidence in the effectiveness of intervention leads to feelings of powerlessness and therapeutic nihilism, which in turn create dissonance with the participants' objective of relieving suffering and give rise to perceived failure. Such feelings of inadequacy, powerlessness and failure may compromise patient care and staff well-being, including work stress and burn-out.[211,212]

In summary, this study finds that palliative medicine specialists have different treatment approaches; conceptualisation and causal explanation are intimately linked to treatment; the basis for selecting treatment modality or type is sometimes

unclear; and treatment of depression is associated with uneasiness. These findings have implications for clinical practice, research, medical education and service structures. Clinically, the different treatment approaches suggest that much variability may exist in practice. Although this is not necessarily undesirable or unexpected for a heterogeneous concept such as depression, primary alliance with a polarised biological or psychosocial orientation may deny patients the opportunity of being considered for alternative or combined approaches. On the other hand, a combination approach may not always be necessary, and an undifferentiated approach may not be an efficient use of resources. Current treatment guidelines lack specificity, especially for selecting among pharmacotherapy, psychotherapy or a combination of both, and for selecting individual medication or psychotherapy. The evidence-based nature of treatment guidelines is dilemmatic for depression, because its evidence base is compromised by fundamental problems with the atheoretical and heterogeneous concept of Major Depressive Disorder,[51,53,58] which has been influential in contemporary depression research, and by the methodological problems in and nascency of palliative care research.[15,36,206] Research on treatments may be more fruitful if more refined concepts of depression were used, which address different types according to phenomenology and causal attributions.[51,54] Specific guidance on the differentiation and selection of therapies, and incorporating factors that influence treatment decisions in the palliative care setting, may be goals for future treatment guidelines.

The present findings support the need for continuing education for palliative care services to increase their capacity to refine concepts of depression, select specific treatments in reference to depressive types, and gain greater comfort with the ambiguities in this area. In particular, participants valued psychotherapeutic skills, which may be enhanced through clinical training or increasing the accessibility of specialist services. Psychiatry and psychology are implicated in this respect.[213-215]

In order to serve in these roles, psychiatrists and psychologists would benefit from training in palliative and EOL care,[213,216] and psychiatrists would benefit from having a more equitable balance of psychotherapeutic and pharmacotherapeutic focus in their training.[217] There is evidence that treatment guidelines and education strategies by themselves are ineffective in improving the management of depression,[218,219] and the integration of psychiatrists and psychologists into palliative care teams may be argued as a superior service model,[214,215] which can allow continuing mental health education and assist teams in maintaining a sense of self-sufficiency while being adequately supported. The finding that prior clinical experience and local cultures play a role in perpetuating treatment practice further underscores the importance of pursuing excellence in mental health care.

As previously discussed elsewhere,[186] the first author's status as a psychiatrist with a specialised interest in palliative care psychiatry may have potentially influenced the interviewing and data analysis processes. Because this potential was acknowledged, trustworthiness measures were utilised, which included the co-authors independently verifying the codes from one transcript against the raw data, and one co-author (ACH) verifying the final themes against the entire dataset. Limitations on the transferability of the present findings are recognised, given the influence of local medical education and practices on the treatment approach of individuals.[186] The current findings are based on participants' descriptions of their treatment approach, which may not replicate actual practice. Nevertheless, this study extends the extant literature by crystallising the guiding principles, treatment approaches and decision-making considerations that palliative medicine specialists utilise, and describing the areas of difficulties and inter-disciplinary dynamics involved in treatment. Depression is a complex issue that cannot be readily reduced to a single concept, cause or treatment approach. It requires of clinicians a level of clarity and equanimity regarding the conceptual ambiguities, ability to make sense of depressive

presentations, and a nuanced treatment approach. These skills can be fostered within palliative care services.

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**CHAPTER 6 DEPRESSION MEANS DIFFERENT THINGS: A
QUALITATIVE STUDY OF PSYCHIATRISTS' CONCEPTUALISATION OF
DEPRESSION IN THE PALLIATIVE CARE SETTING**

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6.1 Statement of author contributions

Statement of Authorship

Title of Paper	Depression means different things: A qualitative study of psychiatrists' conceptualisation of depression in the palliative care setting
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Author Contributions

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Name of Principal Author (Candidate)	Felicity Ng		
Contribution to the Paper	Performed background literature review, designed and conducted the study (including recruitment, data collection, transcription), performed data analysis, interpreted the data, wrote the manuscript and revised this in response to comments from supervisors, acted as corresponding author for the submission to the journal and revised the manuscript during the submission process in consultation with co-authors.		
Signature		Date	26/11/14

Name of Co-Author	Gregory B. Crawford		
Contribution to the Paper	Supervised the development and conduct of this study, verified results of data analysis, reviewed and assisted in editing of the manuscript.		
Signature		Date	26/11/14

Name of Co-Author	Anna Chur-Hansen		
Contribution to the Paper	Supervised the development and conduct of this study, verified results of data analysis, reviewed and assisted in editing of the manuscript.		
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6.2 Abstract

Objective: Medical practitioners conceptualise depression in different ways, which adds to the challenges of its diagnosis, treatment and research in the palliative care setting. Psychiatric assessment is often considered the “gold standard” for diagnosis, therefore how psychiatrists conceptualise depression in this setting is pertinent. This study aimed to investigate this issue.

Methods: Psychiatrists working in palliative care in Australia were individually interviewed with a semi-structured approach. Nine participants were interviewed to reach data saturation. Interview transcripts were analysed for themes.

Results: Three overarching themes were identified: (1) Depression means different things; (2) depression is conceptualised using different models; and (3) depression is the same concept in and outside of the palliative care setting. Participants explicitly articulated the heterogeneous nature of depression, and described different breadths of concepts, ranging from a narrow construct of a depressive illness to a broader one that encompassed depressive symptoms and emotions. However, depressive illness was a consistent concept, and participants considered this in terms of phenotypic subtypes. Participants used three models (spectral, dichotomous and mixed) to relate various depressive presentations.

Conclusions: Psychiatrists did not subscribe to a unitary model of depression, but understood it as a heterogeneous concept comprised of depressive illness and other less clearly defined depressive presentations. Given the influence of psychiatric opinion in the area of depression, these findings may serve as a platform for further discussions to refine the concepts of depression in the palliative care setting, which in turn may improve diagnostic and treatment outcomes.

6.3 Introduction

Diagnosing depression in the palliative care context has been associated with challenges that include difficulties in distinguishing depression from sadness and advanced disease, the stigma of psychiatric diagnoses, and clinician factors such as the belief that depression is an expected part of dying, insufficient skills and therapeutic nihilism.[203,220,221] A perhaps less emphasised challenge relates to the conceptual ambiguity of depression, which has been complicated by the numerous definitions and classifications that have been applied to depression over time, in reflection of the prevailing psychiatric and social paradigms.[41,43,46-49,190] Although the concept of major depression, arising from the advent of the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) in 1980,[50] is widely used in clinical practice and research,[48] its conceptual foundation has been criticised and validity challenged.[51,53,55,58-60,68]

Research has identified that medical practitioners experience difficulties in reconciling the biomedical and psychosocial models of understanding depression.[102,103] Similar difficulties have been identified in the palliative care setting, with previous research showing two distinct ways in which palliative medicine specialists conceptualised depression, as pathology and as contextual phenomena.[186] The tension between these concepts is clinically important as they may signify different assessment and treatment approaches.[210]

In the absence of somatic diagnostic markers, assessment by psychiatrists has often been referred to as the “gold standard” for diagnosing depression,[29,222-224] although psychiatrists only assess a minority of patients who may be depressed. Understanding how psychiatrists conceptualise depression may be informative and of relevance in comparison with other practitioners in palliative medicine. As there are no published empirical studies on this subject, the present study aimed to investigate

this using a qualitative approach. The research question was: What are psychiatrists' conceptualisations of depression in the palliative care setting?

6.4 Methods

6.4.1 Participants and recruitment

This study targeted consultant psychiatrists who practised in Australia and had clinical involvement in the palliative care setting. Recruitment took place through the Royal Australian and New Zealand College of Psychiatrists (RANZCP), which claims approximately 85% of practising psychiatrists in Australia as its members.[144] A recruitment notice was placed in a RANZCP electronic bulletin that was distributed to its members. An email was also sent via RANZCP to members of its Section of Consultation-Liaison Psychiatry, which was anticipated to capture members with the most clinical involvement with palliative care services.

From those who responded to the notice and email, participants were selected using purposive sampling that took into consideration gender, geographical location (state) and duration of qualification as a psychiatrist. Recruitment continued until data saturation was reached. This occurred after 9 psychiatrists were interviewed. Their demographic characteristics are shown in Table 1.

Table 1. Participant characteristics

<i>Characteristic</i>	<i>Numbers of participants</i>
<i>Gender</i>	
Male	3
Female	6
<i>Psychiatric practice details</i>	
<i>Location</i>	
City	8
Regional or rural	1
<i>Setting^a</i>	
Hospital	8
Community	1
Private practice	1
Academic	3

Area in psychiatry ^a	
Consultation-Liaison Psychiatry	7
Psycho-oncology	4
Private Sector Psychiatry	1
Psychiatry of Old Age	1
Academic Psychiatry	3
<i>Years qualified as a psychiatrist</i>	Years
Range	1 – 26
Mean	12.3
Median	11
<i>Years of working in palliative care or psycho-oncology^b</i>	
Range	2 – 20
Mean	9
Median	8

^aSome participants worked in multiple settings and/or areas in psychiatry.

^bSome participants worked in both palliative care and psycho-oncology services, and reported commonalities in the nature of the work involved in these two services.

6.4.2 Data collection

The first author conducted all interviews between February and April 2011. She was introduced to participants as a psychiatrist with an interest in palliative care psychiatry, and was conducting this research as part of a doctoral degree. She did not have a personal or working relationship with any of the participants, although she had previously met the local participants within the professional circle. Local participants were interviewed in person in a private setting at their workplace, while interstate participants were interviewed over the telephone. All participants consented to their interviews being audiotaped.

Interviews were semi-structured and assisted by an interview guide. This comprised of participant details (training background, details of psychiatric practice and involvement in palliative care), followed by in-depth exploration of content areas that included concept of depression, its causality, pathogenetic mechanisms, timing and onset of symptoms, course, and treatment. Interviews were open-ended and participants were given freedom to develop their responses. Consistent with the practice of qualitative interviewing,[145] the contents of each interview were used to

guide and modify subsequent interviews. Participants were assumed to hold different concepts of depression, and the term “depression” was used without specification other than the clinical usage of the term.

An audit trail was kept to record interim analysis, and constant comparison was performed to determine when data saturation was reached, i.e. when no new themes for the research question were identified.[146,147]

The interviews ranged from 47 to 76 minutes in duration, with a mean duration of 63 minutes.

6.4.3 Data analysis

All interviews were transcribed verbatim by the first author and de-identified. Three participants agreed to review their transcripts for participant validation, and made no modifications to content.

The first author performed thematic analysis as described by Braun and Clarke, which involved the stages of data familiarisation, generation of initial codes, search for themes, review of themes, definition and labelling of themes, and finally, report-writing.[142] Coding was performed deductively in reference to interview content areas and inductively to emergent contents relevant to the research question. The criteria for quality outlined by Braun and Clarke[142] were used as a reference for rigor. The final themes were verified against the raw data by the co-authors (ACH and GC) to enhance the trustworthiness of the analysis. NVivo9 software[141] was used to facilitate data organisation.

6.4.4 Ethics

This study received institutional approval from the University of Adelaide Human Research Ethics Committee (H-086-2010).

6.5 Results

Three overarching themes were identified: depression means different things, depression is conceptualised using different models, and depression is the same concept in and outside of the palliative care setting.

6.5.1 Depression means different things

As a clinical term, participants saw depression as representing different things and as unhelpful since it could neither provide an understanding of the problem nor guide intervention. Depression being a heterogeneous concept and being variously conceptualised by clinicians formed the two subthemes, which are illustrated in Table 2.

Table 2. Illustrative data extracts for the theme: Depression means different things

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Depression is a heterogeneous concept	<i>“Depression...for me means a couple of different things. There is the...emotional state, which is quite common in the sort of patient population that I see as a result of...life stressors or physical illness. And then there is...the more extreme, pervasive, persistent form of...emotional state, where it...crosses an ill-defined boundary into what’s called clinical depression or Major Depressive Episode.” (Participant #2)</i>
Depression is conceptualised by clinicians in various ways	<i>“I think (concepts of depression) is varied. I think it depends a great deal on the opportunity the clinicians have had for any training in the mental health area...People working in palliative care who probably have worked more closely with psychiatrists, probably would differ from those who haven’t.” (Participant #7)</i>

Depression is a heterogeneous concept

Participants considered depression to be a heterogeneous concept, but individual participants varied in conceptual breadth. Those who conceptualised depression in broad terms of being an illness and emotional state and/or symptom warned against adopting a narrow view of equating depression with Major Depressive Disorder or an illness requiring antidepressants, because of the risk of thinking that depression falling outside of such criteria was insignificant or not requiring assistance. In comparison, those with narrow concepts of depression as an illness considered it to be over-diagnosed and often represented a mislabelling of distress and normal sadness, thus exposing patients to inappropriate treatment with antidepressants.

Collectively, participants defined depression variously as an emotional state, a symptom and an illness. As an emotional state, it was thought to be ubiquitous in the palliative care setting and to reflect a normal response to adverse life events. It was also considered to be an inevitable stage of grief that must be traversed to reach acceptance. As a symptom, depression signalled a potential cause of suffering and a need for assessment and intervention, akin to other symptoms addressed in palliative care. Depression as a symptom was divorced from the notions of normality or pathology. Participants emphasised the need to distinguish between depression as a symptom and as an illness. Confusing the two was thought to account for inflated prevalence estimates of depressive illness in research, which did not reflect their observations in clinical practice. Depressive illness was considered to be a syndrome with anhedonia as its cardinal feature, to be a biological illness, pathological, and not an emotional reaction or part of the dying process. Participants objected to depressive illness being interpreted as a spiritual issue or as a normal part of dying, both of which would deny patients the opportunity for intervention. They explicitly distinguished depressive illness from other forms of depression.

Depression is conceptualised by clinicians in various ways

Participants believed that clinicians differed in their conceptualisations of depression, but also noted overlap between disciplines as well as variability within them. Conceptual differences were primarily attributed to differences in the clinicians' training backgrounds, for example, between palliative medicine specialists with general practice and physician training backgrounds. Participants articulated the potential for shaping clinicians' conceptualisation through education, either through explicit training or more implicitly through collaborative clinical work with psychiatrists. Some participants observed an approximation of concepts between themselves and their palliative medicine colleagues after long periods of working together. Despite noting conceptual differences among clinicians, disagreement over diagnosis or management was not encountered, with participants indicating that their views seemed readily accepted by their palliative medicine colleagues.

6.5.2 Depression is conceptualised using different models

Participants described three conceptual models that respectively viewed depression as a spectrum, a dichotomy, and a mixture of spectrum and subtypes (Table 3).

Table 3. Illustrative data extracts for the theme: Depression is conceptualised using different models

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Spectral model of depression	<i>"I think...to me it's really a spectrum problem. You know, someone's catatonic, that's easy, and if they're happy as larry, that's easy. I think it's that sort of grey area in the middle, it's very difficult to tease that out and I really struggle with that and I think a lot of CL [Consultation-Liaison] psychiatrists do. On the one hand, you don't want to medicalise an understandable reaction, on the other hand, you don't want to deny treatment to someone who's really struggling." (Participant #1)</i>
Dichotomy of reactive versus melancholic depression	<i>"I'm going to refer to the reactive depression versus melancholic depression sort of dichotomy...I think they're two very different processes...The patients that we see in palliative care can fall into either group...but</i>

	<i>they often have a very different nature of presentation in terms of their...depressive symptoms and their mood.” (Participant #2)</i>
Mixed model of depression	<i>“Starting right at the normal end of the spectrum, some depression is entirely understandable and simply a normal reaction and not at all a psychiatric problem or even a psychological concern. Right up to the other end of the spectrum where I’m looking at a depressive disorder, so I would see the notion of the depressive disorder as involving either intense symptomatology or an associated functional impairment or difficulty. At that end of the spectrum, I tend to break it up into the melancholic and non-melancholic framework.” (Participant #5)</i>

Spectral model of depression

In the spectral model, depression was seen as a dimensional rather than a categorical construct, spanning from normal emotional reaction to depressive illness that included major depression and its melancholic, catatonic and psychotic forms. In this model, depression had considerable overlap with other psychological states such as distress, grief and demoralisation. The spectrum therefore encompassed both normal and pathological depressive states, and the ill-defined boundaries between these made differentiation of clinical depression difficult in the less severe portion of the spectrum. For participants who described this model, this ambiguity gave rise to conflicting concerns about medicalising and stigmatising patients for understandable emotional responses on the one hand, and denying them appropriate treatment for depression on the other. The DSM diagnosis of Adjustment Disorder was a disputed construct because it called for a judgement to delineate unacceptable from acceptable depressive responses to previously uncharted adversities, when such division was considered arbitrary within this spectral perspective. Similarly, some participants saw the concept of major depression as categorical, rigid and incompatible with the dimensional nature of depression.

Dichotomous model of depression

In the dichotomous model, depression was broadly divided into reactive and endogenous types, which were considered to be separate processes with different manifest qualities. Reactive depression was regarded as an understandable response to a situation, likened to an “extreme type of sadness”. However, it was emphasised that its understandability did not imply a lesser severity. Participants analogously compared reactive depression with pain, which despite being an expected response to tissue pathology, caused suffering and could be ameliorated through appropriate treatment. Endogenous depression was also referred to as melancholic depression, and was viewed as a biological illness. Very ill patients were seen to be more vulnerable to developing this type of depression, but differentiating this from effects of advanced disease could be challenging.

Mobility was a feature within both the spectral and dichotomous models. This refers to the view held by some participants that one type of depression could transform to another, for example, reactive depression turning into melancholic depression. Some also expressed the corollary that timely intervention for reactive depression could prevent a melancholic progression.

Mixed model of depression

The mixed model viewed depression in both spectral and typological terms. Melancholic and psychotic depressions were seen to be distinct biological depressive illnesses, which sat separately from a continuum of depressive presentations that spanned from “normal reactions” to non-melancholic depression. Non-melancholic depression was considered to be a heterogeneous disorder underpinned by a variety of interplaying biopsychosocial aetiological factors. Participants applying this model referred to and endorsed the hierarchical model, as proposed by Parker,[167] which

distinguished psychotic, melancholic and non-melancholic depressions as three types of depression, with the last being a spectral construct.

6.5.3 Depression is the same concept in and outside of the palliative care setting

Participants considered depression to be the same condition when occurring in the palliative care setting as in other settings, explainable using the same aetiological framework and responsive to the same treatments (Table 4). They also believed the prevalence of depression to be similar in and outside of the palliative care setting, with the reported higher prevalence in palliative care attributed to methodological artefact arising from measuring depressive symptomatology instead of disorders. The artificiality of distinguishing depression occurring in the palliative care setting was emphasised by a participant who referred to this as a “mock concept”.

Nevertheless, participants described two peripheral differences about depression in the palliative care setting, involving context and ease of diagnosis (Table 4). Contextual differences referred to the influence of advanced illness and dying on the presentation of depression. Separation, loss, grief, death and dying, and existential concerns were cited as dominant issues for depressed patients in this setting, and together with issues of family dynamics, formed a major focus in intervention. Although participants applied the same biopsychosocial aetiological framework to depression in this setting, specific contributory factors were considered to more commonly relate to advanced illness and its psychological and social consequences, such as uncontrolled symptoms, brain disease, organ failure, treatments, disability, loss of autonomy, existential crisis, and sense of being abandoned by family and treating clinicians. Diagnosing depression in this setting was considered harder due to the difficulty of distinguishing between symptoms of depression from those of life-limiting diseases and dying, and from psychological adaptation, distress and

demoralisation. Judgement was required to interpret symptoms in the illness and dying context, and in some situations, to determine the relevance, if any, of making a diagnosis.

Table 4. Illustrative data extracts for the theme: Depression is the same concept in and outside of the palliative care setting

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Depression is the same condition in and outside of palliative care	<i>“The content of the distress might be different, but I think (it is) the same condition, and I’d also have to say, gets better with the same treatment, you know, so anti-depressants definitely work, CBT definitely works” (Participant #3)</i>
Depression in palliative care differs in context	<i>“The most obvious thing is that people in a palliative care setting are facing death in the immediate future, so the way that they’re processing things that are going on around them or are thinking about their future, their relationships, has a different quality to people who don’t have that immediate poor prognosis in front of them.” (Participant #8)</i>
Depression is harder to diagnose in palliative care	<i>“I guess the main challenge is trying to separate what is reasonable and understandable low mood, and what’s a pathological process, and then try and come to some degree of understanding in my own mind about whether that difference is important or relevant” (Participant #2)</i>

6.6 Discussion

In this study, psychiatrists explicitly identified depression as a heterogeneous concept that required specification in order to be meaningful. Individual interpretations of the term varied from the relatively narrow construal of an illness, to broader ones that also encompassed ideas of emotional state and symptom. These interpretations differed in their philosophical bases: restricting the concept of depression to a depressive illness makes a demarcation based on pathology, whereas broader concepts demarcate depression based on clinical significance (i.e. potential benefit from clinical intervention). Herein lies a source of tension, with proponents of the former criticising the mislabelling of sadness and distress as depression, and

proponents of the latter criticising the dismissal of depression that did not meet illness criteria. Such disputes therefore reflect differences in the conceptual breadth of the term depression, rather than differences in conceptualisation of depressive illness. In fact, depressive illness was consistently viewed as a biological type of depression, distinguished from depressive reactions and considered to exist as different types.

The relationship of depressive illness to other depressive presentations was more ambiguous, and was conceptualised by participants using three models. In the spectral model, depressive presentations were considered along a continuum, with no clear demarcation between depressive emotional reactions and depressive illness. This model resembles other dimensional approaches to conceptualising affective disorders.[225-227] In contrast, the dichotomous and mixed models considered depressive illness to be distinct categories and conceptually demarcated from depressive reactions. The dichotomising of endogenous/psychotic depressions from reactive/neurotic depressions has been criticised, among other reasons, for its weak boundary of distinction based on life stressors, and lost currency with terminological and paradigmatic shifts.[190] It is therefore notable that participants continued to find the dichotomous model useful despite its supersedence in recent decades by more contemporary classifications. The continuing relevance of the dichotomous model is also supported by a recent study of psychiatrists, whose explanations to patients and treatment recommendations differed according to the two depression types.[228] Despite using DSM terminologies, participants considered these to be inadequate and conceptualised depressive illness as phenotypic subtypes, such as the melancholic, non-melancholic and psychotic subtypes of the hierarchical model,[167] rather than as major depression.

Compared with palliative medicine specialists,[186] psychiatrists in this study more explicitly articulated depression as a heterogeneous concept, distinguished depressive illness from other depressive presentations, and subtyped depressive illness. The psychiatrists also saw depression to be the same concept in and outside of the palliative care setting, which contrasts with the distinction made by palliative medicine specialists between *de novo* and recurrent/persisting depressions.[186] However, both groups considered the boundaries of depression to be unclear and diagnosis to be difficult, and shared concerns about the medicalisation of human emotions and under-recognition of depressive disorders.

This study finds that contemporary psychiatrists do not subscribe to a unitary model of depression, but understand it as a heterogeneous concept comprised of fairly uniform views of depressive illness and other less clearly defined depressive presentations. They also utilise phenotypic subtyping of depressive illness. Given the apparent clinical influence of psychiatric opinions,[29,222-224] these findings suggest that depressive illness could be more explicitly distinguished in clinical parlance and conceptualisation from other depressive syndromes or symptoms, rather than coalescing these under the single term of “depression”. Furthermore, the unitary and amorphous concept of major depression could be refined with consideration of phenotypic subtypes, in order to promote a more specific approach to assessment and management. These clinical practice recommendations are in line with those advocated by other authors in the psychiatric literature.[51,58,167,229,230] In research, depression as a singular notion could similarly be replaced by specification of depressed mood as a symptom and various subtypes of depressive illness, in order to produce more meaningful data. Distinguishing between depressive symptom and illness may also circumvent the ambiguity arising from the usage of broad and narrow concepts of depression, and emphasise the clinical significance of depression both at the level of a symptom

requiring intervention and at the level of an illness. In health professional education, greater emphasis could be placed on assessment for depressive illness based on phenomenological and contextual appraisal, rather than on diagnostic criteria or severity scales, although the latter remain useful screening measures. Whether depression is different in the palliative care setting, in causality or form, is not known but may be a point of conceptual difference between palliative medicine specialists[186] and psychiatrists. Having more refined concepts of depression in both clinical practice and research may assist in elucidating this matter.

It was recognised throughout the conduct of this study that the first author's profession as a psychiatrist, specialised interest in palliative care psychiatry, and the nature of her own concepts of depression could potentially influence the data collection and analysis processes. Care was taken to avoid conceptual assumptions during interviews, and all interview transcripts were read by the co-authors during the data collection phase and no undue interviewer influence was noted on the participant's responses. In analysis, the final themes were verified by the co-authors with non-psychiatric backgrounds (palliative medicine [GBC] and psychology [ACH]) as a measure of trustworthiness. As there may be local differences in training and practice, the findings of this study may not be transferable to countries where these are very different from the Australian context. However, the findings of this study should have widespread relevance given the clinical importance of depression in palliative care, the challenges of its diagnosis and management in this setting, and its conceptual ambiguity in clinical practice and research. By recruiting psychiatrists with intimate understanding of the palliative care context, this study describes the concepts of those who are providing clinical guidance in this area and may hopefully serve to stimulate further debates around the concepts of depression in the palliative care community.

6.7 Acknowledgements

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CHAPTER 7 CONCLUDING DISCUSSION

7.1 Summary of findings

In view of the lack of consensus on the definition of depression in palliative care research[36] and the varied clinical approach towards its assessment and diagnosis,[37-39] this thesis set out to explore and characterise medical conceptualisations of depression in the Australian palliative care context. Multiple conceptualisations of depression were assumed, and Kleinman's Explanatory Model was used as the framework for investigating these conceptualisations.

Study 1 (reported in the first paper, Chapter 2) used a questionnaire to explore in broad terms concepts of depression as held by medical practitioners working in palliative care. There were two key findings: The first was demonstrating that medical practitioners varied in how they conceptualised depression; the second was highlighting the conceptual distinctions for depression occurring in the palliative care setting. Specifically, medical practitioners were less certain that depression in this setting was an illness, with some considering depression to be normal in the palliative care context or to be part of dying. Depression in this setting was also seen to be qualitatively different, more difficult to define and associated with unique diagnostic and treatment challenges. Furthermore, almost half of the respondents were uncertain as to whether depression had identifiable causes, although psychological and existential/spiritual factors were heavily weighted by the sample, which aligned with psychological support as their preferred intervention. Significant differences in views were found according to work area and position, duration of practice and previous mental health training. This study served as a prelude to in-depth exploration of explanatory models of depression among palliative medicine specialists and psychiatrists.

The second, third and fourth papers (Chapters 3, 4 and 5) each reported on an aspect of Study 2, which investigated palliative medicine specialists' conceptualisations of depression. The second paper (Chapter 3) focused on concepts of depression, and identified two issues that were fundamental to conceptualising depression, namely ontological diversity and conceptual boundaries. With respect to the first issue, palliative medicine specialists variously considered depression as an abnormality, a medical problem, an emotional experience and a social product. These notions reflected understandings of depression as pathology and as contextual, with these being underpinned by different ontological positions, which could be difficult to reconcile when simultaneously applied in practice. A fifth notion of depression as an action-oriented construct was unique in seeing it only as a signal for intervention, and thus disavowed an ontological affiliation. The palliative medicine specialists also described a prototypical model of depression, or in other words, they considered depression to have distinctive features but blurred boundaries with various emotions, psychological phenomena and disease manifestations. Distinguishing between depression and sadness was especially challenging, and was considered to require subjective judgement that generated diagnostic uncertainty and discomfort for the participants.

The third paper (Chapter 4) focused on causal explanations. Palliative medicine specialists were found to utilise multiple causal explanations for depression that were grounded in diverse theories, aligned with the three components of the biopsychosocial model and followed a vulnerability-stress framework. However, individual participants varied in the primacy of focus within the biopsychosocial framework, resulting in explanations that were primarily biological, primarily psychosocial, or equally weighted in both. Multifactoriality was strongly articulated, whereby participants considered multiple parallel explanations to be causally important. For some participants, depression was inexplicable, due to the

inadequacies of existing causal explanation models, such that the occurrence of depression for an individual could not be fully explained and might give rise to an impression of seeming randomness.

The fourth paper (Chapter 5) reported on treatment approaches. The discernment of five distinct approaches, as articulated by the palliative medicine specialists, was a key finding. The biologically oriented and psychosocially oriented approaches were diametrically opposite in their views of core and adjunctive treatments, whereas the combination approach saw both biological and psychosocial interventions as essential. In the undifferentiated approach, all treatments were held to be interchangeable and none was preferred, while in the ambivalent approach, treatments were offered with doubts about their effectiveness. Treatment decisions were shaped by four groups of characteristics relating to the patient, depression, clinician and sociocultural environment. The palliative medicine specialists also described difficulties in treating depression, which were captured by the themes of personal discomfort with treatment, being inadequately equipped to treat depression, a sense of therapeutic limitations, and the risk of trying to simultaneously treat multiple problems.

Two themes traversed all three papers from the study on palliative medicine specialists. The first was the differentiation between *de novo* depression in the palliative care setting and pre-existing depression. These were considered to differ in aetiology, treatment and prognosis, with *do novo* depression being seen to be more understandable due to the terminal illness context, being a cancer-related syndrome, less attributable to the intrinsic vulnerability of the individual, and requiring different treatments. The second theme spanning across the papers was a thread that connected the concept of depression, its causal explanation and treatment approach. Treatments chosen by the palliative medicine specialists were rationalised by their

causal explanations, which they also used as a means of engaging patients in treatment.

The fifth paper (Chapter 6) was based on Study 3 and reported on psychiatrists' concepts of depression. This was included in this thesis as a comparison to the concepts held by palliative medicine specialists, in view of the authority given to psychiatrists as medical experts on depression. The psychiatrists were explicit in articulating the heterogeneous nature of depression. They differentiated depressive illness, which was consistently considered a biological illness and was divided into subtypes, from other depressive presentations. The relationship between depressive presentations were variously conceptualised within the spectral, dichotomous and mixed models. The depressive presentations that the psychiatrists considered under the term "depression" ranged from a narrow construct of depressive illness to broader ones that also encompassed depressive symptoms and emotions. For the psychiatrists, depression was essentially the same concept in the palliative care setting as in other settings, although the context might differ. This contrasted with the theme of depression being different in the palliative care setting that was articulated by palliative medicine specialists.

Both palliative medicine specialists and psychiatrists commented on the challenges of depression. For the former, depression was difficult to understand due to its abstract nature and diagnosis was complicated by the often concealed nature of depression, the need for subjective interpretation and contextual processing, and the stigma of such a diagnosis. The different terminologies used for depression and diffuse meanings of the word "depression" were also seen as complicating factors. Psychiatrists also considered diagnosing depression to be more challenging in the palliative care setting due to the difficulty of differentiating between symptoms of

depression from disease symptoms, dying, and various psychological processes. Judgement was regarded as implicit in the diagnostic process.

As a collection, the five papers in this thesis have fulfilled the objectives of this thesis, which as outlined in Section 1.5, were to explore the medical concepts of depression within the palliative care setting, ascertain and compare the conceptualisations of depression that were held by palliative medicine specialists and psychiatrists working in palliative care, and to identify areas of conceptual difficulties associated with depression in this setting. This thesis has demonstrated that depression was not a unitary concept among medical practitioners, and concepts varied not only between but also within disciplines. For palliative medicine specialists, depression at its core involved divergent ontological perspectives that called for an absolute judgement on normality versus pathology on the one hand, and contextual understanding on the other, which were difficult to unite and generated anxiety over obscure diagnostic boundaries and potential for errors. In comparison, psychiatrists more overtly articulated the heterogeneity of depression and accommodated its multifarious natures within different conceptual models. Specific conceptual, diagnostic and treatment challenges were highlighted with regards to depression in the palliative care setting, including the issue of whether depression in this setting is conceptually distinct. A direct link was also supported between the concept of depression, its causal explanation and treatment approach, thus underscoring the clinical relevance of examining conceptualisations of illness.

7.2 Significance of findings and contribution to knowledge

7.2.1 Contribution to the palliative care literature

Depression as a condition is remarkable for the disparity between its extensive clinical importance in terms of its prevalence, impact and consumption of clinical resources, and its continued ambiguity as a concept with incompletely understood

causality. This is especially apparent in palliative care, where depression is affirmed as a focus area but continues to pose diagnostic challenges and be guided by a precarious evidence base. The primary significance of this thesis is that it delves into the fundamental dilemma of the conceptual ambiguity of depression, which pervades and hinders its clinical approach and research. This foundational issue has not been vigorously addressed in palliative care research to date, despite calls for consensus on how to conceptualise depression and its related conditions in the palliative care setting,[9,36] but must logically be sufficiently addressed in order for advances to be made in this area. By closely examining the concepts that medical specialists apply in their practice, this thesis contributes to this work by crystallising clinically relevant concepts, and identifying core philosophical challenges for depression and specific conceptual issues in the palliative care setting. This approach has the advantage of obtaining an empirical understanding of concepts utilised by the medical specialists, unconfined by psychiatric classification concepts, which may not reflect clinician concepts as suggested in the literature.[38,39]

The findings of this thesis add to the existing palliative care literature on depression in four respects. First, depression has been demonstrated to be a heterogeneous concept for medical practitioners, imbued with multitudinous causal explanations and considered in a prototypical manner. These conceptual characteristics are contrary to the unitary, atheoretical and categorical nature of major depression as proposed by the DSM classification. Such conceptual incongruity suggests that major depression, in spite of its dominance as a clinical and research entity, is inadequate, does not reflect the conceptual operations of medical practitioners, and oversimplifies a complex condition. The findings of this thesis thus support the need for a more sophisticated conceptual framework for depression, which encompasses a variety of depressive prototypes.

Secondly, this thesis has also established the linkage between the array of causal explanations for depression and different treatment approaches. The continuum of causal explanations from the primarily biologically oriented to the primarily psychosocially oriented may apply to different types of depression, and continued efforts towards the phenomenological differentiation of these are indicated, as different types of depression likely entail divergent treatment approaches. The prominence of multifactoriality in the causal explanation of depression has been highlighted in this thesis, and corresponds with the prevailing biopsychosocial framework in psychiatric explanatory models. Although holistic, there is a risk of compromising specificity for comprehensiveness with such a framework, if all constituents are regarded to equally contribute to depression. A pragmatic balance is required to prioritise causal factors in order to provide more specific guidance for treatment and prognosis, while retaining a holistic frame of reference. Whilst on the topic of causal explanations, it is noteworthy that palliative medicine specialists sparsely commented on existential or spiritual issues beyond the psychological impact of impending death. This contrasts with the strong endorsement of existential/spiritual factors as important explanatory factors for depression at the EOL in the questionnaire study, and raises questions around what palliative medicine specialists consider to be existential and spiritual issues, and how these relate to psychological explanatory factors.

Thirdly, this thesis has identified two specific conceptual considerations for depression in the palliative care setting. The first relates to the matter of emotional normality at the EOL, which is the defining standard for determining what is pathological or an illness in this setting. Normality by definition is conformation to conventional or typical standards,[231] and as such, is a fluid and imprecise concept that hinges on personal and sociocultural expectations. In assessing for depression in the palliative care setting, clinicians should reflect on their expectations of normal

emotions in the context of death and dying. Furthermore, standards of normal cannot rest solely on the perspectives of individual clinicians, but should be systemically cross-referenced with those of patients and colleagues. This necessitates emphasis and training on the contextualisation of symptoms in assessing for depression, rather than over-relying on symptomatic screens and checklists. The second issue is concerned with whether depression is conceptually distinct in the palliative care setting. Both palliative medicine specialists and psychiatrists in this research commented on greater difficulties in diagnosis and limitations on treatment in this setting. These differences, however, are peripheral to the concept of depression, which for the psychiatrists was not fundamentally different in the palliative care setting. Among the palliative medicine specialists, there was a notion of *de novo* depression that was considered to be separate from recurring or persisting depression. Caution needs to be applied when making a distinction based on the timing of when depression occurs, so as to avoid excessive investment on past diagnostic labelling without further exploration of context. However, the proposal of a distinct type of depression, akin to cancer-related syndromes, warrants further contemplation and investigation, as this has not been addressed in the literature and may indicate a unique phenomenon in the palliative care and oncology settings, requiring different diagnostic awareness and treatment.

Finally, depression was conceptualised differently between practitioners from different disciplines, as illustrated by the qualitative studies on palliative medicine specialists and psychiatrists. The questionnaire study also indicated conceptual differences between general practitioners and palliative medicine specialists. These inter-disciplinary differences may have relevance at several levels, from misunderstanding clinical communications to using varied approaches to diagnose and treat depression. Differences in terminology use between palliative medicine specialists and psychiatrists were also raised as a barrier to communication and

generated confusion in treatment implications. In research, inter-disciplinary conceptual differences may lead to translational distortions, from both the representation of depression in research methodology and the interpretation and subsequent application of research results in clinical practice. Consideration needs to be given to inter-disciplinary conceptual incongruity in both the clinical and research contexts.

7.2.2 Contribution to the psychiatric literature

The topic of this thesis sits within the scope of consultation-liaison psychiatry. As an established subspecialty, consultation-liaison psychiatry initially developed out of the general hospital psychiatry and psychosomatic medicine movements in the 1930s to 1950s, as an “area of clinical psychiatry which includes all diagnostic, therapeutic, teaching and research activities of psychiatrists in the non-psychiatric parts of a general hospital.”[232,233] Since then, consultation-liaison psychiatry has evolved in conjunction with changes in health service provision, and numerous foci of interest have arisen across the diverse areas of medicine, including an extensive body of knowledge in psycho-oncology.[232] Palliative care psychiatry is an emerging area in consultation-liaison psychiatry, and depression has been one of its major concerns, although much work remains to be done in terms of establishing a sound conceptual framework and clinical approach to depression in this setting.[234] This thesis contributes towards addressing this area of need.

Depression in the palliative care population shares similarities and challenges with other medically ill populations. Areas of overlap include deciphering symptoms of depression from those of somatic disease, the emotional and psychological sequelae of illness and its associated losses, and limitations on treatment posed by disease processes, debility and concurrent treatments. Similarly, EOL issues can be found among certain patient subgroups in psychiatry of old age, for example, among those

with dementia or those for whom late life and EOL psychodevelopmental issues contribute to or coexist with mental illness. In this way, the topic and findings of this thesis may have broader relevance to other areas within consultation-liaison psychiatry and psychiatry of old age.

Being focused on concepts of depression, this thesis is also situated within the sub-discipline area of philosophy of psychiatry, which has professional representation in Australia and internationally.[235,236] Conceptual considerations form a primary focus in this area, in recognition of the inherent conceptual difficulties in psychiatric subject matters and the central importance of conceptualisation in all practical aspects of psychiatry.[237,238] By demonstrating the treatment implications of different concepts of depression, this thesis has reinforced that studying conceptualisation of psychiatric conditions is a clinical necessity, and not merely an intellectual pursuit. This point echoes the call of other authors in the psychiatric literature for renewed interest in the conceptual and philosophical underpinnings of psychiatry, and for greater prominence of these aspects in psychiatric training and practice.[237,239]

The findings of this thesis contribute to the ongoing developments in psychiatric conceptual models. The DSM classification and biopsychosocial model, arguably the prevailing contemporary psychiatric nosology and explanatory framework, respectively, have received growing criticism. As discussed in Chapter 1, the philosophical basis and validity of the DSM construct of major depression have been widely questioned and faulted for the limited progress from research based on the concept.[45,51,53,58-60,63-65,68] Although palliative medicine specialists and psychiatrists in the studies of this thesis referred to major depression, it minimally featured in their conceptualisations of depression. On the contrary, they did not view depression as unitary, atheoretical or categorical, suggesting that major depression

has limited utility in the clinical context beyond that of diagnostic labelling. The biopsychosocial model was a dominant framework in the palliative medicine specialists' causal explanations of depression, confirming its influence on conceptualising causality for psychiatric conditions. Such a framework is meritorious in its holistic emphasis and may be especially appealing to disciplines such as psychiatry and palliative medicine, given the value that these place on holistic practice. However, there have been critiques of the widespread misunderstanding and misuse of the biopsychosocial model in psychiatry.[201,240-243] Originally proposed by the physician George Engel as a counter paradigm to the biomedical model of medicine, the intent of the biopsychosocial model was to encourage primarily non-psychiatrist medical practitioners to approach patients as whole persons rather than diseases, and to incorporate into their clinical approach the effects of human emotions, behaviours and social circumstances on illness.[184,185] The biopsychosocial model was thus not proposed as a causal explanatory model of psychiatric disorders, despite its current application in this manner. When used in this way, a problem of the model is that it lacks specificity and generates multiple, broad, unprioritised causal factors.[240-242] This framework not only poorly guides treatment, but has also been argued to impractically and unreasonably extend the jurisdiction of clinical medicine to matters of social welfare and government.[240] Another problem is that the biopsychosocial model has no predictive power for who will be afflicted by mental illness and when.[201] Both these shortcomings are evident in the findings from the study with palliative medicine specialists. This thesis therefore provides findings that support the inadequacies of the present dominant psychiatric conceptual frameworks, at least as applicable to depression. More nuanced nosologies and causal explanatory frameworks, preferably with links between these, are clearly needed.

7.2.3 Contribution to the Explanatory Model literature

This thesis used Kleinman's Explanatory Model as the theoretical framework for exploring conceptualisations of illness. The five areas involved in the understanding of illness (i.e. aetiology, time and mode of onset of symptoms, pathophysiology, course of sickness, and treatment) and the eight questions suggested by Kleinman to help elicit explanatory models were used to inform the content of the questionnaire in Study 1 and the interview guide for Studies 2 and 3. As such, the Explanatory Model served as a valuable reference framework for this thesis. During the research process, however, two observations could be made about the use of the Explanatory Model in studying medical conceptualisations of depression.

First, the palliative medicine specialists and psychiatrists in the studies did not equally elaborate upon all five designated areas of the Explanatory Model. There was a relative paucity of comments on the timing of onset and on the untreated course of depression, even when questions about these two aspects were posed during the interviews. In contrast, ample and rich content was elicited with ease in relation to aetiology and treatment. Influence from the interviewing process needs to be acknowledged, but the relatively poor yield of content for select aspects of the Explanatory Model is of interest and may contradict Kleinman's claim that professional explanatory models tend to be more fully articulated.[118] This may be an important distinction for the explanatory models of psychiatric disorders compared with non-psychiatric illnesses, owing to their complexities and incompletely understood mechanisms. In addition, the extensive overlap in content between the areas of aetiology and pathophysiology in Study 2 resulted in the combining of these into the composite domain of causal explanations. Together, the domains of causal explanations and treatment provided the thematic structure for the reporting of the principal findings from the study on palliative medicine

specialists, in the form of the papers on their causal explanations and treatment approach towards depression.

The second observation was that much content in the interviews with both the palliative medicine specialists and psychiatrists related to the nature of depression, or what kind of phenomenon they considered depression to be and its boundaries with normality and other conditions. Again, the interviewing process did direct participants to discuss issues of nature, but this direction had in turn been shaped by the questionnaire data and the participants' responses from preceding interviews during the conduct of the qualitative studies. In the interviews, consideration of nature was the conceptual backbone for depression and anchored all aspects of its explanatory models. It also formed the basis for the two papers that reported on the conceptual constructs of depression from both medical specialist groups. However, this issue of the nature of illness was not captured by the Explanatory Model, in its five areas or suggested questions.

These observations raised the question of whether explanatory models for depression and other psychiatric conditions, owing to their conceptual and aetiological complexities, have different emphases compared with somatic illness, and may not be precisely or fully articulated by the existing framework of the Explanatory Model. If this model is used for future research on psychiatric illness conceptualisation, especially for depression, the research conducted for this thesis suggests that modification or addition to the model should be considered. For example, the conglomeration of aetiology and pathophysiology into one area may be more parsimonious, and an additional area of nature could enhance the comprehensiveness of exploration. Alternatively, new theoretical frameworks may be developed that are perhaps more suited to capture the ambiguities of psychiatric

explanatory models, including foci on ontological perspectives and the interrelationships between concurrent threads of explanations.

7.3 Implications of findings

The findings of this thesis have implications for psychiatric nosology and causal explanation frameworks, treatment of depression in the palliative care setting, medical education and palliative care service models.

7.3.1 Philosophical basis of depression

This thesis adds to the growing literature on the inadequacies of the prevailing DSM classification system for depression and the biopsychosocial model as an explanatory framework. The development of a more refined nosology for depression should be a priority, as nosology underpins all aspects of research in this area and the currently widely used DSM classification of depression has been unprofitable in this regard. This is clearly an issue that extends beyond palliative care, but the need for a more sophisticated nosology for depression is perhaps more evident in this setting, given the diagnostic ambiguities in the palliative care context. Based on the conclusions of this thesis and the supporting literature, I suggest that a more useful nosology for depression would be one that adopts heterogeneity as a basic assumption, and incorporates a spectrum of normative and pathological depressive presentations, with the use of prototypic subtypes distinguished by core phenotypic features. Phenomenological differentiation should be reprised as the essence of diagnosis, rather than symptom counting from an undifferentiated checklist. Furthermore, ontological diversity and ambiguity would need to be explicitly accommodated. Such an inclusive nosology is likely to be more clinically meaningful, although this inclusivity would challenge the definitude that is required by a predominantly positivist paradigm in health and medical research. The threshold of compromise between a variegated nosology that more closely resembles clinical reality and an

artificial but neat one that is more conducive to positivist epistemology will be an ongoing issue for consideration and debate. The undertaking of a nosological redevelopment would naturally require concerted effort from international psychiatric, medical and mental health communities, and is unlikely to be expeditious. In the meantime, there is a growing body of literature on the refining of depression classification[51,229,230,244] and alternative nosologies to the DSM, such as the hierarchical model,[167] may satisfy some of the above suggested qualities and are worth consideration for more widespread usage in clinical practice and research.

The limitations of the biopsychosocial model as a framework for causal explanations of depression and other psychiatric disorders need to be more prominently discussed within psychiatric communities, and its dominance as the standard in psychiatric teaching curricula should be re-examined, at least in the form of its current usage. The strength of the biopsychosocial model is its holistic scope,[201] but in itself it fails to explain how illness arise from a list of potentially relevant factors.[240-242] Therefore, while a biopsychosocial scope should be retained, further efforts are required to cultivate and propagate causal explanatory models for psychiatric disorders that have greater guiding power for treatment. Economical, single perspective causal explanations that have traditionally been favoured in physical sciences are not suited to psychiatric disorders and can encourage detrimental reductionism.[108] Instead, multi-perspective and multi-level approaches have been advocated to replace biopsychosocial eclecticism in psychiatric causal explanatory models.[106,108,241,242] An integrationist approach, which strives to unite different theories of explanation under one overarching theoretic model, is aspirational for psychiatry but is still some distance away from actualisation.[241] A pluralistic approach, which holds that different methods or paradigms have relative strengths and weaknesses and should be selectively applied for specific circumstances, is

perhaps at present the most pragmatic causal explanatory framework for psychiatric disorders.[106,241]

7.3.2 Treatment of depression in the palliative care setting

The findings relating to the palliative medicine specialists' treatment approaches to depression support the identified need for specific treatment guidelines for the palliative care population.[38] Given the deficiencies of the existing research on depression treatment in this setting, treatment guidelines would require extrapolation from the non-palliative care literature and ongoing validation through research. Nevertheless, there are several aspects that should be incorporated in future treatment guidelines for depression in the palliative care setting. The first is the specification of depression subtypes to address the problem of heterogeneity and to provide more specific guidance for intervention. This hinges on nosological developments, which are ultimately the foundation for depression terminologies and research. The second aspect is a need for more deliberate efforts to guide the selection between pharmacotherapeutic and psychotherapeutic options, as well as the selection of specific treatments within these groups. Factors relating to the patient's age, disease profile, comorbidities, prognosticated survival, depression subtype and severity, and psychological mindedness would be relevant to guiding treatment. These considerations were already mostly utilised by palliative medicine specialists in forming treatment decisions, as described in Study 2, but a systematic approach to considering these pertinent factors in the palliative care setting could be facilitated by guidelines.

7.3.3 Medical education and professional development

Palliative medicine specialists who participated in Study 2 reported that depression as a concept was difficult to understand, by virtue of its intangible and imprecise nature, with terminological variations further complicating the concept. In light of

this, one of the important implications of this thesis relates to education and training on depression for medical undergraduates and practitioners, and for other health disciplines.

Education on depression needs to emphasise its heterogeneity as a concept, rather than fostering a unitary notion. Although seductive in its simplicity, a unitary concept has neither assisted the understanding of causality nor guided treatment. The indistinct boundaries and diagnostic complexities of depression should also be highlighted, and not eluded or diminished, in order to encourage a realistic clinical approach. Therefore, education ought to place the construct of major depression in perspective as one definition and extend beyond this to include alternative conceptual models. The psychiatric revolution brought on by the DSM classification has been held responsible for the devolution of phenomenology, the meticulous study of psychopathological symptoms and signs, which has been a founding tradition for psychiatry and underpins much of its practice and understanding of illness.[245] Phenomenology distinguishes depression subtypes, and its associated knowledge and skills should once again be given greater importance in the diagnosis of depression and education for this purpose.

Additionally, the *status quo* in psychiatric education of indoctrinating the biopsychosocial model as an explanation for psychiatric disorders should be supplanted by a pluralistic approach to causal explanation. This should be retained within a holistic scope of biopsychosocial, cultural and spiritual considerations, although not all aspects need to be aetiologically relevant for all conditions. In the training of psychiatrists, who are expected to have expertise in the complex manifestations of mental illness and to work within different ontological and epistemological perspectives, the conceptual and philosophical foundations of

medicine and psychiatry should be mandatory. This has also been previously advocated by others in the field.[237,239]

Professional developmental practice and maturity in outlook are important aspects of education, and are highly relevant to the subject of depression. A culture of open collegial discussion could allow more rounded understandings of depression and refinement of personal conceptualisations, and defend against insular views. Sharing of experiences and uncertainties also serves to validate the difficulties that clinicians face in this area of work and to minimise any sense of professional inadequacy that may arise from dealing with inherently complex issues. The capacity for personal reflection can also be a valuable quality in dealing with an issue such as depression, for which clinicians are assumed to be skilled in its differentiation from normative emotions and experiences. The self-examination of personal beliefs on normality in terms of emotional and psychological experiences at the EOL is therefore crucial for all clinicians working in palliative care, as set views may contribute to the under- or over-diagnosis of depression in this setting. Being indistinct, depression also demands of clinicians the ability to work with ambiguities, rather than seeing these as obstacles that hamper clinical care, and this can be fostered through learning and modelling in the clinical environment.

7.3.4 Palliative care and psychiatry interface service models

The complexities of depression illustrate the potential benefits of integrating psychiatric and other mental health disciplines within palliative care services. In relation to depression, psychiatrists can assist in its assessment and treatment, taking into account the complex medical and psychosocial factors at play in the EOL setting. They may also offer assistance through clinical discussions to support the palliative care team in managing particularly challenging patients or situations. Apart from these consultative roles, psychiatrists can provide education and training for

palliative care teams, thus building capacity and a higher level of self-sufficiency in addressing depression. Other contributions may include research, as demonstrated in this thesis, and service development. There are also less tangible roles that psychiatrists may fulfil within palliative care services, such as serving as a resource, facilitating reflective practice and understanding of psychodynamics within clinical interactions, influencing the team culture, and combating stigma associated with mental illness. Whilst depression is a key problem area in palliative care, it is not the only area in which psychiatry can contribute to the discipline, with others including anxiety, delirium, psychological adaptation issues, behavioural disturbances, complicated grief, existential issues, interpersonal issues between patients and their families and/or treating teams, psychotropic medication use, psychotherapy, and the management of patients with pre-existing mental illness.[213,234]

There are two models under which psychiatric services can be offered to palliative care. The traditional model of consultation-liaison psychiatry is a collaborative model,[234] whereby psychiatric input is available to palliative care services, mainly in hospital in-patient settings and on a referral basis. On the other hand, psychiatrists can be incorporated as integral members of palliative care services. This integrative model[234] better allows psychiatrists to have an extended scope within the service and to fulfil non-consultative roles such as education, professional and team development, research and service improvement. This model would also best accommodate a balance between self-sufficiency as a team to manage depression and having ready access to specialist support when needed, which was valued by palliative medicine specialists in this thesis.

Regardless of the model in which psychiatry contributes to palliative care, training in this area has generally been neglected. There is a need to provide psychiatrists who work in this interface area with training on the medical, psychiatric, psychosocial and

existential issues pertinent to palliative care and the EOL. Benefits for psychiatry trainees have been demonstrated by an American program that offers clinical rotations in palliative medicine,[216] but formalised training in palliative care psychiatry remains to be further developed in Australia and internationally.

7.4 Suggestions for future research

A contiguous progression from this thesis is the analysis of data from Study 3 on the psychiatrists' explanatory models of depression, to identify their causal explanations for depression and treatment approaches. This has not been included as part of this thesis out of consideration of its length, but would serve as an informative comparison with causal explanations and treatment approaches of the palliative medicine specialists. The perspectives of these two groups of medical specialists would have relevance for the development of future causal explanatory models and treatment guidelines for depression.

As an extension of this thesis, further research can be conducted to more broadly investigate the conceptualisation patterns, causal explanations and treatment approaches of different groups of medical practitioners in relation to depression. Having established themes for each of these aspects of depression using a qualitative method of inquiry, further research can use quantitative methods as a means to measure and compare these within and among medical practitioner groups. A practical method may be the use of questionnaires. This direction of research may be illuminative in establishing the prevalence of the different themes and the correlation between different concepts, causal explanations and treatment approaches. Differences in conceptualisation, causal explanations and treatment approaches may also be found among medical disciplines or demographic groups of medical practitioners, which may have implications on medical education and professional development.

Further qualitative research into the conceptualisations of depression of other clinical stakeholders in the palliative care setting would also be instructive and would complement the studies in this thesis. Among medical practitioners, the conceptualisations of oncologists and geriatricians, for example, would be relevant to palliative care. Other professional groups may include nurses, social workers and psychologists in palliative care services, and nurses in residential aged care facilities who increasingly provide EOL care for patients. Patients receiving palliative care form an important group, whose conceptualisations of depression are expected to play an integral part throughout the clinical process from the detection to management of depression. Research on patient accounts of depression has generally emphasised the diversity of patient concepts, the dissonance between patient and clinician accounts, and clinicians' inability to incorporate the experiential and social aspects of depression.[78,110,111,246-248] Importantly, the concordance between the patient's and the clinician's conceptualisations is a determinant of therapeutic alliance and patient satisfaction with treatment.[249] However, research to date has been conducted outside of the palliative care setting,[120,137,246-248,250] but findings among patients receiving palliative care may differ owing to the unique circumstances and personal expectations at the EOL. Despite ethical concerns about burdening a vulnerable population, qualitative research interviews have been shown to be both helpful to patients at the EOL and feasible,[251-253] and this should not hinder future research in this line provided that appropriate considerations are given to the specific needs of this population.

Lastly, one of the questions raised in this thesis is whether depression is inherently different as a concept in the palliative care setting, rather than merely differing in presenting greater diagnostic and treatment challenges. To assist in elucidating this issue, future research could examine the phenomenology and epidemiological

characteristics of depression in this setting and its response to treatment, and compare these with non-palliative care settings. Such undertakings would need to negotiate the specific difficulties associated with research in palliative care, such as confounds and high attrition. As such, case reports or case series may be sensible initial approaches to this research question.

7.5 Thesis strengths and limitations

7.5.1 Strengths of this thesis

A principal strength of this thesis is its demonstration of the feasibility of conducting research that is both philosophically based and clinically relevant, thus exposing the indivisible link between philosophy and psychiatry. Although philosophy is fundamental to clinical psychiatric practice, it is an often neglected area in the literature.[254] This may in part relate to the intangibility and expansive scope of subject matters and the obscurity of language in the philosophical literature, rendering it inaccessible to clinical psychiatrists and impractical for application.[255] By examining specific philosophical issues such as conceptual and nosological considerations, causal explanations and treatment approaches, this thesis addresses pertinent subject matters that underscore some of the core dilemmatic aspects of depression in the palliative care setting.

Methodologically, the most appropriate paradigms and techniques were selected according to the research questions and assumptions. The intention of Study 1 was to conduct a preliminary, broad exploration of depression as a concept among medical practitioners working in the palliative care setting, the results of which could then guide further foci of investigation in the subsequent qualitative in-depth studies. Given this objective and sample size, a quantitative method in the form of a questionnaire was considered most suitable. The use of qualitative semi-structured interviewing was suited to the research questions in Studies 2 and 3, which formed

the main part of this thesis. In seeking to understand the ways in which palliative medicine specialists and psychiatrists thought about depression, these research questions assumed different perspectives of understanding, and involved the clarification of concepts, and the exploration of meanings, contexts and interrelationships, all of which implicated a qualitative epistemology and in particular qualitative interviewing.[256] A semi-structured format of interview allowed the exploration of pre-determined areas as set by the framework of the Explanatory Model, but also the freedom to pursue divergent ideas from participants.[257] Similarly, the choice of techniques in data analysis for all studies was carefully considered and based on clear rationale. For Study 1, a mainly descriptive study, descriptive statistics were applied. Non-parametric statistics were used to compare responses among groups due to the non-parametric data distribution, but the limited comparative power due to the small groups was acknowledged. For Studies 2 and 3, the flexibility of thematic analysis in simultaneously allowing inductive and deductive approaches, its freedom from fixed theoretical traditions and transparency, were characteristics that led to its usage.

The use of both quantitative and qualitative methods, and data gathering from different sources, are forms of triangulation, which harvests the strengths of different methods and can generate a fuller understanding of the subject under investigation. In this thesis, the use of a questionnaire allowed a larger sample of palliative medicine practitioners to be surveyed, and highlighted critical issues around the concept of depression specific to the palliative care setting, such as the ambiguity as to whether it is an illness or a normal aspect of the EOL, the uncertainties around its causality, and differences in its quality, diagnosis and treatment. In addition to the usefulness of these findings in guiding foci for exploration in the qualitative studies, the findings of the questionnaire and qualitative studies complement one another in several ways. First, consistent themes identified using the two methodologies serve to

enhance confidence in the findings, for example, the identification of dichotomised concepts of depression as an illness and as normal, the idea that depression is qualitatively different and difficult to delineate in the palliative care setting. Second, the depth of data obtained from the qualitative studies enabled different concepts, causal explanations and treatment approaches towards depression to be articulated, which was not possible from the questionnaire study. Third, albeit not reflecting a representative sample of palliative medical practitioners, the questionnaire findings could place the individual concepts, causal explanations and treatment approaches, as identified through the qualitative study of palliative medicines specialists, in perspective in terms of their approximate prevalence. Lastly, inconsistent findings between the questionnaire and qualitative studies have identified areas that may warrant further research, such as the relative paucity of comments on existential/spiritual issues in understanding the causality of depression at the EOL.

The target populations in all studies were likewise carefully considered, and their relevance to the research topic enhanced the quality of this thesis. In Study 1, all respondents to the questionnaire practised in palliative medicine and the vast majority worked primarily in this area. By not restricting the population to particular disciplines, training backgrounds, positions or work settings, the sample was conducive to reflect the views of medical practitioners who work within the clinical palliative care setting, and to demonstrate concepts that affect clinical care. The qualitative interview studies deliberately targeted palliative medicine specialists and psychiatrists as two medical specialist groups with authority and impact in relation to depression in palliative care. In particular, only psychiatrists who worked in the palliative care setting were recruited, in recognition of the specialised knowledge within palliative care psychiatry and the reality that only this subgroup of psychiatrists are involved in clinical aspects of palliative care.

The attention to methodological rigour is another important strength of this thesis. The main qualitative studies adhered to guiding standards of holistic rigour in qualitative research and of rigour in conducting thematic analysis, as discussed in detail in Section 1.7.4. The consistent practice of reflexivity throughout the conduct of this research, and the contributions of the supervisors towards independent analysis and thematic validation, served to enhance the transparency and trustworthiness of the findings. Reviewer comments for the first three peer-reviewed and published papers included comments about the relevance and significance of the research topic and resonance of the findings (Appendices H, I and J), which are encouraging indications of the holistic rigour of this thesis.

7.5.2 Limitations of this thesis

A key methodological consideration in the conduct of this research has been my professional role as a psychiatrist, and one with a specialised interest in palliative care psychiatry. The potential influences of this on this research have been discussed in each of the papers from the qualitative studies and in the section on reflexivity (Section 1.8). In my function as a research instrument in all the studies, but especially in the qualitative studies, my own understandings and opinions cannot be fully dissociated from the research. This is particularly the case in the interpretation of the data. Although in other methodological traditions, this could be seen to be a source of potential bias, such concerns can be minimised by methodological rigour and reflexive practice. In fact, there may be benefits from my professional status as a psychiatrist. The possession of intimate “insider” knowledge in the field of palliative care psychiatry may have assisted in the formulation of a pertinent research topic and questions, and a pragmatic approach to conducting research in this field, including efficient recruitment strategies. It may have also enhanced my ability to interpret the findings in a clinically meaningful and nuanced light. The line between bias and expertise is unclear, as is often the case in research, and reflexive transparency can

best help readers to form their opinions on the research findings and the researcher's interpretations.

The findings in this thesis also need to be contextualised within their methodological confines. Being studies of Australian medical practitioners, the findings reflect the Australian context and may differ from concepts of depression that are held by medical practitioners in other countries, where local sociocultural considerations may influence interpretations of depression and mental illness, medical education, and ideas around normative experiences at the EOL. As such, the findings of Studies 2 and 3 may not be transferable to other countries, although they may be expected to share more commonalities with countries that have similar medical education curricula and sociocultural environments. The sample in Study 1 was self-selected (by volunteering to respond to the questionnaire) rather than randomly selected, and therefore its results may indicate but may not statistically represent the views of all Australian medical practitioners working in palliative care. This thesis has also restricted its focus in in-depth qualitative exploration to two medical specialties, which share common values rooted in humanistic and holistic practice, although each has its unique focus and theoretical foundations. Therefore, the concepts derived from these groups cannot be transferred to other medical specialties. Lastly, the use of interviewing as a method of inquiry is ideal for eliciting concepts and mental processes involved in the approach to clinical problems. However, it cannot confirm the actual practices of medical practitioners in regards to the diagnosis and treatment of depression, which require methods other than self-report to ascertain.

7.6 Problems encountered and learnings from this research

The main challenge in the conduct of this thesis has been one of terminology, which is an intrinsic problem to depression. Given that the purpose of this thesis was to explore the range of contemporary clinical concepts of depression, the dilemma was

the choice of language that would facilitate the elicitation of all relevant concepts without imposing specific ones on the participants. The unqualified use of the term “depression” was considered to be an acceptable solution, with the specification, if required, that for this research this term referred to its clinical meanings. The dominance of the prevailing DSM classification system also presented a challenge, in that their constructs and terminologies at times almost precluded consideration of alternative concepts and terminologies. This was perhaps more so for experts on depression than for participants, who on the whole did not object to the use of the term “depression” or appeared confused by its meaning during data collection. Crucially, from my clinical experience, palliative care medical practitioners (and other non-psychiatric medical practitioners) infrequently specify “major depression” in everyday clinical parlance and generally favour the term “depression”. This differs from the medical research literature, which values more precise terminologies that are aligned with the major classification systems. As an illustration of this issue, one of the reviewers for Paper 3 suggested that the term “depression” be replaced by “major depression” (Appendix J), which was precisely what this thesis wished to avoid in its examination of the broader conceptualisations of depression. The premise of a broader concept of depression presented greater difficulties for Study 1, since no clarification of terminology could be provided, should this be required by the respondents. In retrospect, a brief explanation could have been included for respondents to the questionnaire, outlining that the study sought their views on depression, in whichever manner they conceptualised this in clinical practice. One of the reviewers for Paper 1 saw the broad concept of depression used in this study as a methodological limitation that complicated the interpretation of the results (Appendix H). Contrarily, a broad conceptualisation was the deliberate intent of the study and subsequently led on to the development of the qualitative interviews. The reading of these papers as a collection would hopefully create improved coherence and understanding of their intent.

An issue that arose during the peer-review process for some of the qualitative papers was the dismissal of the quality of the papers because the number of interviews was considered by editors and reviewers to be insufficient. The issue of sample size in qualitative research has been thoroughly debated, and there is no definitive threshold to the adequacy of sample size.[258-260] The actual sample size *per se* is not a criterion of quality in qualitative research. The number of interviews that reach the point of data saturation has always been held as the gold standard for qualitative interview research,[147] and this number is contingent on many factors, including epistemological orientation, nature and breadth of the topic, type of sampling, homogeneity of the sample, quality of the interviews and data, level of organisation sought for in the themes, and the experience of the researcher with data analysis.[258,259,261] This is an essential difference between qualitative and quantitative research. Although there is already a body of literature on the epistemology and applications of qualitative research in medicine,[257,262-265] it may be useful to further promote more widespread understanding of the relevance of sample size and markers of quality in qualitative interview research within the medical research community. Explicit, step-by-step practical guidance for researchers on how to determine the point of data saturation in qualitative interviews may also be useful. For researchers of this methodology, an awareness of the relative unfamiliarity with and common misperceptions and misunderstandings about qualitative methodologies within the medical community may assist in adopting measures to pre-empt and overcome such obstacles in the process of seeking publication of their work.

In concluding this thesis, I would like to reflect on my learnings on the topic of depression conceptualisation through the conduct of this research. I believe that my thinking in this respect has changed in two ways. My core concepts of depressive

illness and my affinity with the hierarchical model of considering depressive illness have remained constant, and have in fact been affirmed through both my review of the literature and my interviews with the psychiatrist participants. However, from an initially narrower view of depression as illness, my overall concept of depression has broadened, and I can appreciate the merits of considering depression from the perspective of a symptom requiring assistance at the EOL. In clinical practice and in my teaching, I now more overtly articulate the differences in narrow versus broad concepts of depression, and take care to define my meaning and clarify that of other clinicians and patients. To me, depression is a complex, heterogeneous and evolving group of human conditions. This premise should form the basis of any clinician's attempt to understand and conceptualise depression, for although much remains to be deliberated and clarified, progress cannot be made without accepting and working with this fundamental conceptual complexity.

REFERENCES

1. Fallon M, Smyth J. Terminology: the historical perspective, evolution and current usage—room for confusion? *Eur J Cancer* 2008; 44: 1069-1071.
2. Hui D, Mori M, Parsons HA, et al. The lack of standard definitions in the supportive and palliative oncology literature. *J Pain Symptom Manage* 2012; 43: 582-592.
3. Pastrana T, Junger S, Ostgathe C, et al. A matter of definition—key elements identified in a discourse analysis of definitions of palliative care. *Palliat Med* 2008; 22: 222-232.
4. Billings JA. What is palliative care? *J Palliat Med* 1998; 1: 73-81.
5. World Health Organization. National cancer control programmes: policies and managerial guidelines. 2nd ed. Geneva: World Health Organization; 2002.
6. Adult Medicine Division, Paediatrics & Child Health Division, Australasian Chapter of Palliative Medicine. Palliative medicine. Advanced training curriculum: The Royal Australasian College of Physicians; 2010.
7. Doyle D. Palliative medicine—a time for definition? *Palliat Med* 1993; 7: 253-255.
8. Palliative Care Australia. Standards for providing quality palliative care for all Australians. ACT: Palliative Care Australia; 2005.
9. National Institutes of Health. National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care. 2004 [cited 2012 23 August]; Available from: <http://consensus.nih.gov/2004/2004EndOfLifeCareSOSo24html.htm>.
10. Palliative Care Australia. Strategic plan 2008-2011. ACT: Palliative Care Australia; 2008.
11. Barraclough J. ABC of palliative care. Depression, anxiety, and confusion. *BMJ* 1997; 315: 1365-1368.

12. Irwin SA, Rao S, Bower K, et al. Psychiatric issues in palliative care: recognition of depression in patients enrolled in hospice care. *J Palliat Med* 2008; 11: 158-163.
13. Laugsand EA, Kaasa S, de Conno F, et al. Intensity and treatment of symptoms in 3,030 palliative care patients: a cross-sectional survey of the EAPC Research Network. *J Opioid Manag* 2009; 5: 11-21.
14. Radbruch L, Nauck F, Ostgathe C, et al. What are the problems in palliative care? Results from a representative survey. *Support Care Cancer* 2003; 11: 442-451.
15. Hotopf M, Chidgey J, Addington-Hall J, et al. Depression in advanced disease: a systematic review Part 1. Prevalence and case finding. *Palliat Med* 2002; 16: 81-97.
16. Mitchell AJ, Chan M, Bhatti H, et al. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011; 12: 160-174.
17. Lloyd-Williams M, Dennis M, Taylor F. A prospective study to determine the association between physical symptoms and depression in patients with advanced cancer. *Palliat Med* 2004; 18: 558-563.
18. Rayner L, Lee W, Price A, et al. The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: cross-sectional survey with four-week follow-up. *Palliat Med* 2011; 25: 229-241.
19. Minton O, Strasser F, Radbruch L, et al. Identification of factors associated with fatigue in advanced cancer: a subset analysis of the European palliative care research collaborative computerized symptom assessment data set. *J Pain Symptom Manage* 2012; 43: 226-235.
20. Mystakidou K, Parpa E, Tsilika E, et al. How is sleep quality affected by the psychological and symptom distress of advanced cancer patients? *Palliat Med* 2009; 23: 46-53.

21. Austin P, Wiley S, McEvoy PM, et al. Depression and anxiety in palliative care inpatients compared with those receiving palliative care at home. *Palliat Support Care* 2011; 9: 393-400.
22. Lloyd-Williams M, Shiels C, Taylor F, et al. Depression—an independent predictor of early death in patients with advanced cancer. *J Affect Disord* 2009; 113: 127-132.
23. Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA* 2000; 284: 2907-2911.
24. Mystakidou K, Parpa E, Tsilika E, et al. Depression, hopelessness, and sleep in cancer patients' desire for death. *Int J Psychiatry Med* 2007; 37: 201-211.
25. Levene I, Parker M. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review. *J Med Ethics* 2011; 37: 205-211.
26. McCabe MP, Mellor D, Davison TE, et al. Detecting and managing depressed patients: palliative care nurses' self-efficacy and perceived barriers to care. *J Palliat Med* 2012; 15: 463-467.
27. Rayner L, Loge JH, Wasteson E, et al. The detection of depression in palliative care. *Curr Opin Support Palliat Care* 2009; 3: 55-60.
28. Rhondali W, Perceau E, Saltel P, et al. Depression assessment by oncologists and palliative care physicians. *Palliat Support Care* 2012; 10: 255-263.
29. Stiefel R, Die Trill M, Berney A, et al. Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association for Palliative Care. *Support Care Cancer* 2001; 9: 477-488.
30. Hallford DJ, McCabe MP, Mellor D, et al. Intervention for depression among palliative care patients and their families: A study protocol for evaluation of a training program for professional care staff. *BMC Palliat Care* 2011; 10: 11. doi: 10.1186/1472-684X-10-11.

31. European Palliative Care Research Collaborative. Project overview - Introduction. 2009 [cited 2012 28 August]; Available from: http://www.eperc.org/project_info.php.
32. Rayner L, Price A, Hotopf M, et al. The development of evidence-based European guidelines on the management of depression in palliative cancer care. *Eur J Cancer* 2011; 47: 702-712.
33. Ewing G, Rogers M, Barclay S, et al. Recruiting patients into a primary care based study of palliative care: why is it so difficult? *Palliat Med* 2004; 18: 452-459.
34. Jordhoy MS, Kaasa S, Fayers P, et al. Challenges in palliative care research; recruitment, attrition and compliance: experience from a randomized controlled trial. *Palliat Med* 1999; 13: 299-310.
35. Wohleber AM, McKittrick DS, Davis SE. Designing research with hospice and palliative care populations. *Am J Hosp Palliat Care* 2012; 29: 335-345.
36. Wasteson E, Brenne E, Higginson IJ, et al. Depression assessment and classification in palliative cancer patients: a systematic literature review. *Palliat Med* 2009; 23: 739-753.
37. Lawrie I, Lloyd-Williams M, Taylor F. How do palliative medicine physicians assess and manage depression. *Palliat Med* 2004; 18: 234-238.
38. Porche K, Reymond L, Callaghan JO, et al. Depression in palliative care patients: a survey of assessment and treatment practices of Australian and New Zealand palliative care specialists. *Aust Health Rev* 2014; 38: 44-50.
39. Warmenhoven F, van Rijswijk E, van Hoogstraten E, et al. How family physicians address diagnosis and management of depression in palliative care patients. *Ann Fam Med* 2012; 10: 330-336.
40. Berrios GE. Melancholia and depression during the 19th century: a conceptual history. *Br J Psychiatry* 1988; 153: 298-304.
41. Jansson A. Mood disorders and the brain: depression, melancholia, and the historiography of psychiatry. *Med Hist* 2011; 55: 393-399.

42. Lewis AJ. Melancholia: a historical review. *Br J Psychiatry* 1934; 80: 1-42.
43. Misbach J, Stam HJ. Medicalizing melancholia: exploring profiles of psychiatric professionalization. *J Hist Behav Sci* 2006; 42: 41-59.
44. Pilgrim D, Bentall R. The medicalisation of misery: a critical realist analysis of the concept of depression. *J Ment Health* 1999; 8: 261-274.
45. Shorter E. The doctrine of the two depressions in historical perspective. *Acta Psychiatr Scand Suppl* 2007; 115: 5-13.
46. Farmer A, McGuffin P. The classification of the depressions. Contemporary confusion revisited. *Br J Psychiatry* 1989; 155: 437-443.
47. Kendell RE. The classification of depressions: a review of contemporary confusion. *Br J Psychiatry* 1976; 129: 15-28.
48. McPherson S, Armstrong D. Social determinants of diagnostic labels in depression. *Soc Sci Med* 2006; 62: 50-58.
49. Boyce P, Hadzi-Pavlovic D. Issues in classification: I. Some historical aspects. In: Parker G, Hadzi-Pavlovic D, editors. *Melancholia. A disorder of movement and mood*. Cambridge, UK: Cambridge University Press; 1996, p. 9-19.
50. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Third Edition*. Washington: American Psychiatric Association; 1980.
51. Parker G. Beyond major depression. *Psychol Med* 2005; 35: 467-474.
52. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision*. Washington: American Psychiatric Association; 2000.
53. Galatzer-Levy IR, Galatzer-Levy RM. The revolution in psychiatric diagnosis: problems at the foundations. *Perspect Biol Med* 2007; 50: 161-180.
54. Ghaemi SN, Vohringer PA, Vergne DE. The varieties of depressive experience: diagnosing mood disorders. *Psychiatr Clin North Am* 2012; 35: 73-86.

55. Horwitz AV, Wakefield JC. Loss of sadness: How psychiatry transformed normal sorrow into depressive disorder. London: Oxford University Press; 2007.
56. Jablensky A. Categories, dimensions and prototypes: critical issues for psychiatric classification. *Psychopathology* 2005; 38: 201-205.
57. Jablensky A. The disease entity in psychiatry: fact or fiction? *Epidemiol Psychiatr Sci* 2012; 21: 255-264.
58. Jacob KS. Major depression: revisiting the concept and diagnosis. *Ad Psychiatr Treat* 2009; 15: 279-285.
59. Kendler KS, Gardner CO, Jr. Boundaries of major depression: an evaluation of DSM-IV criteria. *Am J Psychiatry* 1998; 155: 172-177.
60. van Praag HM. Nosologomania: a disorder of psychiatry. *World J Biol Psychiatry* 2000; 1: 151-158.
61. Rapley M, Moncrieff J, Dillon J. De-medicalizing misery: Psychiatry psychology and the human condition. Palgrave Connect: Palgrave Macmillan; 2011.
62. Baumeister H, Parker G. Meta-review of depressive subtyping models. *J Affect Disord* 2012; 139: 126-140.
63. Andrews G. Placebo response in depression: bane of research, boon to therapy. *Br J Psychiatry* 2001; 178: 192-194.
64. Khan A, Warner HA, Brown WA. Symptom reduction and suicide risk in patients treated with placebo in antidepressant clinical trials: an analysis of the Food and Drug Administration database. *Arch Gen Psychiatry* 2000; 57: 311-317.
65. Kirsch I, Deacon BJ, Huedo-Medina TB, et al. Initial severity and antidepressant benefits: a meta-analysis of data submitted to the Food and Drug Administration. *PLoS Med* 2008; 5: e45.
66. Kendler KS, Walters EE, Kessler RC. The prediction of length of major depressive episodes: results from an epidemiological sample of female twins. *Psychol Med* 1997; 27: 107-117.

67. McLeod JD, Kessler RC, Landis KR. Speed of recovery from major depressive episodes in a community sample of married men and women. *J Abnorm Psychol* 1992; 101: 277-286.
68. Mulder RT. An epidemic of depression or the medicalization of distress? *Perspect Biol Med* 2008; 51: 238-250.
69. Parker G, Fletcher K, Hadzi-Pavlovic D. Is context everything to the definition of clinical depression? A test of the Horwitz and Wakefield postulate. *J Affect Disord* 2012; 136: 1034-1038.
70. Jutel A. Sociology of diagnosis: a preliminary review. *Sociol Health Illn* 2009; 31: 278-299.
71. Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Ann Intern Med* 1978; 88: 251-258.
72. Barney LJ, Griffiths KM, Jorm AF, et al. Stigma about depression and its impact on help-seeking intentions. *Aust N Z J Psychiatry* 2006; 40: 51-54.
73. Sims A. The scar that is more than skin deep: the stigma of depression. *Br J Gen Pract* 1993; 43: 30-31.
74. Frazzetto G. The drugs don't work for everyone. Doubts about the efficacy of antidepressants renew debates over the medicalization of common distress. *EMBO Rep* 2008; 9: 605-608.
75. Rosenman S, Nasti J. Psychiatric diagnoses are not mental processes: Wittgenstein on conceptual confusion. *Aust N Z J Psychiatry* 2012; 46: 1046-1052.
76. Mechanic D. The concept of illness behaviour: culture, situation and personal predisposition. *Psychol Med* 1986; 16: 1-7.
77. Eisenberg L. Disease and illness. Distinctions between professional and popular ideas of sickness. *Cult Med Psychiatry* 1977; 1: 9-23.
78. Rogers A, May C, Oliver D. Experiencing depression, experiencing the depressed: the separate worlds of patients and doctors. *J Ment Health* 2001 10: 317-333.

79. Lewis AJ. Melancholia: a clinical survey of depressive states. *Journal of Mental Science* 1934; 80: 277-378.
80. Parker G, Hadzi-Pavlovic D. Melancholia: a disorder of movement and mood: a phenomenological and neurobiological review. Cambridge: Cambridge University Press; 1996.
81. Beck AT. Depression: clinical, experimental, and theoretical aspects. New York: Hoeber Medical Division, Harper & Row; 1967.
82. Wilson KG, Lander M, Chochinov HM. Diagnosis and management of depression in palliative care. In: Chochinov HM, Breitbart W, editors. Handbook of psychiatry in palliative medicine. 2nd ed. New York: Oxford University Press; 2009, p. 39-68.
83. Leonard M, Spiller J, Keen J, et al. Symptoms of depression and delirium assessed serially in palliative-care inpatients. *Psychosomatics* 2009; 50: 506-514.
84. Marchington KL, Carrier L, Lawlor PG. Delirium masquerading as depression. *Palliat Support Care* 2012; 10: 59-62.
85. Chochinov HM, Wilson KG, Enns M, et al. Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgments. *Am J Psychiatry* 1994; 151: 537-540.
86. Gotay CC. Why me? Attributions and adjustment by cancer patients and their mates at two stages in the disease process. *Soc Sci Med* 1985; 20: 825-831.
87. Linn MW, Linn BS, Stein SR. Beliefs about causes of cancer in cancer patients. *Soc Sci Med* 1982; 16: 835-839.
88. Taylor SE, Lichtman RR, Wood JV. Attributions, beliefs about control, and adjustment to breast cancer. *J Pers Soc Psychol* 1984; 46: 489-502.
89. Price A, Goodwin L, Rayner L, et al. Illness perceptions, adjustment to illness, and depression in a palliative care population. *J Pain Symptom Manage* 2012; 43: 819-832.

90. Ando M, Morita T, Lee V, et al. A pilot study of transformation, attributed meanings to the illness, and spiritual well-being for terminally ill cancer patients. *Palliat Support Care* 2008; 6: 335-340.
91. Taylor EJ. Whys and wherefores: adult patient perspectives of the meaning of cancer. *Semin Oncol Nurs* 1995; 11: 32-40.
92. Taylor EJ. Transformation of tragedy among women surviving breast cancer. *Oncol Nurs Forum* 2000; 27: 781-788.
93. Turnquist DC, Harvey JH, Andersen BL. Attributions and adjustment to life-threatening illness. *Br J Clin Psychol* 1988; 27 (Pt 1): 55-65.
94. Kubler-Ross E. On death and dying. London: Tavistock Publishing Limited; 1970.
95. Jacobs S. Pathologic grief: maladaptation to loss. Washington, DC: American Psychiatric Press; 1993.
96. Freud S. Mourning and melancholia. In: Strachey J, ed. The Standard Edition of the complete psychological works of Sigmund Freud. Volume XIV (1914-1916): On the history of the psycho-analytic movement, papers on metapsychology and other works. London: The Hogarth Press 1917, p. 237-258.
97. Zisook S, Shear K. Grief and bereavement: what psychiatrists need to know. *World Psychiatry* 2009; 8: 67-74.
98. American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition. Washington: American Psychiatric Association; 2013.
99. Wakefield JC, Schmitz MF. Normal vs. disordered bereavement-related depression: are the differences real or tautological? *Acta Psychiatr Scand* 2013; 127: 159-168.
100. Zisook S, Shear K, Kendler KS. Validity of the bereavement exclusion criterion for the diagnosis of major depressive episode. *World Psychiatry* 2007; 6: 102-107.

101. Mellor D, McCabe MP, Davison TE, et al. Barriers to the detection and management of depression by palliative care professional carers among their patients: perspectives from professional carers and patients' family members. *Am J Hosp Palliat Care* 2013; 30: 12-20.
102. Thomas-MacLean R, Stoppard JM. Physicians' constructions of depression: inside/outside the boundaries of medicalization. *Health (London)* 2004; 8: 275-293.
103. Schumann I, Schneider A, Kantert C, et al. Physicians' attitudes, diagnostic process and barriers regarding depression diagnosis in primary care: a systematic review of qualitative studies. *Fam Pract* 2012; 29: 255-263.
104. Burroughs H, Lovell K, Morley M, et al. 'Justifiable depression': how primary care professionals and patients view late-life depression? A qualitative study. *Fam Pract* 2006; 23: 369-377.
105. Murray J, Banerjee S, Byng R, et al. Primary care professionals' perceptions of depression in older people: a qualitative study. *Soc Sci Med* 2006; 63: 1363-1373.
106. Ghaemi SN. The concepts of psychiatry: a pluralistic approach to the mind and mental illness. Baltimore, Maryland: The Johns Hopkins University Press; 2003.
107. Kendler KS. Toward a philosophical structure for psychiatry. *Am J Psychiatry* 2005; 162: 433-440.
108. Kendler KS. Explanatory models for psychiatric illness. *Am J Psychiatry* 2008; 165: 695-702.
109. Aidoo M, Harpham T. The explanatory models of mental health amongst low-income women and health care practitioners in Lusaka, Zambia. *Health Policy Plan* 2001; 16: 206-213.
110. Wittink MN, Dahlberg B, Biruk C, et al. How older adults combine medical and experiential notions of depression. *Qual Health Res* 2008; 18: 1174-1183.
111. Kokanovic R, Bendelow G, Philip B. Depression: the ambivalence of diagnosis. *Sociol Health Illn* 2012 Aug 16. doi: 10.1111/j.1467-9566.2012.01486.x.

112. Leventhal H, Meyer D, Nerenz D. The common sense representation of illness danger. In: Rachman S, editor. *Medical psychology*. New York: Pergamon Press; 1980, p. 7-30.
113. Leventhal H, Nerenz D, Steele D. Illness representations and coping with health threats. In: Baum A, Taylor S, Singer J, editors. *Handbook of psychology and health*. New Jersey: Hillsdale; 1984, p. 219-250.
114. Heider F. *The psychology of interpersonal relations*. New York: John Wiley & Sons; 1958.
115. Bhui K, Bhugra D. Explanatory models for mental distress: implications for clinical practice and research. *Br J Psychiatry* 2002; 181: 6-7.
116. Rosenstock IM. Why people use health services. *Milbank Mem Fund Q* 1966; 44: 94-124.
117. Rosenstock IM. Historical origins of the health belief model. *Health Educ Monogr* 1974; 2: 328-335.
118. Kleinman A. Orientations 3: Core clinical functions and explanatory models. In: Kleinman A. *Patients and healers in the context of culture. An exploration of the borderland between anthropology, medicine, and psychiatry*. Berkeley: University of California Press; 1980, p. 71-118.
119. William B, Healy D. Perceptions of illness causation among new referrals to a community mental health team: "explanatory model" or "exploratory map"? *Soc Sci Med* 2001; 53: 465-476.
120. Kokanovic R, Butler E, Halilovich H, et al. Maps, models, and narratives: the ways people talk about depression. *Qual Health Res* 2013; 23: 114-125.
121. Kleinman A, Benson P. Anthropology in the clinic: the problem of cultural competency and how to fix it. *PLoS Med* 2006; 3: e294.
122. Bhui K, Bhugra D, Goldberg D. Causal explanations of distress and general practitioners' assessments of common mental disorder among Punjabi and English attendees. *Soc Psychiatry Psychiatr Epidemiol* 2002; 37: 38-45.

123. Cabassa LJ, Hansen MC, Palinkas LA, et al. Azucar y nervios: explanatory models and treatment experiences of Hispanics with diabetes and depression. *Soc Sci Med* 2008; 66: 2413-2424.
124. Dejman M, Ekblad S, Forouzan AS, et al. Explanatory model of help-seeking and coping mechanisms among depressed women in three ethnic groups of Fars, Kurdish, and Turkish in Iran. *Arch Iran Med* 2008; 11: 397-406.
125. Henningsen P, Jakobsen T, Schiltenswolf M, et al. Somatization revisited: diagnosis and perceived causes of common mental disorders. *J Nerv Ment Dis* 2005; 193: 85-92.
126. Jacob KS, Bhugra D, Lloyd KR, et al. Common mental disorders, explanatory models and consultation behaviour among Indian women living in the UK. *J R Soc Med* 1998; 91: 66-71.
127. McCabe R, Priebe S. Explanatory models of illness in schizophrenia: comparison of four ethnic groups. *Br J Psychiatry* 2004; 185: 25-30.
128. Okello ES, Neema S. Explanatory models and help-seeking behavior: Pathways to psychiatric care among patients admitted for depression in Mulago hospital, Kampala, Uganda. *Qual Health Res* 2007; 17: 14-25.
129. Ugarriza DN. Elderly women's explanation of depression. *J Gerontol Nurs* 2002; 28: 22-29.
130. Weiss M. Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. *Transcult Psychiatry* 1997; 34: 235-263.
131. Lloyd KR, Jacob KS, Patel V, et al. The development of the Short Explanatory Model Interview (SEMI) and its use among primary-care attenders with common mental disorders. *Psychol Med* 1998; 28: 1231-1237.
132. Cohen D, Crabtree B. Qualitative Research Guidelines Project. July 2006 [cited 2012 4 December]; Available from: <http://www.qualres.org/>.

133. Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. Thousand Oaks, CA: SAGE; 1994, p. 105-117.
134. Cabassa LJ, Lester R, Zayas LH. "It's like being in a labyrinth:" Hispanic immigrants' perceptions of depression and attitudes toward treatments. *J Immigr Minor Health* 2007; 9: 1-16.
135. Okello ES, Ekblad S. Lay concepts of depression among the Baganda of Uganda: a pilot study. *Transcult Psychiatry* 2006; 43: 287-313.
136. Yeung A, Chang D, Gresham RL, Jr., et al. Illness beliefs of depressed Chinese American patients in primary care. *J Nerv Ment Dis* 2004; 192: 324-327.
137. Cornford CS, Hill A, Reilly J. How patients with depressive symptoms view their condition: a qualitative study. *Fam Pract* 2007; 24: 358-364.
138. Karasz A, Garcia N, Ferri L. Conceptual models of depression in primary care patients. A comparative study. *J Cross Cult Psychol* 2009; 40: 1041-1059.
139. Wittink MN, Joo JH, Lewis LM, et al. Losing faith and using faith: older African Americans discuss spirituality, religious activities, and depression. *J Gen Intern Med* 2009; 24: 402-407.
140. SPSS Inc. SPSS version 18.0 for Windows. 18.0 ed. Chicago, IL 2009.
141. QSR International Pty Ltd. NVivo qualitative data analysis software. Version 9 ed. Doncaster 2011.
142. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77-101.
143. ANZSPM Inc. ANZSPM. The Australian and New Zealand Society of Palliative Medicine. [updated January 2011; cited 2012 18 November]; Available from: <http://www.anzspm.org.au>.
144. RANZCP. About the College. [cited 2013 14 October]; Available from: <https://http://www.ranzcp.org/About-us/About-the-College.aspx>.

145. Braun V, Clarke V. Interactive data collection 1: Interviews. In: Braun V, Clarke V. Successful qualitative research. A practical guide for beginners. London: SAGE Publications Ltd; 2013, p. 85.
146. Bowen GA. Naturalistic inquiry and the saturation concept: a research note. *Qual Res* 2008; 8: 137-152.
147. Morse JM. The significance of saturation. *Qual Health Res* 1995; 5: 147-149.
148. Joffe H. Thematic analysis. In: Harper D, Thompson AR, editors. Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners. First ed. Chichester: John Wiley & Sons, Ltd; 2012.
149. Boyatzis RE. Transforming qualitative information: thematic analysis and code development. Thousand Oaks, CA: Sage Publications, Inc.; 1998.
150. Braun V, Clarke V. Moving towards analysis. In: Braun V, Clarke V. Successful qualitative research. A practical guide for beginners. London: SAGE Publications Ltd; 2013, p. 174-180.
151. Howitt D. Thematic analysis. Introduction to qualitative methods in psychology. Harlow, England: Pearson Education Limited; 2010.
152. Sandelowski M. Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS Adv Nurs Sci* 1993; 16: 1-8.
153. Lincoln YS, Guba EG. Naturalistic inquiry. Newbury Park, CA: Sage Publications; 1985.
154. Mays N, Pope C. Quality in qualitative health research. In: Pope C, Mays N, editors. Qualitative research in health care. 2nd ed. London: BMJ Books; 2000, p. 89-102.
155. Miles MB, Huberman AM. Qualitative data analysis. 2nd ed. Thousand Oaks, CA: Sage Publications; 1994.
156. Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998; 8: 341-351.

157. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; 358: 483-488.
158. Giacomini MK, Cook DJ. Users' guides to the medical literature: XXIII. Qualitative research in health care A. Are the results of the study valid? Evidence-Based Medicine Working Group. *JAMA* 2000; 284: 357-362.
159. Tracy SJ. Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qual Inq* 2010; 16: 837-851.
160. Hansen EC. Research design and rigour. Successful qualitative health research: a practical introduction. Crows Nest NSW: Allen & Unwin; 2006, p. 46-75.
161. Rice PL, Ezzy D. Qualitative research methods: a health focus. Melbourne: Oxford University Press; 1999.
162. Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ* 2001; 322: 1115-1117.
163. Guba EG, Lincoln YS. Judging the quality of fourth generation evaluation. Fourth generation evaluation. Newbury Park, CA: SAGE Publications, Inc.; 1989.
164. Angen MJ. Evaluating interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qual Health Res* 2000; 10: 378-395.
165. Australian Government, National Health and Medical Research Council, Australian Research Council, et al. Revision of the joint NHMRC/AVCC statement and guidelines on research practice. Australian code for the responsible conduct of research. Canberra: Australian Government; 2007.
166. Finlay L. "Outing" the researcher: the provenance, process, and practice of reflexivity. *Qual Health Res* 2002; 12: 531-545.
167. Parker G. Classifying depression: should paradigms lost be regained? *Am J Psychiatry* 2000; 157: 1195-1203.
168. Lloyd-Williams M, Friedman T. Depression in palliative care patients—a prospective study. *Eur J Cancer Care (Engl)* 2001; 10: 270-274.

169. Wilson KG, Chochinov HM, Skirko MG, et al. Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage* 2007; 33: 118-129.
170. Delgado-Guay M, Parsons HA, Li Z, et al. Symptom distress in advanced cancer patients with anxiety and depression in the palliative care setting. *Support Care Cancer* 2009; 17: 573-579.
171. Hui D, de la Cruz M, Thorney S, et al. The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. *Am J Hosp Palliat Care* 2011; 28: 264-270.
172. Rayner L, Price A, Hotopf M, et al. Expert opinion on detecting and treating depression in palliative care: A Delphi study. *BMC Palliat Care* [Internet]. 2011 May 27; 10(1):[10 p.]. Available from:
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=21619580.
173. Chew-Graham CA, May CR, Cole H, et al. The burden of depression in primary care: a qualitative investigation of general practitioners' constructs of depressed people in the inner city. *Int J Psychiatry Clin Pract* 2000; 6: 137-141.
174. Endicott J. Measurement of depression in patients with cancer. *Cancer* 1984; 53: 2243-2249.
175. Akechi T, Nakano T, Akizuki N, et al. Somatic symptoms for diagnosing major depression in cancer patients. *Psychosomatics* 2003; 44: 244-248.
176. Mitchell AJ, Lord K, Symonds P. Which symptoms are indicative of DSMIV depression in cancer settings? An analysis of the diagnostic significance of somatic and non-somatic symptoms. *J Affect Disord* 2012; 138: 137-148.
177. Ng F, Crawford GB, Chur-Hansen A. Palliative medicine practitioners' views on the concept of depression in the palliative care setting. *J Palliat Med* 2013; 16: 922-928.
178. Zachar P. Psychiatric disorders are not natural kinds. *Philos Psychiatry Psychol* 2000; 7: 167-182.

179. Wakefield JC. Are you as smart as a 4th grader? Why the prototype-similarity approach to diagnosis is a step backward for a scientific psychiatry. *World Psychiatry* 2012; 11: 27-28.
180. Westen D. Prototype diagnosis of psychiatric syndromes. *World Psychiatry* 2012; 11: 16-21.
181. Jacobsen PB, Donovan KA, Weitzner MA. Distinguishing fatigue and depression in patients with cancer. *Semin Clin Neuropsychiatry* 2003; 8: 229-240.
182. Reuter K, Harter M. The concepts of fatigue and depression in cancer. *Eur J Cancer Care (Engl)* 2004; 13: 127-134.
183. Colman I, Ataullahjan A. Life course perspectives on the epidemiology of depression. *Can J Psychiatry* 2010; 55: 622-632.
184. Engel GL. The need for a new medical model: a challenge for biomedicine. *Science* 1977; 196: 129-136.
185. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry* 1980; 137: 535-544.
186. Ng F, Crawford GB, Chur-Hansen A. How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study. *J Palliat Med* 2014; 17: 318-324.
187. Ingram RE, Luxton D. Vulnerability-stress models. In: Hankin BL, Abela JRZ, editors. *Development of psychopathology: A vulnerability-stress perspective*. New York: Sage; 2005, p. 32-46.
188. Schotte CK, Van Den Bossche B, De Doncker D, et al. A biopsychosocial model as a guide for psychoeducation and treatment of depression. *Depress Anxiety* 2006; 23: 312-324.
189. Schildkraut JJ. The catecholamine hypothesis of affective disorders: a review of supporting evidence. *Am J Psychiatry* 1965; 122: 509-522.
190. Paykel ES. Basic concepts of depression. *Dialogues Clin Neurosci* 2008; 10: 279-289.

191. Clarke DM, Kissane DW. Demoralization: its phenomenology and importance. *Aust N Z J Psychiatry* 2002; 36: 733-742.
192. Kissane DW, Clarke DM, Street AF. Demoralization syndrome—a relevant psychiatric diagnosis for palliative care. *J Palliat Care* 2001; 17: 12-21.
193. Eysenck HJ, Eysenck MW. Personality and individual differences. New York: Plenum Press; 1985.
194. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer; 1984.
195. Lakey B, Cohen S. Social support theory and measurement. In: Cohen S, Underwood LG, Gottlieb BH, editors. Social support measurement and intervention: a guide for health and social scientists. New York: Oxford University Press; 2000, p. 29-52.
196. Doka KJ. Disenfranchised grief: Recognizing hidden sorrow. Lexington, MA, England: Lexington Books/D.C. Heath and Com; 1989.
197. Chochinov HM, Hack T, McClement S, et al. Dignity in the terminally ill: a developing empirical model. *Soc Sci Med* 2002; 54: 433-443.
198. Breslau N, Davis GC, Peterson EL, et al. A second look at comorbidity in victims of trauma: the posttraumatic stress disorder-major depression connection. *Biol Psychiatry* 2000; 48: 902-909.
199. Hirschfeld RM. History and evolution of the monoamine hypothesis of depression. *J Clin Psychiatry* 2000; 61 Suppl 6: 4-6.
200. Epstein RM, Borrell-Carrio F. The biopsychosocial model: Exploring six impossible things. *Fam Syst Health* 2005; 23: 426-431.
201. McLaren N. A critical review of the biopsychosocial model. *Aust N Z J Psychiatry* 1998; 32: 86-92; discussion 93-86.
202. McHugh PR, Slavney PR. The perspectives of psychiatry. 2nd ed. Baltimore: Johns Hopkins University Press; 1998.

203. Block SD. Assessing and managing depression in the terminally ill patient. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians - American Society of Internal Medicine. *Ann Intern Med* 2000; 132: 209-218.
204. Rodin G, Katz M, Lloyd N, et al. Treatment of depression in cancer patients. *Curr Oncol* 2007; 14: 180-188.
205. Qaseem A, Snow V, Shekelle P, et al. Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: a clinical practice guideline from the American College of Physicians. *Ann Intern Med* 2008; 148: 141-146.
206. Ly KL, Chidgey J, Addington-Hall J, et al. Depression in palliative care: a systematic review. Part 2. Treatment. *Palliat Med* 2002; 16: 279-284.
207. Price A, Hotopf M. The treatment of depression in patients with advanced cancer undergoing palliative care. *Curr Opin Support Palliat Care* 2009; 3: 61-66.
208. Lloyd-Williams M, Payne S. A qualitative study of clinical nurse specialists' views on depression in the palliative care patients. *Palliat Med* 2003; 17: 334-338.
209. Hultman T, Reder EA, Dahlin CM. Improving psychological and psychiatric aspects of palliative care: the national consensus project and the national quality forum preferred practices for palliative and hospice care. *Omega* 2008; 57: 323-339.
210. Ng F, Crawford GB, Chur-Hansen A. Palliative medicine specialists' causal explanations for depression in the palliative care setting: A qualitative in-depth interview study. *BMJ Support Palliat Care* 2014; published online 28 April doi:10.1136/bmjspcare-2013-000626.
211. Meier DE, Back AL, Morrison RS. The inner life of physicians and care of the seriously ill. *JAMA* 2001; 286: 3007-3014.
212. Vachon ML. Staff stress in hospice/palliative care: a review. *Palliat Med* 1995; 9: 91-122.
213. Irwin SA, Ferris FD. The opportunity for psychiatry in palliative care. *Can J Psychiatry* 2008; 53: 713-724.

214. Meier DE, Beresford L. Growing the interface between palliative medicine and psychiatry. *J Palliat Med* 2010; 13: 803-806.
215. Billings JA, Block SD. Integrating psychiatry and palliative medicine: The challenges and opportunities. In: Chochinov HM, Breitbart W, editors. Handbook of psychiatry in palliative medicine. 2nd ed. New York: Oxford University Press; 2009, p. 13-19.
216. Irwin SA, Montross LP, Bhat RG, et al. Psychiatry resident education in palliative care: opportunities, desired training, and outcomes of a targeted educational intervention. *Psychosomatics* 2011; 52: 530-536.
217. Harari E. Adolescent psychopathology and the death of meaning in psychiatry. *Aust N Z J Psychiatry* 2013; 47: 605-608.
218. Lin EH, Katon WJ, Simon GE, et al. Achieving guidelines for the treatment of depression in primary care: is physician education enough? *Med Care* 1997; 35: 831-842.
219. Gilbody S, Whitty P, Grimshaw J, et al. Educational and organizational interventions to improve the management of depression in primary care: a systematic review. *JAMA* 2003; 289: 3145-3151.
220. Noorani NH, Montagnini M. Recognizing depression in palliative care patients. *J Palliat Med* 2007; 10: 458-464.
221. Pessin H, Olden M, Jacobson C, et al. Clinical assessment of depression in terminally ill cancer patients: a practical guide. *Palliat Support Care* 2005; 3: 319-324.
222. Golden RN, McCartney CF, Haggerty JJ, Jr., et al. The detection of depression by patient self-report in women with gynecologic cancer. *Int J Psychiatry Med* 1991; 21: 17-27.
223. Jefford M, Mileskin L, Richards K, et al. Rapid screening for depression—validation of the Brief Case-Find for Depression (BCD) in medical oncology and palliative care patients. *Br J Cancer* 2004; 91: 900-906.

224. Power D, Kelly S, Gilsean J, et al. Suitable screening tests for cognitive impairment and depression in the terminally ill—a prospective prevalence study. *Palliat Med* 1993; 7: 213-218.
225. Angst J, Sellaro R, Merikangas KR. Depressive spectrum diagnoses. *Compr Psychiatry* 2000; 41: 39-47.
226. Ayuso-Mateos JL, Nuevo R, Verdes E, et al. From depressive symptoms to depressive disorders: the relevance of thresholds. *Br J Psychiatry* 2010; 196: 365-371.
227. Akiskal HS, Pinto O. The evolving bipolar spectrum. Prototypes I, II, III, and IV. *Psychiatr Clin North Am* 1999; 22: 517-534, vii.
228. Mizushima J, Sakurai H, Mizuno Y, et al. Melancholic and reactive depression: a reappraisal of old categories. *BMC Psychiatry* 2013; 13: 311.
229. Restifo S. A nosological review of depressive disorders based on observations in clinical practice, Part 1: terminology and phenomenology. *Australas Psychiatry* 2012; 20: 483-486.
230. Restifo S. A nosological review of depressive disorders based on observations in clinical practice, Part 2: a working typology for clinicians. *Australas Psychiatry* 2013; 21: 13-16.
231. OED Online. "normal, adj. and n.". Oxford University Press; June 2014 [cited 2014 4 July]; Available from: <http://www.oed.com/view/Entry/128269?redirectedFrom=normal>
232. Ali S, Ernst C, Pacheco M, et al. Consultation-liaison psychiatry: how far have we come? *Curr Psychiatry Rep* 2006; 8: 215-222.
233. Lipowski ZJ. Consultation-liaison psychiatry: an overview. *Am J Psychiatry* 1974; 131: 623-630.
234. Fairman N, Irwin SA. Palliative care psychiatry: update on an emerging dimension of psychiatric practice. *Curr Psychiatry Rep* 2013; 15: 374.

235. RANZCP. Special interest group in the history, philosophy and ethics of psychiatry. The Royal Australian and New Zealand College of Psychiatrists; [cited 2014 4 July]; Available from: <http://www.ranzcp.org/Membership/Subspecialty-groups/Interest-Groups/History-Philosophy.aspx>.
236. The International Network for Philosophy & Psychiatry. About INPP. INPP; [cited 2014 4 July]; Available from: <http://inpponline.com/about-inpp/>.
237. Fulford KW, Stanghellini G, Broome M. What can philosophy do for psychiatry? *World Psychiatry* 2004; 3: 130-135.
238. Rosenberg R. Some themes from the philosophy of psychiatry: a short review. *Acta Psychiatr Scand* 1991; 84: 408-412.
239. Denys D. How new is the new philosophy of psychiatry? *Philos Ethics Humanit Med* 2007; 2: 22.
240. Freudenreich O, Kontos N, Querques J. The muddles of medicine: a practical, clinical addendum to the biopsychosocial model. *Psychosomatics* 2010; 51: 365-369.
241. Ghaemi SN. Paradigms of psychiatry: eclectic and its discontents. *Curr Opin Psychiatry* 2006; 19: 619-624.
242. Ghaemi SN. The rise and fall of the biopsychosocial model. *Br J Psychiatry* 2009; 195: 3-4.
243. Tavakoli HR. A closer evaluation of current methods in psychiatric assessments: a challenge for the biopsychosocial model. *Psychiatry* 2009; 6: 25-30.
244. Carragher N, Adamson G, Bunting B, et al. Subtypes of depression in a nationally representative sample. *J Affect Disord* 2009; 113: 88-99.
245. Andreasen NC. DSM and the death of phenomenology in America: an example of unintended consequences. *Schizophr Bull* 2007; 33: 108-112.
246. Kokanovic R, Dowrick C, Butler E, et al. Lay accounts of depression amongst Anglo-Australian residents and East African refugees. *Soc Sci Med* 2008; 66: 454-466.

247. Lewis SE. A search for meaning: making sense of depression. *J Ment Health* 1995; 4: 369-382.
248. Srinivasan J, Cohen NL, Parikh SV. Patient attitudes regarding causes of depression: implications for psychoeducation. *Can J Psychiatry* 2003; 48: 493-495.
249. Callan A, Littlewood R. Patient satisfaction: ethnic origin or explanatory model? *Int J Soc Psychiatry* 1998; 44: 1-11.
250. Danielsson U, Bengs C, Lehti A, et al. Struck by lightning or slowly suffocating - gendered trajectories into depression. *BMC Fam Pract* 2009; 10: 56.
251. Gysels M, Shipman C, Higginson IJ. Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Med Ethics* 2008; 9: 7. doi: 10.1186/1472-6939-9-7.
252. Gysels M, Shipman C, Higginson IJ. "I will do it if it will help others:" motivations among patients taking part in qualitative studies in palliative care. *J Pain Symptom Manage* 2008; 35: 347-355.
253. Bellamy G, Gott M, Frey R. 'It's my pleasure?': the views of palliative care patients about being asked to participate in research. *Prog Palliat Care* 2011; 19: 159-164.
254. Wallace Et, Radden J, Sadler JZ. The philosophy of psychiatry: who needs it? *J Nerv Ment Dis* 1997; 185: 67-73.
255. Kendler KS. Introduction: Why does psychiatry need philosophy? In: Kendler KS, Parnas J, editors. *Philosophical issues in psychiatry: explanation, phenomenology, and nosology*. Baltimore: The Johns Hopkins University Press; 2008, p. 4.
256. Braun V, Clarke V. Ten fundamentals of qualitative research. In: Braun V, Clarke V. *Successful qualitative research. A practical guide for beginners*. London: SAGE Publications Ltd; 2013, p. 19-41.

257. Britten N. Qualitative interviews in health care research. In: Pope C, Mays N, editors. *Qualitative research in health care*. 2nd ed. London: BMJ Books; 2000, p. 11-19.
258. Baker SE, Edwards R. How many qualitative interviews is enough. Expert voices and early career reflections on sampling and cases in qualitative research. ESRC National Centre for Research Methods Review Paper, 2012. http://eprints.ncrm.ac.uk/2273/4/how_many_interviews.pdf
259. Guest G, Bunce A, Johnson L. How many interviews are enough?: An experiment with data saturation and variability. *Field Methods* 2006; 18: 59-82.
260. Sandelowski M. Sample size in qualitative research. *Res Nurs Health* 1995; 18: 179-183.
261. Morse JM. Determining sample size. *Qual Health Res* 2000; 10: 3-5.
262. Steinhauser KE, Barroso J. Using qualitative methods to explore key questions in palliative care. *J Palliat Med* 2009; 12: 725-730.
263. Pope C, Mays N. *Qualitative research in health care*. 3rd ed. Oxford: Blackwell Publishing Ltd; 2006.
264. Hansen EC. *Successful qualitative health research. A practical introduction*. Crows Nest, NSW: Allen & Unwin; 2006.
265. Braun V, Clarke V. *Successful qualitative research*. London: SAGE Publications Ltd; 2013.

APPENDICES

Appendix A Study 1 Questionnaire for Doctors in Palliative Medicine: Views on Depression at the End-of-life

General information

What is your main area of work?

- General practice Palliative medicine Oncology Pain medicine
 Psychiatry Other (please specify if you are willing to do so _____)

Which of the following best describes your current work position?

- Trainee Specialist General practitioner Career medical officer
 Other (please specify _____)

If you are a palliative medicine specialist or trainee, in which area did you do your primary training?

- Not applicable General practice Physician
 Other (please specify if you are willing to do so _____)

How would you describe your current area of work in relation to palliative medicine? (tick all that apply)

- Clinical Academic Administration Other (please specify _____)

What is the current setting of your work? (tick all that apply)

- Hospital Hospice Community Academic

What is your gender?

- Male Female

How long have you been practising in medicine?

- 0-5 yrs 6-10 yrs 11-20 yrs 21-30 yrs >30 yrs

How long have you been involved in palliative medicine?

- 0-5 yrs 6-10 yrs 11-20 yrs 21-30 yrs >30 yrs

Have you had any specific training in mental health?

- Yes No

If yes, what was the training? _____

Working with Depression

In your estimate, how often are you involved in caring for palliative care patients?

- Most days At least once per week At least once per month
 Several times per year Less than once a year Never

In your estimate, how often are you involved in caring for palliative care patients who have depression?

- Most days At least once per week At least once per month
 Several times per year Less than once a year Never

Who, if anyone, do you usually involve in managing depression in palliative care patients?
(tick all that apply)

- No one Nurses Social workers General practitioners
 Psychologists Psychiatrists Chaplains/Pastoral care workers Family
 Others (please specify _____)

Views on Depression

The following questions relate to views that individuals may hold about depression. Please indicate how much you endorse the following statements, ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). There are no right or wrong responses.

	Strongly Disagree		Neutral		Strongly Agree
1. Depression is more common at the end-of-life.	1	2	3	4	5
2. Depression is normal at the end-of-life.	1	2	3	4	5
3. The quality of depression at the end-of-life is the same as depression in other settings.	1	2	3	4	5
4. Depression in general (not just at the end-of-life) is an illness.	1	2	3	4	5
5. Depression at the end-of-life is an illness.	1	2	3	4	5
6. Depression is a distinct concept.	1	2	3	4	5
7. Depression is distinct from grief.	1	2	3	4	5
8. Depression is part of the dying process.	1	2	3	4	5
9. All doctors understand depression as a concept in the same way.	1	2	3	4	5
10. Depression is understood by doctors and by patients in the same way.	1	2	3	4	5
11. Symptoms of depression are reasonably consistent from person to person.	1	2	3	4	5
12. There are core features of depression.	1	2	3	4	5
13. End-of-life depression has identifiable causes.	1	2	3	4	5
14. Biological factors are important in explaining depression at the end-of-life.	1	2	3	4	5

	Strongly Disagree		Neutral		Strongly Agree
15. Psychological factors are important in explaining depression at the end-of-life.	1	2	3	4	5
16. Existential and spiritual factors are important in explaining depression at the end-of-life.	1	2	3	4	5
17. Socioeconomic status is important in explaining depression at the end-of-life.	1	2	3	4	5
18. Culture is important in explaining depression at the end-of-life.					
19. Depression at the end-of-life should always be treated.	1	2	3	4	5
20. Depression at the end-of-life can be managed with medications.	1	2	3	4	5
21. Depression at the end-of-life can be managed with psychological support.	1	2	3	4	5
22. If untreated, depression at the end-of-life will worsen the person's quality of life.	1	2	3	4	5
23. If untreated, depression at the end-of-life will negatively affect the person's family.	1	2	3	4	5
24. Patients expect doctors to treat depression.	1	2	3	4	5
25. Depression at the end-of-life can abate without any active interventions.	1	2	3	4	5

Do you have any comments on your experience with depression in palliative care patients?

Yes No

If yes, please elaborate:

□

Thank you very much for your time and input.

**Appendix B Introductory letter to conference registrants
accompanying questionnaire**

Dear Doctor,

I am a psychiatrist from Adelaide with an interest in palliative care, and am hoping to learn how doctors in the field think about depression in the end-of-life context. I would be very grateful if you could spare a few minutes to complete the attached questionnaire during this conference – all responses would be valued, regardless of your medical discipline or career stage. Please be assured that your responses will be anonymous. This questionnaire is part of my PhD study, and has been approved by the University of Adelaide Human Research Ethics Committee.

There are boxes at the conference venue for you to deposit your completed questionnaire, or you could return it in the reply paid envelope provided.

May I also draw your attention to the attached flyer for another part of my study, which involves interviews with consultant palliative medicine specialists and consultant psychiatrists. If you would consider being a participant, please let me know by dropping off your name and contact details in the collection boxes, or contacting me.

Regardless of your participation, I hope to have the opportunity to speak with you during this conference, and would be most happy to answer any questions or receive any feedback.

With sincere thanks for your kind attention,

Felicity Ng
Senior Lecturer and PhD candidate
University of Adelaide
Email: felicity.ng@adelaide.edu.au
Phone: +61 411 244 013

Appendix C Flyer and reply slip for in-depth interview studies
(Studies 2 & 3) distributed to all conference registrants

Medical Views of Emotions in the Palliative Care Setting
- A qualitative study

Dr Felicity Ng (PhD candidate), Prof Anna Chur-Hansen (PhD supervisor), Dr Gregory Crawford (PhD supervisor) and Dr Rajan Nagesh (PhD supervisor)

This study is part of a PhD research project that explores doctors' and patients' views of emotions in the palliative care context.

If you are

- A **palliative medicine consultant**

OR

- A **consultant psychiatrist** practising in palliative care,

And would consider undertaking a single interview,

Please provide your contact details below and drop the tear-off slip in the deposit boxes at the conference venue, or return in the reply-paid envelope provided,

OR

Contact Felicity Ng at your convenience.

Office: +61 8 8182 9388

Mobile: +61 411 244 013

Email: felicity.ng@adelaide.edu.au

Medical Views of Emotions in the Palliative Care Setting

I would consider taking part in an interview for this study.

Name: _____

I am a palliative medicine consultant consultant psychiatrist

I prefer to be contacted via post phone email

Postal address: _____

Telephone: _____

Email: _____

Appendix D Information for potential palliative medicine specialist participants in Study 2: Participant information sheet, consent form, and contacts & complaints form

Participant Information Sheet

Study title: Medical specialists' views of emotions in the palliative care setting
Investigators: Dr Felicity Ng^{1,2}, Prof Anna Chur-Hansen¹, Dr Gregory Crawford^{3,4}, Dr Rajan Nagesh^{1,2}
Institutional affiliations: ¹Discipline of Psychiatry, University of Adelaide; ²Central Northern Adelaide Health Service; ³Discipline of Medicine, University of Adelaide; ⁴Mary Potter Hospice, Calvary Health Care Adelaide

Study background

Emotional issues, in particular depression, form a major focus area in palliative care practice and research. However, the distinction between situationally-appropriate and pathological emotional states is particularly challenging in the end-of-life setting, and is often complicated by contextual considerations. The understanding of emotional issues has been demonstrated to differ between medical professionals and patients, which can impinge on the quality of care and therapeutic outcomes. An understanding of how emotional issues are conceptualised by health professionals and patients could therefore inform the approach to managing such issues in clinical practice.

Aim of this study

This study aims to explore how palliative physicians and psychiatrists practising in palliative care conceptualise emotional issues, in particular depression, in the palliative care setting.

What this study involves

This study involves one interview, which can be conducted either face-to-face at your workplace or via telephone, depending on your location at the time of participation. During the interview, you will be asked to comment on the emotions that you have encountered in palliative care patients, and your thoughts in relation to these. You will also be asked to comment on your views on the conceptual boundaries between depression and other psychological or medical phenomena. We are not looking for any particular responses, and any insight from you would be a valuable contribution for this study.

The duration of the interview may vary, but is expected to take approximately 30 minutes to 1 hour. Your permission will be asked to have the interview audio-taped.

After the interview, you will have the option of reviewing the interview transcript.

Your decision to participate in this study is entirely voluntary. Even if you consent to participate, you are able to withdraw from the study at any time without the need for explanations.

Benefits and risks

There are no compensations for your time and participation, and no direct benefits such as in the form of payment.

This study may pose low level risks, such as inconvenience relating to the time required of you to consider and participate in the interview.

Research output

The findings of this study will be published in a thesis and in journals. The findings may also be presented at conferences.

Confidentiality

Your name and contact details will not be disclosed to anyone else other than the investigators. Your responses in the interview will be held in confidence by the investigators, with the exception of the unlikely event where unprofessional or unethical conduct is disclosed. In such instances, the investigators may be required to report details relating to these conducts to the relevant medical board. You will not be identifiable in any potential conference presentations or publications.

Ethics approval

This study has been approved by the Human Research Ethics Committees of the Royal Adelaide Hospital, Calvary Health Care Adelaide, and the University of Adelaide.

Further information

Please ensure that you have read and understood the information on this document prior to making the decision to participate in this study.

If you would like to clarify any information on this document, or to obtain further information about this study, please contact one of the investigators listed below.

If you wish to speak to someone not directly involved in the study about your rights as a volunteer, or about the conduct of the study, you may also contact the following:

- Chairman, Research Ethics Committee, Royal Adelaide Hospital, on phone +61 8 8222 4139
- Chairman, Research Ethics Committee, Calvary Health Care Adelaide, on phone +61 8 8239 9100
- Secretary, Human Research Ethics Committee, University of Adelaide, on phone +61 8 8303 6028

Contact details for further information

Dr Felicity Ng (Principal Investigator)

Phone: 8182 9388 or 0411 244 013 (Afterhours 0418 817 780)

Email: felicity.ng@adelaide.edu.au

Prof Anna Chur-Hansen (Principal Supervisor)

Phone: 8222 5785

Email: anna.churhansen@adelaide.edu.au

Dr Gregory Crawford (Supervisor)

Phone: 8239 9117

Email: gregory.crawford@adelaide.edu.au

Dr Rajan Nagesh (Supervisor)

Phone: 8282 0501

Email: rajan.nagesh@health.sa.gov.au

Opt-out

If you do not wish to be further contacted about this study, you can simply complete this slip and return it to us by post in the reply paid envelope, or by fax.

Name _____

I do not wish to be contacted again about this study

Please return this slip either in the reply paid envelope, or by fax to Felicity Ng on 8182 9385

Consent Form

Study Title: Medical specialists' views of emotions in the palliative care setting

Investigators: Dr Felicity Ng, Professor Anna Chur-Hansen, Dr Gregory Crawford, Dr Rajan Nagesh

1. The nature, purpose and potential risks of this research project have been explained to me. I understand these, and agree to take part in this research.
2. I understand that I may not benefit from taking part in this study.
3. I understand that I can withdraw from the study at any stage.
4. I understand that, while information gained during the study may be published, I will not be identified and my personal details will remain confidential.
5. I understand that there are exceptions to confidentiality, in instances where I disclose information that indicates unprofessional or unethical conduct.
6. I understand that, although all efforts will be made to ensure the confidentiality of my participation, anonymity cannot be guaranteed.

I agree to my interview being audio-taped. Yes No

I wish to view a transcript of the interview. Yes No

Name of Participant: _____

Signed: _____

Dated: _____

I certify that I have explained the study to this participant and consider that he/she understands what is involved.

Name of Investigator: _____

Signed: _____

Dated: _____

Investigator

**THE UNIVERSITY OF ADELAIDE
HUMAN RESEARCH ETHICS COMMITTEE**

Document for people who are participants in a research project

**CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT
COMPLAINTS PROCEDURE**

The Human Research Ethics Committee is obliged to monitor approved research projects. In conjunction with other forms of monitoring it is necessary to provide an independent and confidential reporting mechanism to assure quality assurance of the institutional ethics committee system. This is done by providing research participants with an additional avenue for raising concerns regarding the conduct of any research in which they are involved.

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

Project title: Medical specialists' views of emotions in the palliative care setting
Ethics approval number: H-086-2010

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinator:

Name: Professor Anna Chur-Hansen (Principal Supervisor)

Telephone: (+61 8) 8222 5785

Or

Name: Dr Felicity Ng (Principal Investigator)

Telephone: (+61 8) 8182 9388.

2. If you wish to discuss with an independent person matters related to
- making a complaint, or
 - raising concerns on the conduct of the project, or
 - the University policy on research involving human participants, or
 - your rights as a participant

contact the Human Research Ethics Committee's Secretary on phone (+61 8) 8303 6028

**Appendix E Recruitment email sent via the Royal Australian
and New Zealand College of Psychiatrists to members of its Section
of Consultation-Liaison Psychiatry (Study 3)**

Dear Doctor,

I am a psychiatrist who is seeking your consideration to participate in a qualitative study, which aims to explore how depression is conceptualised in the palliative care setting, from the perspectives of patients, palliative medicine specialists and psychiatrists. This research hopes to address the gap that exists in the literature on how patients and medical practitioners understand depression in the context of dying, the significance of which lies in its implications on the assessment and management of this prevalent issue. This research forms part of my PhD candidature at the University of Adelaide, under the supervision of Professor Anna Chur-Hansen and Dr Rajan Nagesh from the Discipline of Psychiatry, and Associate Professor Gregory Crawford from the Discipline of Medicine (Palliative Medicine).

I am looking for consultant psychiatrists in Australia who are involved in liaison work with palliative care services (can be either the private or public sector).

Participation involves a single interview on the subject, and can be done over the telephone. There is no stipulated length for the interview, but on average, an interview would be expected to take about an hour. Any data used in publications will be de-identified.

Participation is of course voluntary. However, as there may be a limited number of Fellows who are involved in palliative care liaison, I would be much obliged if eligible psychiatrists would consider taking part.

If you are willing to participate, or would like further information, please email me at felicity.ng@adelaide.edu.au. Alternatively, I can be contacted on 0411 244 013.

Please be assured that I have no access to your email addresses or other contact details, and this message is sent to you by the College administrators.

With kind regards,

Felicity Ng
PhD Candidate
Discipline of Psychiatry, School of Medicine
University of Adelaide
Adelaide SA 5005

Appendix F Recruitment notice for psychiatrists placed in the Royal Australian and New Zealand College of Psychiatrists' electronic bulletin (Study 3)

**How Do Psychiatrists Think About Depression in Terminally-Ill Patients?
– Psychiatrists Needed for Research Study**



THE UNIVERSITY
of ADELAIDE

Depression is a common reason for involving psychiatrists in the shared care of terminally-ill patients, but how patients and clinicians understand depression in the context of dying has not been explored. Yet, the way that depression is conceptualised underpins assessment and management, and may have widespread implications on end-of-life care practices.

We are seeking psychiatrists to participate in a qualitative study, which explores how depression is conceptualised in the palliative care setting, from the perspectives of patients, palliative medicine specialists and psychiatrists. This research is part of a PhD candidature at the University of Adelaide, under the supervision of Professor Anna Chur-Hansen and Dr Rajan Nagesh from the Discipline of Psychiatry, and Associate Professor Gregory Crawford from the Discipline of Medicine (Palliative Medicine).

Participation in the study involves a single qualitative interview on the subject, and can be done over the telephone. There is no set length for the interview, but an hour's duration is a reasonable estimate. Any data used in publications will be de-identified.

We are seeking:

- Consultant psychiatrists in Australia,
- Who work in a liaison role with palliative care services (private or public sector)

to participate in our study.

If you are willing to participate, or would like further information, please contact:

Dr Felicity Ng (Psychiatrist & PhD candidate)

Phone: (08) 8182 9388 or 0411 244 013

Email: felicity.ng@adelaide.edu.au

Appendix G Interview guide for interviews with palliative medicine specialists and psychiatrists

Starting the interview:

“Can you tell me a bit about your professional background?” (training, duration since fellowship, areas of practice/interest, experience/involvement in palliative care)

“In your experience, what emotions does a person go through when they are at the palliative stage of care?”

Probes:

“You mentioned (X emotion – e.g. depression, anxiety, anticipation) – can you tell me more about that?”

“Why do you think people experience X emotion?”

“When do you think X emotion usually becomes apparent?”

“Do you talk to your patients about that emotion? If you do, can you tell me what you would typically say?” (OR “Do patients talk to you about that emotion? If they do, can you tell me what they would typically say?”)

“What is your approach/what do you do when patients feel X emotion?”

“What do you think would help when patients feel X emotion?”

“Can you tell me if X emotion is one you consider “normal”? Under what circumstances would it be normal/abnormal?”

Questions about depression:

“Could you explain your idea of what depression is as a concept in general?”
(*prompt*: depression as a clinical concept)

“How do you think depression is different in the palliative care setting?”
(*prompt*: as a concept, mechanism, in diagnosis, phenomenology, treatment)

“To your mind, how does depression differ from the other emotional states that people experience at the end-of-life?”

“How do you think depression differs from the dying process?”

“How common do you believe depression is among patients receiving palliative care?”

“When do you think depression usually presents as a problem in palliative care?”

“For patients in the palliative phase of care, when would you consider them to be depressed?” “How do you make a diagnosis of depression in the palliative care context?”

“What, if any, do you think are the challenges in assessing depression in the palliative care setting?”

“How do patients describe depression to you? What words do they use?”
“How do you explain depression to your patients? What is the language/words that you use?”

“How do patients response to your explanation of depression?” “How do patients tend to understand depression?”

“How do you make sense of depression in the palliative care context?” “What do you think cause depression in the palliative care context?” “How do you think depression comes about in patients under palliative care?” “What is/are the mechanism(s) for depression at the end-of-life?” AND “Are the mechanisms different from depression in other settings?”

“How do you think depression should be managed at the end-of-life?” “What is your approach to depression in patients under palliative care?”

“How have you developed this approach?” “What education has been provided in the care of dying patients in your training years?”

“How do you think other palliative care doctors/psychiatrists understand and approach depression?” “What do you think are the differences in terms of how psychiatrists and palliative care clinicians think about and approach depression?”

“What are your views on using antidepressants or other psychotropic medications for your patients?”

“Do you always intervene when a patient has depression at the end-of-life?”

“What do you think depression entails for (can do to) a patient at the end-of-life?” “What do you think would happen to a patient if his/her depression is not treated?”

“What do you think are the challenges with the whole issue of depression in palliative care?”

**Appendix H Paper 1: Palliative Medicine Practitioners' Views
on the Concept of Depression in the Palliative Care Setting**

Citation

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Palliative Medicine Practitioners' Views on the Concept of Depression in the Palliative Care Setting

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Abstract

Background: Despite its clinical importance in palliative care, depression remains an ambiguous concept.

Objective: The purpose of this study was to explore how medical practitioners working in palliative care conceptualize depression in that setting.

Design: Medical practitioners who attended a palliative medicine conference ($N = 185$) were invited to respond to a questionnaire, which explored their views on the concept of depression in the palliative care context. Descriptive statistics were used to summarize responses, and comparison between groups was conducted using nonparametric statistics. Themes in free-text comments were identified.

Results: Seventy-nine responses were obtained (response rate 43%). Depression was not a unified concept, but was generally considered to be an illness with psychological, spiritual, and existential causes. Respondents were more uncertain about depression being an illness in the palliative care setting compared with other settings, and were ambivalent about its causality. Treatment preferences leaned towards psychological interventions. Depression being different in the palliative care setting was a theme. It was considered to be more prevalent, different in quality, harder to define, and associated with greater barriers to diagnosis and treatment. Conceptual differences were associated with the respondents' area of work, work position, duration of practice, and previous mental health training.

Conclusions: Depression in the palliative care setting is a variable concept for palliative medicine practitioners. The conceptual diversity and complexities of depression in this setting must be acknowledged and further explored in order to develop nuanced approaches in clinical practice and in research.

Introduction

DEPRESSION IS WIDELY ACKNOWLEDGED to be an important clinical issue in palliative care, with an estimated prevalence of 5%–26%¹⁻⁴ and association with adverse outcomes such as high symptom burden,⁵ spiritual distress,⁶ poor performance status,⁷ shorter survival,⁸ longer length of hospice stay,⁹ and desire for hastened death.^{7,10} Nevertheless, depression remains an ambiguous concept. This situation is not unique to the palliative care setting, as multitudinous concepts of depression have beleaguered the field of psychiatry over the course of its history¹¹⁻¹³ and continue to be actively debated.^{13,14} The palliative care setting, however, arguably adds to the ambiguity because of the symptomatic similarities

between depression and conditions commonly occurring at the end of life (EOL), such as illness and the dying processes and the attendant emotions in this context.^{15,16}

Health professionals have reported difficulties with assessing and managing depression in the palliative care setting.¹⁷⁻²⁰ In particular, the distinction between depression and sadness or grief has been reported as challenging by family physicians,²⁰ palliative medicine physicians,¹⁷ nurses,¹⁸ and professional carers.¹⁹ In a U.K. survey, palliative medicine physicians reported using an assortment of screening methods to assess for depression and endorsed different symptoms as useful for this purpose,¹⁷ whereas general practitioners in the Netherlands emphasized clinical judgement of contextual factors in their assessment.²⁰ Discordant approaches to the

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detection and treatment of depression in the palliative care setting have similarly been reported among recognized experts in the area.²¹ Diversity in the definitions of depression and assessment approaches is reflected in the research literature,^{1,22} with one systematic review identifying 106 different assessment methods in 202 published studies and an assortment of criteria for defining caseness.²²

It is evident from the extant literature that EOL depression is a heterogeneous concept. Insofar as conceptualization fundamentally guides clinical and research efforts, it is crucial to understand how depression is conceptualized in the palliative care setting, in order to develop context-appropriate clinical and research approaches. How medical practitioners think about depression has been investigated to a far lesser extent than their clinical practice, and no study has primarily focussed on how they conceptualize depression in the palliative care setting. Therefore, this study was devised to explore how EOL depression is conceptualized by palliative medicine practitioners.

In view of the lack of terminological standardization in palliative care,^{23,24} it should be clarified that "palliative care" in this paper refers to an approach to care as defined by the World Health Organization,²⁵ and neither implies the involvement of specific health professionals nor the provision of care in particular settings such as hospitals, hospices, or the community. "End-of-life" is used as defined by Palliative Care Australia to mean "that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown."²⁶ It thus captures the period of time during which patients receive palliative care.

Methods

The authors developed a questionnaire specifically for this study and conducted a small pilot ($n=7$) in order to test its comprehensibility and estimate completion time. The pilot participants had either research and/or clinical backgrounds in palliative care or psychiatry of old age, and were not in the study's target population. Minor formatting and wording modifications and the addition of a question about frequency of work in palliative medicine were made in response to the pilot. The final questionnaire comprised the following: (1) demographic information; (2) the respondent's level of clinical involvement with EOL depression; and (3) a series of 25 statements about EOL depression, relating to its distinction as a concept, prevalence, symptomatic consistency, causality, treatment, and outcome (see Table 1). These statements were informed by the literature and clinical anecdotal experience, and respondents were asked to indicate their level of endorsement of each statement on a five-point Likert scale that extends from "1 = Strongly Disagree" through "3 = Neutral" to "5 = Strongly Agree." Respondents were also asked to provide free-text comments on their experiences with depression in patients receiving palliative care. The term "depression" was deliberately used without further qualification, because multiple constructs of depression were assumed and narrow definitions were avoided. Responses were anonymous.

The target population consisted of registrants of a palliative medicine conference held in Australia in 2010, who were primarily Australian and New Zealand medical practitioners involved in palliative medicine. The sample was one of

TABLE 1. STATEMENTS ABOUT DEPRESSION USED IN THE QUESTIONNAIRE

1. Depression is more common at the EOL.
2. Depression is normal at the EOL.
3. The quality of depression at the EOL is the same as depression in other settings.
4. Depression in general (not just at the EOL) is an illness.
5. Depression at the EOL is an illness.
6. Depression is a distinct concept.
7. Depression is distinct from grief.
8. Depression is part of the dying process.
9. All doctors understand depression as a concept in the same way.
10. Depression is understood by doctors and by patients in the same way.
11. Symptoms of depression are reasonably consistent from person to person.
12. There are core features of depression.
13. EOL depression has identifiable causes.
14. Biological factors are important in explaining depression at the EOL.
15. Psychological factors are important in explaining depression at the EOL.
16. Existential and spiritual factors are important in explaining depression at the EOL.
17. Socioeconomic status is important in explaining depression at the EOL.
18. Culture is important in explaining depression at the EOL.
19. Depression at the EOL should always be treated.
20. Depression at the EOL can be managed with medications.
21. Depression at the EOL can be managed with psychological support.
22. If untreated, depression at the EOL will worsen the person's quality of life.
23. If untreated, depression at the EOL will negatively affect the person's family.
24. Patients expect doctors to treat depression.
25. Depression at the EOL can abate without any active interventions.

EOL, end-of-life.

convenience. With permission from the organizing committee, a paper version of the questionnaire was distributed with the registration package at the conference site, and verbal and visual reminders (announcement, poster display, collection boxes) were used to encourage participation. A reminder e-mail that included a link to an electronic version of the questionnaire was sent to all registrants one week after the conference.

Descriptive statistics were used to summarize respondent characteristics and endorsement of statements about depression. Comparison of respondent views according to characteristics was performed using the Mann-Whitney U test and Kruskal-Wallis 1-way ANOVA, because of nonparametric data distribution. Significance was at $p < 0.05$ (2-tailed). Analyses were conducted using PASW version 18 (SPSS, Inc., Chicago, IL).²⁷ Free-text responses were examined for themes by the first author (FN) with the aid of NVivo9 software (QSR International Pty. Ltd., Doncaster).²⁸ A second author (ACH) undertook an independent analysis. The two analyses were compared and themes revised until consensus was reached.

This study received approval from the Human Research Ethics Committee at the University of Adelaide (H-086-2010).

TABLE 2. RESPONDENT CHARACTERISTICS SHOWN IN ABSOLUTE NUMBERS AND PERCENTAGES

Respondent characteristics	Number (percentage) n = 78 ^a
<i>Gender</i>	
Male	31 (39.7%)
Female	47 (60.3%)
<i>Main area of work</i>	
Palliative medicine	64 (82.1%)
General practice	7 (9.0%)
Other	7 (9.0%)
<i>Work position</i>	
Specialist	48 (61.5%)
Trainee	17 (21.8%)
Other (including GPs)	13 (16.7%)
<i>Training background for those who are palliative medicine specialists or trainees</i>	n = 64 ^b
General practice	32 (50%)
Physician	24 (37.5%)
Other	8 (12.5%)
<i>Work type^d</i>	
Clinical palliative medicine	78 (100%)
Academic palliative medicine	21 (26.9%)
Administrative palliative medicine	20 (25.6%)
<i>Work setting^d</i>	
Hospital	54 (69.2%)
Hospice	43 (55.1%)
Community	39 (49.4%)
Academic	15 (19.2%)
<i>Duration of practice (in years)</i>	
<i>Years in medicine</i>	
0–10 years	14 (17.9%)
11–20 years	18 (23.1%)
21–30 years	19 (24.4%)
> 30 years	27 (34.6%)
<i>Years in palliative medicine</i>	
0–10 years	34 (43.6%)
11–20 years	26 (33.3%)
21–30 years	15 (19.2%)
> 30 years	3 (3.8%)
<i>Mental Health Training</i>	
Received specific training ^c	20 (25.6%)
<i>Frequency of palliative care provision for patients</i>	
Most days	68 (87.2%)
At least once per week	8 (10.3%)
At least once per month	1 (1.3%)
Several times per year	1 (1.3%)
<i>Frequency of providing care for depression in the palliative care setting</i>	
Most days	26 (33.8%)
At least once per week	33 (42.9%)
At least once per month	12 (15.6%)
Several times per year	6 (7.8%)
<i>Usual personnel involved in the management of depression in the palliative care setting^d</i>	
None	4 (5.1%)
Social workers	57 (73.1%)
Nurses	55 (70.5%)

(continued)

TABLE 2. (CONTINUED)

Respondent characteristics	Number (percentage) n = 78 ^a
GPs	51 (65.4%)
Psychiatrists	51 (65.4%)
Chaplains/pastoral care workers	45 (57.7%)
Family	43 (55.1%)
Psychologists	37 (47.4%)
Others	14 (17.9%)

^an = 78 unless stated otherwise due to 1 missing response.^bn = 64 due to 1 missing response and 14 not applicable responses (i.e., not a palliative medicine specialist or trainee).^c12 respondents undertook psychiatric placements during pre-vocational or vocational medical training, 4 undertook accredited mental health training for general practice, 3 completed honors or masters degree in psychology or psychological medicine, 2 undertook psychotherapy training.^dThe total percentages for these characteristics are over 100 because multiple answers were possible.

GP, general practitioner.

Results

Respondent characteristics

Seventy-nine of 185 registrants (43%) responded to the questionnaire. All respondents practiced palliative medicine and 64 (82.1%) identified this as their main area of work. Respondent characteristics are detailed in Table 2.

Views on depression

Whilst respondents generally deemed depression to be an illness (92.3%), fewer considered it an illness at the EOL (80.5%), with 14.3% viewing depression as normal in this context and 11.5% viewing it as part of the dying process. A further 22.1% and 17.9% neither agreed nor disagreed with these latter statements, respectively. The vast majority (91.0%) saw depression and grief as distinct concepts. Most considered depression to be not only more common at the EOL (59.0%), but different in quality from depression occurring in other settings (59.7%). Although 89.7% believed core features of depression to exist, only 23.1% thought that depression symptoms were consistent between individuals. Understandings of depression were generally considered to differ among medical practitioners (93.6%) and between medical practitioners and patients (94.9%). Distributions are shown in Tables 3 and 4.

There was uncertainty about causality, with 47.4% of respondents indicating ambivalence about whether depression had identifiable causes. Of the proposed factors that could be considered to be causally important, psychological (88.5%) and existential/spiritual factors (84.4%) were most frequently endorsed, while biological factors (56.4%), culture (55.8%), and socioeconomic status (32.5%) were less often endorsed. Respondents showed a clear preference for psychological support as intervention compared with medications (87.0% versus 54.5%). Depression was considered by 93.5% to adversely impact on the patient's quality of life and by 87.0% to negatively affect the family. Over half of the respondents (54.7%) believed that depression should always be treated, while 51.9% believed that depression could abate without intervention. About half of the respondents (51.9%) agreed

TABLE 3. RESPONDENTS' ENDORSEMENT OF STATEMENTS RELATING TO DEPRESSION AS A CONCEPT, IN ABSOLUTE NUMBERS AND IN PERCENTAGES

Statement	Disagree in n (%)	Neutral in n (%)	Agree in n (%)
Depression (in general) is an illness (n=78)	2 (2.6)	4 (5.1)	72 (92.3)
Depression at the EOL is an illness (n=77)	4 (5.2)	11 (14.3)	62 (80.5)
Depression is normal at the EOL (n=77)	49 (63.6)	17 (22.1)	11 (14.3)
Depression is part of the dying process (n=78)	55 (70.5)	14 (17.9)	9 (11.5)
Depression is a distinct concept (n=78)	10 (12.8)	13 (16.7)	55 (70.5)
Depression is distinct from grief (n=78)	3 (3.8)	4 (5.1)	71 (91.0)
Doctors and patients understand depression in the same way (n=78)	74 (94.9)	4 (5.1)	0 (0)
All doctors understand depression in the same way (n=78)	73 (93.6)	4 (5.1)	1 (1.3)

Responses are collapsed into "agree," "neutral," and "disagree" categories. EOL, end-of-life.

that patients expected medical practitioners to treat their depression. Distributions are shown in Tables 5 and 6.

Comparison of views between groups

Views held by respondents differed according to their area of work, work position, duration of practice, and previous mental health training. The primary training background for those who were palliative medicine trainees or specialists did not significantly influence responses.

Compared with those mainly working in palliative medicine or other areas, respondents who primarily worked in general practice were more likely to consider depression as normal at the EOL (H(2)=13.472; p=0.001) and as part of the dying process (H(2)=12.672; p=0.002). They were also more likely than those mainly working in palliative medicine to agree that depression had identifiable causes (U=121.500; p=0.031) and that patients expected medical practitioners to treat depression (U=125.000; p=0.044). Those who worked in academic palliative medicine were more likely than nonacademics to view depression as a distinct concept (U=808.500; p=0.003) with core features (U=754.500; p=0.013) and consistent symptoms between individuals (U=818.000; p=0.002).

Trainees were more likely than specialists and those in other positions to consider depression an illness at the EOL (H(2)=9.195; p=0.010).

Respondents who had practiced in medicine for the shortest duration (≤10 years) more often agreed with depression in general being an illness than those with longer durations of practice (H(2)=6.071; p=0.048). Those who had practiced in palliative medicine the longest (>20 years) were most likely to regard the quality of depression at the EOL to be the same as in other settings (H(2)=6.431; p=0.040), and were

least likely to view socioeconomic status as important in the causality of depression (H(2)=8.493; p=0.014).

Those who had received specific mental health training were more likely to identify socioeconomic status as causally important (U=719.500; p=0.22), and to consider that EOL depression should always be treated (U=726.500; p=0.009).

Free-text themes

Thirty-nine respondents (49.4%) commented on their experience with depression in patients receiving palliative care. Comments are captured by the following seven themes.

Depression at the EOL is different from other times in life

Depression was seen to differ at the EOL in terms of its notion (e.g., "a totally different entity"); delineation (e.g., "harder to define," "bound up with spiritual distress"); and manifestation (e.g., "fewer vegetative features"). The idea of the intransferability of treatments from general to EOL settings also distinguished depression at the EOL and was expressed in reference to the limited timeframes for intervention, the complex physical and psychological milieu, and the illogicality of cognitive therapy where patients' concerns were considered to be realistic.

Depression at EOL is a difficult problem

The difficulty of depression at EOL was conveyed in terms of diagnostic and treatment difficulties and systemic barriers.

TABLE 4. RESPONDENTS' ENDORSEMENT OF STATEMENTS RELATING TO THE PREVALENCE AND SYMPTOMATIC CONSISTENCY OF DEPRESSION, IN ABSOLUTE NUMBERS AND IN PERCENTAGES

Statement	Disagree in n (%)	Neutral in n (%)	Agree in n (%)
Depression is more common at the EOL (n=78)	10 (12.8)	22 (28.2)	46 (59.0)
Quality of depression at the EOL is the same as in other settings (n=77)	46 (59.7)	12 (15.6)	19 (24.7)
There are core features of depression (n=78)	3 (3.8)	5 (6.4)	70 (89.7)
Symptoms of depression are consistent from person to person (n=78)	54 (69.2)	6 (7.7)	18 (23.1)

Responses are collapsed into "agree," "neutral," and "disagree" categories. EOL, end-of-life.

TABLE 5. RESPONDENTS' ENDORSEMENT OF STATEMENTS RELATING TO THE CAUSALITY OF DEPRESSION AT THE EOL, IN ABSOLUTE NUMBERS AND IN PERCENTAGES

Statement	Disagree in n (%)	Neutral in n (%)	Agree in n (%)
Depression has identifiable causes (n=78)	19 (24.4)	37 (47.4)	22 (28.2)
Biological factors are important (n=78)	11 (14.1)	23 (29.5)	44 (56.4)
Psychological factors are important (n=78)	2 (2.6)	7 (9.0)	69 (88.5)
Existential/spiritual factors are important (n=77)	4 (5.2)	8 (10.4)	65 (84.4)
Socioeconomic status is important (n=77)	18 (23.4)	34 (44.2)	25 (32.5)
Culture is important (n=77)	11 (14.3)	23 (29.9)	43 (55.8)

Responses are collapsed into "agree," "neutral," and "disagree" categories.
EOL, end-of-life.

Diagnostic difficulties were linked to the interchangeable use of terms such as "depressed," "sad," and "grieving;" the understandable context ("There is reason to be depressed"); and unclear delineation from natural emotions ("reactive sadness") and medical conditions. Respondents described depression as an affect (e.g., "Some people who are very sad or grief stricken...can be deemed as depressed"); a syndrome ("low mood, insomnia, loss of interest, agitation and anxiety, anorexia, constipation etc."); and an illness. Depression was also referred to as both "reasonable" and "never normal," and as both an "entity" and existing "in degrees." Difficulties of treating depression at the EOL included the short timeframes of expected survival and the physical weakness of patients, limiting both pharmacological and psychological treatment options. Systemic barriers, such as late referrals to palliative care, inadequate funding of professional time, and the inaccessibility of psychiatric services also challenged the assessment and management of depression at the EOL.

Depression is underrecognized

Depression was considered to be common and important but underreported by patients and underrecognized or dismissed as normal by clinicians. Several respondents commented on the need for screening and early recognition.

Causes of depression at the EOL

A variety of factors were linked to the occurrence of depression at the EOL, including premorbid cognitive style; stress of having a terminal illness; and symptoms such as pain, poor sleep, anxiety, and spiritual distress.

Depression has negative impact

Depression was seen to cause suffering, worsen prognosis, and negatively affect family. It was also seen to impede the assessment of patient progress and limit access to treatments.

Treatment of depression at EOL

Several respondents emphasized that treatment for EOL depression could not be generalized. Pharmacotherapy was seen to have a lesser role in treating EOL depression, with reasons including ineffectiveness, side effects, unacceptability to patients, inability of some patients to take oral medication, and the view that prescribing antidepressants is a "cop-out" for the clinician. Nonpharmacological interventions were considered to be key, and included good communication; counseling; support; acknowledgement of the patient's experiences; and making human connection (e.g., compassion, empathy, accompanying). Some commented on treatment choice as determined by severity (e.g., mild to moderate depression not needing medication). Several referred to a multidisciplinary approach.

Stigma

Stigma was perceived to underlie the unwillingness of some patients to accept a diagnosis of depression or its treatment, including referrals to psychologists or psychiatrists. "Psychiatric patients" were also considered to suffer discrimination in hospices.

Discussion

This study highlights the variability among palliative medicine practitioners in how they think about depression at

TABLE 6. RESPONDENTS' ENDORSEMENT OF STATEMENTS RELATING TO THE TREATMENT AND OUTCOME OF DEPRESSION AT THE EOL, IN ABSOLUTE NUMBERS AND IN PERCENTAGES

Statement	Disagree in n (%)	Neutral in n (%)	Agree in n (%)
Can be managed with medications (n=77)	12 (15.6)	23 (29.9)	42 (54.5)
Can be managed with psychological support (n=77)	2 (2.6)	8 (10.4)	67 (87.0)
Should always be treated (n=75)	20 (26.7)	14 (18.7)	41 (54.7)
Can abate without intervention (n=77)	23 (29.9)	14 (18.2)	40 (51.9)
Depression will worsen quality of life (n=77)	2 (2.6)	3 (3.9)	72 (93.5)
Depression will negatively affect family (n=77)	3 (3.9)	7 (9.1)	67 (87.0)
Patients expect doctors to treat depression (n=77)	12 (15.6)	25 (32.5)	40 (51.9)

Responses are collapsed into "agree," "neutral," and "disagree" categories.
EOL, end-of-life.

the EOL and the complexity of this clinical problem. On the whole, depression in this setting was considered to be an illness, with causes that were largely psychological and spiritual/existential in nature, in contrast with traditional biomedical frameworks of illness explanations. This may not be unique to the EOL, as there is evidence that primary care medical practitioners face dissonance from applying a biomedical framework of depression to various populations, where social contexts are recognized as etiologically important.²⁹⁻³¹

One of the main conceptual challenges identified in this study is the notion of whether depression at the EOL is an illness or is part of normative processes. This quandary was reflected in the finding that depression was less often considered to be an illness at the EOL than in general settings. The lack of specificity in the language used to convey depression, the emotionally evocative nature of the EOL, and the overt similarities between depression and sadness are relevant to this conceptual challenge. The difficulty of differentiating between depression and sadness is consistent with earlier studies in the palliative care setting¹⁷⁻²⁰ and is salient, given that depression was almost unequivocally considered by participants in this study to be distinct from grief. This suggests a division between the intellectual clarity of concepts and clinical reality, which resonates with observations in the literature of the tension that arises from negotiating between categorical and dimensional concepts of illness.³²⁻³⁴ In this study, both of these concepts were applied to depression, which was variously described as an affect, a syndrome, and an illness. Such diversity in constructs is likely to fundamentally contribute to the ambiguity of depression when applied in the clinical setting.

Another conceptual issue apparent in this study is the uncertain causality of depression at EOL. Respondents were ambivalent as to whether identifiable causes existed. All proposed etiological factors for depression occurring at EOL were endorsed, but psychological, spiritual, or existential factors were more strongly endorsed than biological, cultural, or socioeconomic factors in terms of etiological importance. The clear preference for psychological intervention over pharmacotherapy suggests a relationship between attributed causality and treatment approach. Similar findings were reported by a study of family physicians active in palliative care, with management of depression mainly seen to be supportive and nonspecific in nature, while antidepressants were seldom prescribed.²⁰ In contrast, a qualitative study that explored the construction of depression among primary care physicians found a primarily biochemical etiological explanation,²⁹ which may suggest etiological conceptual differences in the EOL context. Indeed, depression being different at EOL was a theme in the respondents' comments, being seen to be more difficult to define, qualitatively different, and associated with unique diagnostic and treatment challenges.

Both area and duration of practice were associated with conceptual differences. Those mainly working in general practice were more likely to consider EOL depression to be a normative process and to have identifiable causes. A possible explanation is that general practitioners and palliative medicine specialists may hold different concepts of depression. Alternatively, the affective presentations of patients may differ between primary care and specialist palliative care settings. Trainees were more likely to view depression as an

illness at EOL, while those with the shortest medical careers were more likely to see depression as an illness in general. The reasons for these findings are unclear and warrant further investigation. Respondents involved in academic work had a qualitatively different view of EOL depression, being more likely to see it as a distinct concept with core features and as symptomatically consistent between individuals. This may signify a conceptual gap between academic and clinical practitioners, and by extension, between the published literature and clinical practice. Having had specific mental health training was associated with few differences in how respondents considered depression, except for a more proactive attitude towards treatment, which may reflect greater knowledge, skills, experience, and/or personal interest in mental health.

The results of this study need to be interpreted within the context of its limitations. The target population was restricted to Australasian medical practitioners who attended a palliative medicine conference, and is therefore not a representative sample of all palliative medicine practitioners. Nevertheless, the sample was highly relevant, being comprised entirely of practitioners who were active in clinical palliative medicine. The response rate was modest and the sample size was relatively small, which limited the comparative power among groups. Importantly, although this study demonstrates conceptual variability for depression at EOL, it does not characterize those concepts, their nuances, ambiguities, and overlaps. These concepts may be influenced by the medical practitioners' experience and training in both palliative medicine and mental health (which were varied in this sample), their areas of clinical interest and expertise, and their personal and cultural ideologies. Further understandings may be obtained through qualitative exploration of palliative medicine practitioners' constructs of depression.

The findings of this study have implications for clinical practice, education, and research. Palliative medicine practitioners have variable concepts of EOL depression and view depression to be different and complex in this setting. Yet clinical guidelines and research have not adequately acknowledged or addressed these conceptual challenges. This likely restricts the fruitfulness and clinical applicability of research that uses a unitary concept of depression. Medical education that implies depression is a well-defined concept with clear diagnostic boundaries and treatment pathways is similarly misleading, and may lead to over- or under-treatment of depression. For depression in the palliative care setting to be more meaningfully addressed, its conceptual ambiguities and diversity need to be acknowledged and further characterized through research. In particular, qualitative exploration of health professionals' and patients' concepts of EOL depression would be a useful focus for future research. This will complement knowledge regarding the diagnosis and treatment of EOL depression to inform the development of more sophisticated clinical guidelines for diagnosis and treatment decisions in this patient population.

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References

- Hotopf M, Chidgey J, Addington-Hall J, et al.: Depression in advanced disease: A systematic review. Part 1. Prevalence and case finding. *Palliat Med* 2002;16:81–97.
- Lloyd-Williams M, Friedman T: Depression in palliative care patients: A prospective study. *Eur J Cancer Care (Engl)* 2001;10:270–274.
- Mitchell AJ, Chan M, Bhatti H, et al.: Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: A meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;12:160–174.
- Wilson KG, Chochinov HM, Skirko MG, et al.: Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage* 2007;33:118–129.
- Delgado-Guay M, Parsons HA, Li Z, et al.: Symptom distress in advanced cancer patients with anxiety and depression in the palliative care setting. *Support Care Cancer* 2009;17:573–579.
- Hui D, de la Cruz M, Thorney S, et al.: The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. *Am J Hospice Palliat Care* 2011;28:264–270.
- Rayner L, Lee W, Price A, et al.: The clinical epidemiology of depression in palliative care and the predictive value of somatic symptoms: cross-sectional survey with four-week follow-up. *Palliat Med* 2011;25:229–241.
- Lloyd-Williams M, Shiels C, Taylor F, et al.: Depression: An independent predictor of early death in patients with advanced cancer. *J Affect Disord* 2009;113:127–132.
- Irwin SA, Rao S, Bower K, et al.: Psychiatric issues in palliative care: Recognition of depression in patients enrolled in hospice care. *J Palliat Med* 2008;11:158–163.
- Breitbart W, Rosenfeld B, Pessin H, et al.: Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA* 2000;284:2907–2911.
- Berrios GE: Melancholia and depression during the 19th century: A conceptual history. *Br J Psychiatry* 1988;153:298–304.
- Kendell RE: The classification of depressions: A review of contemporary confusion. *Br J Psychiatry* 1976;129:15–28.
- Shorter E: The doctrine of the two depressions in historical perspective. *Acta Psychiatr Scand Suppl* 2007;5–13.
- Ghaemi SN, Vohringer PA, Vergne DE: The varieties of depressive experience: Diagnosing mood disorders. *Psychiatr Clin North Am* 2012;35:73–86.
- Stiefel R, Die Trill M, Berney A, et al.: Depression in palliative care: A pragmatic report from the Expert Working Group of the European Association for Palliative Care. *Support Care Cancer* 2001;9:477–488.
- Leonard M, Spiller J, Keen J, et al.: Symptoms of depression and delirium assessed serially in palliative-care inpatients. *Psychosomatics* 2009;50:506–514.
- Lawrie I, Lloyd-Williams M, Taylor F: How do palliative medicine physicians assess and manage depression. *Palliat Med* 2004;18:234–238.
- McCabe MP, Mellor D, Davison TE, et al.: Detecting and managing depressed patients: Palliative care nurses' self-efficacy and perceived barriers to care. *J Palliat Med* 2012;15:463–467.
- Mellor D, McCabe MP, Davison TE, et al.: Barriers to the detection and management of depression by palliative care professional carers among their patients: Perspectives from professional carers and patients' family members. *Am J Hosp Palliat Care* 2012. Epub ahead of print. DOI: 10.1177/1049909112438705.
- Warmenhoven F, van Rijswijk E, van Hoogstraten E, et al.: How family physicians address diagnosis and management of depression in palliative care patients. *Ann Fam Med* 2012;10:330–336.
- Rayner L, Price A, Hotopf M, et al.: Expert opinion on detecting and treating depression in palliative care: A Delphi study. *BMC Palliat Care* 2011;10:10.
- Wasteson E, Brenne E, Higginson IJ, et al.: Depression assessment and classification in palliative cancer patients: A systematic literature review. *Palliat Med* 2009;23:739–753.
- Fallon M, Smyth J: Terminology: The historical perspective, evolution and current usage—room for confusion? *Eur J Cancer* 2008;44:1069–1071.
- Hui D, Mori M, Parsons HA, et al.: The lack of standard definitions in the supportive and palliative oncology literature. *J Pain Symptom Manage* 2012;43:582–592.
- World Health Organization: *National Cancer Control Programmes: Policies and Managerial Guidelines, 2nd ed.* Geneva: World Health Organization, 2002.
- Palliative Care Australia: *Strategic Plan 2008–2011.* Australian Capital Territory: Palliative Care Australia, 2008.
- SPSS Inc.: *SPSS 18.0 for Windows.* Chicago, IL, 2009.
- QSR International Pty Ltd.: *NVivo qualitative data analysis software.* Version 9, 2011.
- Thomas-MacLean R, Stoppard JM: Physicians' constructions of depression: Inside/outside the boundaries of medicalization. *Health (London)* 2004;8:275–293.
- Burroughs H, Lovell K, Morley M, et al.: 'Justifiable depression': How primary care professionals and patients view late-life depression? A qualitative study. *Fam Pract* 2006;23:369–377.
- Chew-Graham CA, May CR, Cole H, et al.: The burden of depression in primary care: A qualitative investigation of general practitioners' constructs of depressed people in the inner city. *Int J Psychiatry Clin Pract* 2000;6:137–141.
- Galatzer-Levy IR, Galatzer-Levy RM: The revolution in psychiatric diagnosis: Problems at the foundations. *Perspect Biol Med* 2007;50:161–180.
- Jablensky A: Categories, dimensions and prototypes: Critical issues for psychiatric classification. *Psychopathology* 2005;38:201–205.
- Jablensky A: The disease entity in psychiatry: Fact or fiction? *Epidemiol Psychiatr Sci* 2012;21:255–264.

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Journal of Palliative Medicine reviewers' comments on first submitted manuscript

28-Nov-2012

Dear Dr. Ng:

Thank you for submitting manuscript JPM-2012-0502 entitled "Palliative medicine practitioners' views on the concept of depression in the palliative care setting" to Journal of Palliative Medicine. The comments of the reviewer(s) are included at the bottom of this letter.

In light of the reviewer's enthusiasm for the manuscript, I would like to tentatively accept your manuscript for publication pending satisfactory revision. Therefore, I invite you to respond to the reviewer(s)' comments and revise your manuscript.

To revise your manuscript, log into <http://mc.manuscriptcentral.com/palliative> and enter your Author Center, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

Please submit your revision by 27-Jan-2013.

You will be unable to make your revisions on the originally submitted version of the manuscript. Instead, revise your manuscript using a word processing program and save it on your computer. Please also highlight the changes to your manuscript within the document by using the track changes mode in MS Word or by using bold or colored text.

Once the revised manuscript is prepared, you can upload it and submit it through your Author Center.

When submitting your revised manuscript, you will be able to respond to the comments made by the reviewer(s) in the space provided. You can use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the reviewer(s).

IMPORTANT: Your original files are available to you when you upload your revised manuscript. Please delete any redundant files before completing the submission.

NOTE: Original Manuscripts may NOT exceed 3,000 words. Submissions over 3,000 words will be returned to the author.

Because we are trying to facilitate timely publication of manuscripts submitted to Journal of Palliative Medicine, your revised manuscript should be uploaded as soon as possible. If it is not possible for you to submit your revision in a reasonable amount of time, we may have to consider your paper as a new submission.

Once again, thank you for submitting your manuscript to Journal of Palliative Medicine and I look forward to receiving your revision.

Sincerely,
Dr. Charles von Gunten
Editor, Journal of Palliative Medicine
cvongunten@ucsd.edu, lpelzek@mcw.edu

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

Thank you for the opportunity to review this well-written and professionally-presented manuscript. The author(s) present a contemporary issue (understanding depression in palliative care from the providers' perspective). This article is well-written with a clear methodology and presentation of findings. The strengths of the manuscript include: 1) The presentation of this study is cohesive and professionally written; 2) Contemporary issue that warrants further research; 3) Study enhances current knowledge-base in the area of depression and palliative care/EOL; 4) Implications for research and practice are effectively presented and discussed; 5) Recent citations.

Two minor suggestions to address is the notion of "palliative care" and "end of life care," and writing a distinct literature review section. While there may be an intersection, these terms are operationally different and more clarity regarding such definitions may need to be explored in the introduction. Secondly, it may be helpful to separate the introduction into a clear introduction followed by a literature review section. Perhaps by focusing attention on a literature review section may address the issue of the operationalization of the terms "palliative care," and "EOL". By doing so, the author(s) can present, from a historically perspective, the progression of our understanding of the intersection of depression at the end of life. The author(s) are discussing "palliative care" which may not imply the end of life. With recent advances in bio-psychosocial interventions, people diagnosed with a terminal illness can live long after a given prognosis. In other words, the authors may want to address the issue of actually using "terminal illness" in relation to "palliative care." This can be easily and briefly discussed in the literature review.

Reviewer: 2

Comments to the Author

The aim of this study was to explore the ways in which depression is conceptualized by palliative medicine practitioners. The manuscript is well written. It is original work and contributes to our understanding of the challenges in assessing and managing depression in palliative care settings. The following comments are offered for the authors' consideration.

1. The authors report that a questionnaire was specifically developed for the purpose of this study and refined based on a "small pilot." It would be important to provide more information about this process.
 - a. Who participated in the development of this questionnaire?
 - b. How were the original items generated? To what extent were these items informed by the literature?
 - c. Describe the pilot study in more detail, including number and types of participants. What types of modifications were made to the questionnaire based on this pilot?
2. For patient demographics, how was "specific mental health training" defined? For those participants who had training in this area, what type of training did this involve?
3. It is difficult to evaluate the participants' responses without having a better understanding of the definition of depression they were using (either generated by the researchers or reported by the participants).
 - a. How was the concept of depression introduced to the participants?
 - b. Was a definition included by the researchers as part of the questionnaire? Were participants asked to generate their own definition of depression?
 - c. If a definition was not included with the questionnaire, then how might this have impacted the findings? This needs to be added to the study limitations.
4. Discussion
 - a. Please elaborate on what is meant by "discrete and dimensional concepts of illness" (page 10, line 5).
 - b. Please elaborate on the reported differences between general practitioners' and palliative medicine specialists' concepts of depression (page 10, lines 45-48).
 - c. The authors report that palliative medicine practitioners view depression as "different and complex in the EOL setting" (page 11, lines 18-20). This is an equally challenging issue in other medically complex populations, such as medically ill patients and geriatric patients. It would be important to cite some of the literature from these different settings, including some

of the approaches that are being recommended to assess depression in medically complex patients (e.g. exclusion of somatic depressive symptoms, Endicott's substitution criteria). These approaches would also be important to include in medical education and training programs if they are not currently being addressed (page 11, lines 24-31). (Also see Wasteson, E et al. Palliat Med 2009;23:379-753 regarding different assessment approaches)

5. Limitations – As mentioned in Comment #3, the variability in participants' definitions of depression compounded the interpretability of the findings.

Corresponding author's response to reviewers' comments on first submitted manuscript

28th December 2012

Professor Charles F. von Gunten
Editor-in-Chief
Journal of Palliative Medicine

Dear Professor von Gunten,

Re: Revised manuscript JPM-2012-0502, entitled "Palliative medicine practitioners' views on the concept of depression in the palliative care setting"

On behalf of my co-authors, thank you for considering our manuscript for publication in the Journal of Palliative Medicine. We would like to thank the reviewers for their helpful comments, which we have carefully considered in revising our manuscript.

Please find below a point-by-point response to the reviewers' comments. Due to the addition of content raised by the reviewers, we have needed to edit some of the original text in order to confine the word count to the limit of 3000 words. We have not substantially reduced the information in the paper in doing so. All changes made to the manuscript are indicated by coloured track changes.

Reviewer: 1

Comments to the Author

Thank you for the opportunity to review this well-written and professionally-presented manuscript. The author(s) present a contemporary issue (understanding depression in palliative care from the providers' perspective). This article is well-written with a clear methodology and presentation of findings. The strengths of the manuscript include: 1) The presentation of this study is cohesive and professionally written; 2) Contemporary issue that warrants further research; 3) Study enhances current knowledge-base in the area of depression and palliative care/EOL; 4) Implications for research and practice are effectively presented and discussed; 5) Recent citations.

Two minor suggestions to address is the notion of "palliative care" and "end of life care," and writing a distinct literature review section. While there may be an intersection, these terms are operationally different and more clarity regarding such definitions may need to be explored in the introduction. Secondly, it may be helpful to separate the introduction into a clear introduction followed by a literature review section. Perhaps by focusing attention on a literature review section may address the issue of the operationalization of the terms "palliative care," and "EOL". By doing so, the author(s) can present, from a historical perspective, the progression of our understanding of the intersection of depression at the end of life. The author(s) are discussing "palliative care" which may not imply the end of life. With recent advances in bio-psychosocial interventions, people diagnosed with a terminal illness can live long after a given prognosis. In other words, the authors may want to address the issue of actually using "terminal illness" in relation to "palliative care." This can be easily and briefly discussed in the literature review.

The two suggestions are gratefully acknowledged. The issue of operationalised definitions of the terms "palliative care", "EOL" and "terminal illness" has been addressed by adding a paragraph in the Introduction section to define the meaning of "palliative care" and "EOL" in

this paper, and by replacing “terminal illness” with alternative terms. The importance of the terminological inconsistency in palliative care and the roots of this situation in a historical perspective unfortunately cannot be discussed in detail within the word limit and prioritisation of content. A brief reference has been made to this issue (last paragraph in the Introduction section) and readers are directed to two informative papers on this subject. Similarly, because of the word count limitation, an expanded literature review section cannot be accommodated without sacrificing important content relating to the study.

Reviewer: 2

Comments to the Author

The aim of this study was to explore the ways in which depression is conceptualized by palliative medicine practitioners. The manuscript is well written. It is original work and contributes to our understanding of the challenges in assessing and managing depression in palliative care settings. The following comments are offered for the authors’ consideration.

1. The authors report that a questionnaire was specifically developed for the purpose of this study and refined based on a “small pilot.” It would be important to provide more information about this process.

a. Who participated in the development of this questionnaire?

b. How were the original items generated? To what extent were these items informed by the literature?

c. Describe the pilot study in more detail, including number and types of participants. What types of modifications were made to the questionnaire based on this pilot?

All of the above information has been added to the Methods section (first paragraph).

2. For patient demographics, how was “specific mental health training” defined? For those participants who had training in this area, what type of training did this involve?

Because of word count limitation, the breakdown of the types of specific mental health training as reported by respondents has been added to Table 2 (see note c).

3. It is difficult to evaluate the participants’ responses without having a better understanding of the definition of depression they were using (either generated by the researchers or reported by the participants).

a. How was the concept of depression introduced to the participants?

b. Was a definition included by the researchers as part of the questionnaire? Were participants asked to generate their own definition of depression?

c. If a definition was not included with the questionnaire, then how might this have impacted the findings? This needs to be added to the study limitations.

We agree with the reviewer that the use of the term “depression” is important to clarify in this paper. For this study, we deliberately used the term without further elaboration because we wished to keep the term in its broad clinical sense, and because clinicians often refer to depression in clinical practice without added qualifications. We therefore avoided defining depression in terms of specific diagnostic labels or classifications. An explanation to this effect has been added to the Methods section (towards the end of the last paragraph). Rather than considering the use of the term in an unelaborated form to be a limitation of this study, we consider it to be a strength and a necessity for this type of research which aims to explore the various concepts of depression. This point has been added to the Discussion section (end of last paragraph).

4. Discussion

a. Please elaborate on what is meant by “discrete and dimensional concepts of illness” (page 10, line 5).

We replaced the word “discrete” with “categorical”, the meaning of which should hopefully be clearer to readers.

b. Please elaborate on the reported differences between general practitioners’ and palliative medicine specialists’ concepts of depression (page 10, lines 45-48).

This sentence is intended as a possible explanation for the point made in the previous sentence, referring to the differences in views that were identified in this study between those mainly working in general practice and those mainly working in palliative medicine. These sentences have been edited to be clearer in their meanings to readers.

c. The authors report that palliative medicine practitioners view depression as “different and complex in the EOL setting” (page 11, lines 18-20). This is an equally challenging issue in other medically complex populations, such as medically ill patients and geriatric patients. It would be important to cite some of the literature from these different settings, including some of the approaches that are being recommended to assess depression in medically complex patients (e.g. exclusion of somatic depressive symptoms, Endicott’s substitution criteria). These approaches would also be important to include in medical education and training programs if they are not currently being addressed (page 11, lines 24-31). (Also see Wasteson, E et al. *Palliat Med* 2009;23:379-753 regarding different assessment approaches)

There are indeed similar complexities in assessing and managing depression in other clinical subgroups, and a comparison between subgroups would be a worthwhile research topic. However, there are few empirical studies of medical practitioners’ views of depression in other medically complex populations. We have alluded to similarities reported in primary care populations in the Discussion section (last line of first paragraph), because published empirical studies have mainly been in primary care. We have also added references to two studies of primary care professionals’ views of depression, including one in relation to older patients. More detailed discussion cannot be accommodated within the current word count limit. For the same reason, we have regrettably not been able to add discussion of the various diagnostic criteria proposed for depression in medically-ill patients. Our reasons for not prioritising these areas relate to the unresolved debate on alternative diagnostic criteria for medically-ill patients, and the fact that the focus of this study is on the broad concept of depression in the palliative care setting. This study is not primarily concerned with specific diagnostic criteria proposed for medically-ill patients, or the complexities of depression across medically complex patient populations.

5. Limitations – As mentioned in Comment #3, the variability in participants’ definitions of depression compounded the interpretability of the findings.

Please see response to Comment #3 above.

I hope the above explanations are clear, but please let me know if further suggestions are available or clarifications required. I look forward to hearing from you in the near future.

Yours sincerely,

Felicity Ng
Corresponding author

Journal of Palliative Medicine reviewers' comments on revised manuscript

04-Feb-2013

Dear Dr. Ng:

Thank you for submitting manuscript JPM-2012-0502.R1 entitled "Palliative medicine practitioners' views on the concept of depression in the palliative care setting" to Journal of Palliative Medicine. The comments of the reviewer(s) are included at the bottom of this letter.

In light of the reviewer's enthusiasm for the manuscript, I would like to tentatively accept your manuscript for publication pending satisfactory revision. Therefore, I invite you to respond to the reviewer(s)' minor comments and revise your manuscript.

To revise your manuscript, log into <http://mc.manuscriptcentral.com/palliative> and enter your Author Center, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

Please submit your revision by 05-Apr-2013.

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Because we are trying to facilitate timely publication of manuscripts submitted to Journal of Palliative Medicine, your revised manuscript should be uploaded as soon as possible. If it is not possible for you to submit your revision in a reasonable amount of time, we may have to consider your paper as a new submission.

Once again, thank you for submitting your manuscript to Journal of Palliative Medicine and I look forward to receiving your revision.

Sincerely,
Dr. Charles von Gunten
Editor, Journal of Palliative Medicine
charles@pallmed.us, lpelzek@mcw.edu

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

Dr. Von Gunten, thank you for extending me the privilege to review Manuscript #JPM-2012-0502.R1. The author(s) have once again presented a well-written manuscript that is professionally sound, relevant, and focusing on the contemporary issue of end of life care with the main focus on depression in palliative care.

My initial comments/suggestions to the author(s) have been addressed in this revision and thus I do not have any further comments at this time. I appreciate and thank the author(s) for investigating matters related to end of life and wish them much success. I would encourage the author(s) to continue looking at matters related to culture such as acculturation and assimilation--factors that can affect outcomes especially when treatment for depression at the end of life is considered by medical professionals. Thank you again for your work.

Reviewer: 2

Comments to the Author

Thank you for the opportunity to review this resubmitted manuscript, focusing on how medical practitioners working in palliative care conceptualize depression. The authors have adequately addressed my comments for the most part. However, I am still struggling with their assertion that one of the strengths of this study is the broad conceptualization of depression. I agree with their premise that patients' presentations of "depression" can vary substantially, for example, from normal reactions of sadness to profound clinical depressive episodes. However, I still believe that it is difficult to make comparisons of participants' responses, when their conceptions of and experiences with assessing and treating depression are so varied. For example, whether or not depression can be managed with medications or psychological support will depend on how depression is being conceptualized, as well as the severity of symptoms associated with it. It is also difficult to determine whether the participants' responses may have been influenced by limited knowledge of this complex area. Only a quarter of the participants (25.6%) had received any specific mental health training, with variable experiences in this domain. Variations in participants' responses may have been influenced by broad and varying views of depression at end of life, the complexity of making these differentiations in this unique population, a limited exposure to the diverse spectrum of depressed patients in clinical practice, or a lack of training for differentiating a major depressive episode from subsyndromal forms of depression. It would be important to include all of these potentially confounding factors in the Discussion.

Corresponding authors' response to reviewers' comments on revised manuscript

19th February 2013

Professor Charles F. von Gunten
Editor-in-Chief
Journal of Palliative Medicine

Dear Professor von Gunten,

Re: Revision of manuscript JPM-2012-0502.R1, entitled "Palliative medicine practitioners' views on the concept of depression in the palliative care setting"

My co-authors and I would once again like to thank the reviewers for their comments on the above revised manuscript, which we have used to guide our further revision of the paper. All changes made to the manuscript are indicated by coloured track changes.

Reviewer 1 did not identify any further areas requiring address. We are appreciative of his/her encouragement and ideas for future research.

Reviewer 2 indicated the need to discuss the difficulties in interpreting the participants' responses, given the variations in their concepts of depression.

"Comments to the Author

Thank you for the opportunity to review this resubmitted manuscript, focusing on how medical practitioners working in palliative care conceptualize depression. The authors have adequately addressed my comments for the most part. However, I am still struggling with their assertion that one of the strengths of this study is the broad conceptualization of depression. I agree with their premise that patients' presentations of "depression" can vary substantially, for example, from normal reactions of sadness to profound clinical depressive episodes. However, I still believe that it is difficult to make comparisons of participants' responses, when their conceptions of and experiences with assessing and treating depression are so varied. For example, whether or not depression can be managed with medications or psychological support will depend on how depression is being conceptualized, as well as the severity of symptoms associated with it. It is also difficult to determine whether the participants' responses may have been influenced by limited knowledge of this complex area. Only a quarter of the participants (25.6%) had received any specific mental health training, with variable experiences in this domain. Variations in participants' responses may have been influenced by broad and varying views of depression at end of life, the complexity of making these differentiations in this unique population, a limited exposure to the diverse spectrum of depressed patients in clinical practice, or a lack of training for differentiating a major depressive episode from subsyndromal forms of depression. It would be important to include all of these potentially confounding factors in the Discussion."

We agree that one of the limitations of this study is that, although it demonstrates variability among palliative medicine practitioners in their conceptualisation of depression at the EOL, it is not designed to further explore and characterise their different concepts of depression. We also agree with all the potential factors, as outlined by Reviewer 2, that influence palliative medicine practitioners in their constructs of depression. We have therefore added these points in the Discussion section (fifth paragraph), within the confines of the 3000 word limit. We have removed the sentences relating to the advantages of using broad

conceptualisations of depression, which we believe is important in further qualitative explorations, but is not a primary recommendation for this preliminary questionnaire study.

We appreciate the opportunity to resubmit this second revision, and look forward to your response in the near future.

Yours sincerely,

Felicity Ng
Corresponding author

Journal of Palliative Medicine's decision letter

25-Mar-2013

Dear Dr. Ng:

It is a pleasure to accept your manuscript entitled "Palliative medicine practitioners' views on the concept of depression in the palliative care setting" in its current form for publication in Journal of Palliative Medicine.

Please be sure to cite this article to ensure maximum exposure of your work.

All authors will get a follow-up email with instructions on how to complete our online Copyright Agreement form. The corresponding author is responsible for communicating with coauthors to make sure they have completed the online copyright form. Authors not permitted to release the copyright must still return the forms acknowledging the statement of the reason for not releasing the copyright.

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JPM now highlights articles that have potential to advance the field of palliative care using our social media portal.

We are pleased to invite you to participate in this effort and showcase your accepted article on the JPM Social Media (<http://palliativejournal.stanford.edu>)

This is a unique opportunity for you and your co-authors to increase your visibility, promote your work and dialog with the JPM readership about your scientific contributions in an informal manner using the latest social media tools. Please complete the form via link: https://suse.qualtrics.com/SE/?SID=SV_50xf258N7WS2tWk and submit to have your work featured in the JPM Blog Spotlight.

Thank you for your fine contribution. On behalf of the Editors of Journal of Palliative Medicine, we look forward to your continued contributions to the Journal.

Sincerely,
Dr. Charles von Gunten
Editor, Journal of Palliative Medicine
charles@pallmed.us, lpelzek@mcw.edu

*Comments on paper in the Palliative Medicine Research Review 2013
Issue 2 (page 2)*

NOTE:

This appendix is included on pages 232-235 of the print copy
of the thesis held in the University of Adelaide Library.

**Appendix I Paper 2: How Do Palliative Medicine Specialists
Conceptualise Depression? Findings from a Qualitative In-depth
Interview Study**

Citation:

Ng F, Crawford GB, Chur-Hansen A. How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study. *Journal of Palliative Medicine* 2014; 17(3): 318-324. DOI: 10.1089/jpm.2013.0378

How Do Palliative Medicine Specialists Conceptualize Depression? Findings from a Qualitative In-Depth Interview Study

Felicity Ng, MBBS, FRANZCP,¹⁻⁴ Gregory B. Crawford, MBBS, MD, FChPM,^{5,6}
and Anna Chur-Hansen, PhD, FAPS, FHERDSA⁷

Abstract

Background and Objective: Different professional conceptualizations of depression may complicate the clinical approach to depression in the palliative care setting. This study aimed to explore and characterize how palliative medicine specialists conceptualize depression.

Methods: Palliative medicine specialists (i.e., consultants/attending physicians in palliative medicine) practicing in Australia were recruited. Participants were purposively sampled. Individual semi-structured, in-depth interviews were conducted to explore their conceptualizations of depression. Nine participants were interviewed to reach data saturation. Interview transcripts were analyzed for themes.

Results: Four main themes were identified in relation to the conceptualization of depression: (1) depression is a varied concept—it was variously considered as abnormal, a medical problem, an emotional experience, a social product, and an action-oriented construct; (2) depression has unclear boundaries, with differentiation between depression and sadness being especially challenging; (3) depression is different in the palliative care setting—it was seen as more understandable, and distinct from depression that predates life-limiting illnesses; and (4) depression is a challenging issue.

Conclusions: Depression is conceptualized by palliative medicine specialists in divergent, ontologically heterogeneous and ill-defined ways. A unitary concept of depression was not evident in this study. The concepts of depression need to be actively debated and refined in clinical practice, medical education, and research in order for more sophisticated and consistent models to be developed. The distinction of *de novo* depression from recurrent or persistent forms of depression also warrants further study.

Introduction

DEPRESSION IS DIFFICULT TO DIAGNOSE in the palliative care setting,^{1,2} a dilemma that partly lies in its ambiguity as a concept. The lack of specific somatic markers for depression places the onus of diagnosis on the clinician to interpret the patient's narratives and behaviors. This interpretation is subjected to the vicissitudes of language, culture, and individualized notions of depression. Clinically, depression has been variously conceptualized as a symptom, a syndrome, specific depressive disorders, and normal or abnormal reactions to stress.³⁻⁵ In the palliative care setting,

complexity also arises from distinguishing depression from context-appropriate psychological processes and physical conditions, such as advanced disease, delirium, dying, and medication effects.^{3,6,7} The availability of operationalized diagnostic criteria, such as the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) syndrome of "Major Depressive Episode," has not resolved the problem of interpretive variability in diagnosis. The confounding potential of somatic symptoms in medically ill individuals has led to debates about the merits of adopting inclusive, exclusive and substitutive approaches to diagnosis,⁸⁻¹¹ and to views that the criteria for major depression are incompatible with the

¹Discipline of Psychiatry, ²Medicine Learning and Teaching Unit, ⁵Discipline of Medicine, School of Medicine, ⁷School of Psychology, Faculty of Health Sciences, University of Adelaide, South Australia, Australia.

³Consultation-Liaison Psychiatry, Lyell McEwin Health Service, ⁴Northern Adelaide Palliative Care Service, Northern Adelaide Local Health Network, South Australia, Australia.

⁶Central Adelaide Palliative Care Service, Central Adelaide Local Health Network, Woodville South Australia, Australia.
Accepted October 18, 2013.

palliative care setting.² Furthermore, subtly different interpretations of severity thresholds for individual criterion symptoms can result in substantial variations in the prevalence of major depression.¹² Given that diagnosing depression is inherently an interpretive process, clinicians' conceptualizations of depression lie at its core.

How clinicians conceptualize depression in the palliative care setting has received little attention, and variations in conceptualization are infrequently acknowledged^{3,4} or examined.² Previous research has demonstrated conceptual variability among medical practitioners who practiced palliative medicine, and highlighted the belief that depression is different in the palliative care setting, including greater uncertainty about whether it is an illness or a normative process in this context.¹³ The present study was conducted in order to explore, using qualitative in-depth interviewing, how palliative medicine specialists think about depression. The research question is: What are palliative medicine specialists' conceptualizations of depression?

Methods

Participants and recruitment

Palliative medicine specialists (i.e., consultants/attending physicians in palliative medicine) practicing in Australia were recruited through a local palliative medicine conference in 2010. A paper invitation was distributed to all registrants of the conference in their registration packages. Potential participants could register their interest by completing the provided reply slip or by directly contacting the first author. Further information about this study was subsequently sent to potential participants.

Twenty-eight palliative medicine specialists registered an interest in participating in the study. Of those, only 23 were eligible, as 5 practiced overseas. Purposive sampling was used, taking into consideration gender and geographical location. Recruitment continued until data saturation was reached. A total of 9 palliative medicine specialists were interviewed. Their demographic characteristics are shown in Table 1.

Data collection

The first author, a psychiatrist with an interest in palliative care, conducted all interviews between November 2010 and January 2011, either in person for local participants or over the telephone for interstate participants. All participants gave informed consent and permission for audiotaping their interviews.

Demographic information was established at the start of the interview, and included training background, palliative medicine practice details, and duration of practice in this area. The semi-structured interviews allowed in-depth exploration of content areas that included concepts of depression, its causality, pathogenetic mechanisms, timing and onset of symptoms, course, and treatment. The interview process was open-ended and flexible, giving participants freedom to develop their responses. New content areas pertinent to the research question that arose during an interview, were incorporated into subsequent interviews, as consistent with qualitative semi-structured interviewing practice.¹⁴ Different understandings of depression were assumed, and

TABLE 1. PARTICIPANT CHARACTERISTICS

Characteristic	Numbers of participants
<i>Gender</i>	
Male	5
Female	4
<i>Palliative medicine practice details</i>	
<i>Location</i>	
City	6
Regional or rural	2
Combination of city and regional/rural	1
<i>Setting</i>	
Across clinical settings (hospital/hospice/community)	8
Hospital only	1
<i>Time fraction in palliative medicine</i>	
Full-time	7
Part-time	2
<i>Training background</i>	
<i>Palliative medicine^a</i>	
Chapter of Palliative Medicine (grandfather clause)	4
Advanced training in palliative medicine	4
General practice training	1
<i>Mental health</i>	
No specific mental health training	7
Junior medical training in psychiatry ^b	2
<i>Years of practice in palliative medicine</i>	Years
Mean	17.2
Range	7-27

^aThe training backgrounds of palliative medicine specialists are varied and reflect the different training pathways. The Australasian Chapter of Palliative Medicine (AChPM) was established within The Royal Australasian College of Physicians in 1999, and accepted Foundation Fellows under its grandfather clause in 2000. Of the four participants who were accepted under the grandfather clause, three were from a general practice background and one worked exclusively in palliative care. Of the four participants who completed advanced training in palliative medicine, two completed prerequisite training in general practice and two completed prerequisite training in basic physician training.

^bThis includes prevocational and vocational training experience.

the term "depression" was used in interviews without specification other than the clinical usage of the term.

An audit trail was kept to assist in the identification of preliminary themes after each interview in a process of constant comparison, which was used to determine when data saturation was reached, that is, when no new further themes are identified.^{15,16} The audit trail was also used to record information relevant to the process of reflexivity.

The interviews ranged from 46 to 76 minutes in duration, with a mean duration of 60.2 minutes.

Data analysis

The first author transcribed all interviews verbatim, and removed all identifying information in the process. Six participants agreed to view their transcripts for participant validation, resulting in minor changes, which involved clarification of meanings or the editing of potentially identifying material.

The first author performed thematic analysis as described by Braun and Clarke, which involved iterative stages of data

familiarization, generation of initial codes, search for themes, review of themes, definition and labelling of themes, and finally, report-writing.¹⁷ Their criteria for quality¹⁷ were used as a framework for rigor. Coding was performed deductively in reference to interview content areas and inductively to emergent contents relevant to the research question.¹⁷ To enhance the trustworthiness of the analysis, the codes generated from the first transcript were independently verified against the raw data by two co-authors (ACH and GBC), and the final themes were also verified against the raw data by a co-author (ACH). NVivo9 software¹⁸ was used to facilitate data organization during analysis.

Ethics

This study received institutional approval from the University of Adelaide Human Research Ethics Committee (H-086-2010).

Results

Four themes were identified in relation to the conceptualization of depression: depression is a varied concept; depression has unclear boundaries; depression is different in the palliative care setting; and depression is a challenging issue.

Depression is a varied concept

Participants described five key notions of depression: being abnormal; a medical problem; an emotional experience; a social product; and an action-oriented construct (Table 2). The idea of depression as pathology was conveyed in both the notions of abnormality and of being a medical problem. Abnormality was characterized by falling outside of the expected response to illness, deviating from normative disease or dying processes, or being incomprehensible. Having been delineated as abnormal, depression was also placed within the medical realm as a medical problem, which was variously seen as a symptom, a syndrome, a diagnosis, and a disease.

As a medical problem, depression was often described in analogous terms to physical illness, particularly as a means of engaging patients in medical treatments.

In contrast to these pathological notions, some participants considered depression from a predominantly psychosocial perspective as an emotional experience borne out of circumstances, or a product of the social context. In the latter, depression was understood as a Western cultural phenomenon that had been shaped by cultural norms and the pharmaceutical industry, or as a societal interpretation of abstract phenomena such as sadness, fear, and existential isolation. Judgement of normality was not intrinsic to either of these notions, which were instead focused on contextualizing depression and implied fluidity in its conceptualization.

Depression as an action-oriented construct was defined as a signal for the potential need for clinical interventions, and eschewed conceptual issues of normality versus abnormality, diagnostic distinction, or even the nature of depression.

Depression has unclear boundaries

All participants considered depression to have indistinct conceptual boundaries, with some conceptualizing depression as belonging to a spectrum of emotional experiences at the end-of-life (EOL). Within this amorphous idea of depression, there were two juxtaposed subthemes of the distinctness of depression and its overlap with other concepts (Table 3).

For most participants, depression was recognizable by distinctive features, which included specific mood characteristics such as entrenched or pervasive low mood, and distinguishing symptoms such as anhedonia, disconnection, and hopelessness. However, depression overlapped with a number of separate concepts that included anxiety, sadness, grief, demoralization, and physical illness. In particular, the overlap between sadness and depression was a prominent idea. Although depression and sadness were often dichotomously described, they were also seen as merged phenomena

TABLE 2. ILLUSTRATIVE DATA EXTRACTS FOR THE THEME: DEPRESSION IS A VARIED CONCEPT

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Depression is abnormal.	"I don't think depression is a normal part of dying, I don't, and if a patient is depressed, that should be addressed...I never accept it as though, oh well, they're dying and I'm not surprised they feel hopeless and worthless and helpless." (Participant #6)
Depression is a medical problem.	"I will often talk to people about the fact that if you had a broken leg, I wouldn't just ignore your broken leg, I'd try to do something about it...if you're getting angina...I'll do something about it. So if you're feeling really low and very down and very depressed, because your brain chemicals aren't right, I don't want to ignore that anymore than I did other parts of your body." (Participant #5)
Depression is an emotional experience.	"I certainly would see depression as a negative emotion...and as losses, if you like, and of course, it's close to grief." (Participant #4)
Depression is a social product.	"Japanese culture didn't have depression as being an issue, and then the drug companies invented it so they can sell their drugs to Japan...They had introduced a Western concept." (Participant #2)
Depression is an action-oriented construct.	"I tend to use the term depressed mood...I don't sort of class it as anything as such, really. I mean, depressed mood, you know, it doesn't matter if it is supposed to be a depression or not depression, but I think...it describes what we see, and help [us] think about what the treatment should be." (Participant #8)

TABLE 3. ILLUSTRATIVE DATA EXTRACTS FOR THE THEME: DEPRESSION HAS UNCLEAR BOUNDARIES

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Depression belongs in a spectrum.	"I think that the issues that people deal with at the end of their lives, the emotions they experience and so on, don't necessarily fit easily into those boxes...It will always be the case that there's the sort of spectrum of disorders and distress and causation, and we have to pick our way through that." (Participant #2)
Distinctness of depression	"I think depression probably stands a bit apart, say, from anxiety or fear in that there's...that persistent low mood, that low willingness to participate or engage, because of...what I guess we were taught as anhedonia." (Participant #6)
Overlapping concepts	"There is that classical process of understandable depression...where of course a person who has advanced cancer and who's losing their strength and all those sorts of things, of course they would feel depressed. Wouldn't you feel depressed if that was the situation? But, you know, it's not clinical depression, it's just understandable sadness." (Participant #7) "Sometimes enormous sadness is the same as depression." (Participant #4)

in the palliative care context. Determining whether a patient was sad or depressed was seen to call for personal empathic judgement, which could place the palliative medicine specialist in a conflicted position, between therapeutic inactivity when treatment could potentially benefit the patient, and medicalizing a normal process with unnecessary interventions.

Depression is different in the palliative care setting

Whereas some participants saw depression as the same concept in the palliative care setting as any other, some considered depression to be different in palliative care. This difference was grounded in the unique circumstances at the EOL, such as being confronted by impending death and the perceived loss of a future, which imbued depression in this setting with a more understandable quality.

Several participants made a distinction between those who had depression for the first time in their lives during the palliative phase of care, and those who had a history of depression prior to entering into palliative treatment (Table 4). *De novo* depression in the palliative care setting was regarded as easier to understand because of the terminal illness context. One participant conceptualized *de novo* depression as a cancer-related syndrome akin to other systemic effects of malignancy, with different etiology and entailing different treatments. On the other hand, depression that precedes the terminal illness was considered to have less causal association with EOL circumstances, and was either coincidental or a recurrence accounted for by the vulnerability of the indi-

vidual to becoming depressed. These forms of depression were sometimes regarded as more difficult to treat due to their refractory nature.

Depression is a challenging issue

The majority of participants described aspects of depression that were challenging. These can be distilled into six subthemes (Table 5).

As a concept, depression was considered difficult to understand, especially when contrasted with the more tangible nature of physical illness. Depression was also considered to be a gray area, with the absence of somatic diagnostic markers and the subjective nature of discerning what constitutes depression being factors that make depression imprecise. To make sense of depression required processing by the participants, in the form of teasing out the patient's history and circumstances, and having time to reflect on their conceptualizations and to gather alternative perspectives within the health profession.

The language of depression was discussed as a source of ambiguity. Participants commented on the different meanings of the word "depression," and its interchangeable use with the word "sadness." Participants reported that patients communicated depression in diverse ways using a variety of terms including physical symptoms, but noted that these descriptions were influenced by the language that palliative medicine specialists used to make enquiries. The language used within the profession was likewise varied, as indicated by the different terms used by the participants (for example,

TABLE 4. ILLUSTRATIVE DATA EXTRACTS FOR THE THEME: DEPRESSION IS DIFFERENT IN THE PALLIATIVE CARE SETTING

<i>Subthemes</i>	<i>Illustrative data extracts</i>
<i>De novo</i> depression	"You know, what as I think about depression more and more is that...when people get <i>de novo</i> depression in the palliative care setting, most of the time it's a cancer-related syndrome, so it's a bit like anorexia, cachexia, fatigue, those sorts of syndromes that are often associated physically with those things, and the mood is physically associated with that." (Participant #8)
Depression preceding palliative care	"Presumably, a certain number of our patients would have a depressive illness for a substantial part of their lives, and they may suffer exacerbations from time to time, which may coincide with their illness." (Participant #1)

TABLE 5. ILLUSTRATIVE DATA EXTRACTS FOR THE THEME: DEPRESSION IS A CHALLENGING ISSUE

<i>Subthemes</i>	<i>Illustrative data extracts</i>
Difficult to understand	"I think people understand physical illness more than mental disorders...Some patients really do just look at me completely blankly as if they have no idea what I'm talking about at all, and for some of them, I really struggle to come up with a paradigm that seems to make any sense to them at all." (Participant #5)
Gray area	"It's a tricky thing...It's somewhat person-dependent, in terms of the clinician...I guess, because it doesn't have a physical...or you can't do a test actually looking for biological abnormalities, to some extent, it remains a, you know, gray area, I suppose." (Participant #1)
Requires processing	"I find it quite difficult at times to work out. It's really important to try and go back and find out what they were like beforehand, and what their families notice and what changes, and how they feel themselves about it all." (Participant #9)
Language is variable	"Minor and Major Depression, Adjustment Disorders are more terms that psychiatrists I've worked with have used for patients...I guess a lot of psychiatrists think that if it's Adjustment Disorder, you don't give them medication, but you give medication for depression, you know, and it seems to me as though a lot of people are pretty similar." (Participant #8)
Concealed	"People who are depressed are possibly more generally withdrawn...and I guess for that reason, possibly, it may be overlooked." (Participant #1)
Stigmatizing	"I think depression largely in our society is something that people see as a mark of weakness and a stigma, and often people will defend against admitting depression." (Participant #7)

"clinical depression," "organic depression," and "true depression"), and by their comments about the terminological differences between palliative medicine specialists and psychiatrists. For example, participants commented on being unclear about the meaning or implications of the diagnosis of Adjustment Disorder that psychiatrists used, and interpreted this in various ways.

Depression was seen to be often concealed, either being overlooked due to the social withdrawal that occurs in depression, or being obscured by the nature of terminal illness. Participants proposed this as one reason for the under-detection of depression in the palliative care setting, and were occasionally surprised when they inadvertently treated depression and thus "unmasked" it. Finally, stigma associated with depression was regarded as a reason for its denial by some patients, and for clinicians to avoid further exploration and diagnosis.

Discussion

Similar to previous research, this study identified dichotomized concepts of depression as an illness and as normal, the idea that depression is qualitatively different in the palliative care setting, and the difficulties of its delineation.¹³ The current study extends those findings and, to our knowledge, is the first to characterize the concepts of depression that are held by palliative medicine specialists. In particular, it demonstrates that depression was broadly considered in two divergent ways, as pathological (abnormal, medical problem) and contextual (emotional experience, social product). These notions represent different ontological positions, with the construct of pathology being aligned with realism, which assumes depression to exist as an objective external reality with definable boundaries, whereas contextual understanding is aligned with relativism, which assumes multiple versions of reality dependent on interpretation.¹⁹ The simultaneous use of these ontologically distinct notions has generated consternation for health practitioners in attempting to reconcile their understanding of depression as both an objective biomedical condition and an understand-

able consequence of social circumstances.²⁰⁻²³ This study has also identified an alternative conceptualization of depression as an action-oriented construct. With a pragmatic focus and no specific ontological stance, this construct circumvents the dilemma of reconciling realist and relativist perspectives.

In this study, depression was considered to have distinctive defining features but also extensive overlaps with other concepts that include an array of emotions, psychological phenomena, and disease manifestations. This manner of conceptualization does not subscribe to a rigid categorical concept of depression, such as the DSM syndrome of Major Depressive Episode. Instead, the participants' conceptualization more closely resembles a prototypical model of depression. This is characterized by a central "theoretical ideal," around which less prototypical cases form a continuum away from the central prototype and boundaries are blurred.^{24,25} Whether a prototypical model of diagnosing psychiatric disorders is preferable to rigid categories is an unresolved debate in the psychiatric literature,^{26,27} and the boundaries between depression and other forms of human distress continue to generate diagnostic tension. For the participants, discerning depression from sadness was a challenging task that may be complicated by contradictory notions of these as separate and merged concepts. The personal negotiation of this entangled relationship between depression and sadness may partly account for diagnostic variance.

Depression was considered to be different in the palliative care setting in two main ways. Firstly, it was seen to be more understandable, which is linked to the concept of depression as an emotional experience, and to the dilemma of conceptualizing depression in reference to sadness. It also suggests a pervading assumption that the processes and circumstances of death and dying are depressogenic. This calls for an examination of the normative ideas about EOL experiences held by medical practitioners, and how these may influence their diagnosis and management of depression in this setting. The second difference in the palliative care setting relates to the concept of *de novo* depression being distinct from

depression that predates the life-limiting illness. The prevalence of depression specific to the palliative care context has been extensively investigated,^{28–31} but whether the nature of depression arising from this setting differs from other settings has not been determined. Although observations have been made on the overlap between depression and cancer-related fatigue,^{32,33} the status of depression as a cancer-specific or paraneoplastic syndrome is uncertain and deserves further study. The etiological and therapeutic distinction of recurrent or persistent depression from *de novo* depression similarly warrants further exploration.

Diversity of language was identified as a challenge. Palliative medicine specialists used different terms for depression, and referred to diagnostic terms used by psychiatrists that held little relevance or meaning for them. The instability of psychiatric nosology has generated much confusion to the understanding of mental disorders,^{34–36} which may hinder the dissemination of psychiatric knowledge and developments outside of the specialty. This may have ramifications for the diagnosis and management of depression in the palliative care setting, because psychiatric input is not routine. Different conceptualizations between psychiatrists and palliative medicine specialists may also compromise the comparability of clinical experience and research between the two specialties.

In interpreting the findings of this study, it is possible that the first author's status as a psychiatrist might have inadvertently influenced interviews; for example, participants might have refrained from criticizing psychiatric concepts. Any influence from the first author's personal concepts of depression on data analysis was minimized by having the co-authors examine codes and the final themes, in view of their different professional backgrounds in palliative medicine (GBC) and psychology (ACH). The focus on interviewing palliative medicine specialists means that the concepts of depression that are held by other professional stakeholders, such as primary care medical practitioners, nurses, social workers, and patients, cannot be established. The findings of this study may not be transferable to other countries where cultures and medical training and practice differ, but should be relevant to countries where these aspects are comparable.

The findings from this study have several practical implications. Firstly, differentiating concepts of depression is clinically relevant, because these may lead to different professional responses. Pathology emphasizes the individual and implies that intervention and correction are required, whereas a contextual perspective emphasizes interactions at the individual and systems levels, and insinuates normalizing and understanding as appropriate responses. A link between conceptualization and professional attitude is supported by a study of medical practitioners and nurses in primary care, which found that all practitioners held a therapeutically nihilistic attitude toward depression in the elderly, in the context of seeing depression in this group as "understandable" and "justifiable."²⁰ However, a link between conceptualization and attitude or practice cannot be established from this study, and this may be a focus for future research. Secondly, the concepts of depression according to palliative medicine specialists do not resemble neat classifications such as the DSM. Instead, they are varied, ontologically heterogeneous, ill-defined, and at times contradictory. As such, depression should never be treated as a unitary concept or an entity in either clinical practice or research. Rather than ignoring the

conceptual ambiguity and difficulties of depression, it would be more helpful to encourage reflection and debates in clinical practice, medical education, and research. In the future, developing a nuanced system that captures the varieties of depression concepts may allow better communication in the clinical setting, as well as provide a framework for more refined management and research. Such a process would need to address the ontological diversity in conceptualization and the conceptual ambiguity between depression and sadness. It should involve relevant specialties such as primary care, palliative medicine, and psychiatry, as well as disciplines outside of medicine, to broaden the scope beyond that of a biomedical model. The design of such endeavors would benefit from further discussions on international platforms. Finally, the significance that is placed on a previous diagnosis of depression needs further consideration in the palliative medicine literature, including an approach to analyzing the nature and rigor of past depression diagnoses.

Acknowledgments

We wish to thank all the participants for their generous input of time and intellectual contributions to this study. We are also grateful to the conference organizers (Will Organise) for their assistance with distributing recruitment notices in the registration packs. We thank Dr. Rajan Nagesh for his helpful comments.

Author Disclosure Statement

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References

1. Lawrie I, Lloyd-Williams M, Taylor F: How do palliative medicine physicians assess and manage depression. *Palliat Med* 2004;18:234–238.
2. Warmenhoven F, van Rijswijk E, van Hoogstraten E, et al.: How family physicians address diagnosis and management of depression in palliative care patients. *Ann Family Med* 2012;10:330–336.
3. Stiefel R, Die Trill M, Berney A, et al.: Depression in palliative care: A pragmatic report from the Expert Working Group of the European Association for Palliative Care. *Support Care Cancer* 2001;9:477–488.
4. Wasteson E, Brenne E, Higginson IJ, et al.: Depression assessment and classification in palliative cancer patients: A systematic literature review. *Palliat Med* 2009;23:739–753.
5. Parker G: Beyond major depression. *Psychol Med* 2005;35:467–474.
6. Leonard M, Spiller J, Keen J, et al.: Symptoms of depression and delirium assessed serially in palliative-care inpatients. *Psychosomatics* 2009;50:506–514.
7. Marchington KL, Carrier L, Lawlor PG: Delirium masquerading as depression. *Palliat Support Care* 2012;10:59–62.
8. Endicott J: Measurement of depression in patients with cancer. *Cancer* 1984;53:2243–2249.
9. Wilson KG, Lander M, Chochinov HM: Diagnosis and management of depression in palliative care. In: Chochinov HM, Breitbart W (eds): *Handbook of Psychiatry in Palliative Medicine, 2nd ed.* New York: Oxford University Press, 2009, pp. 39–68.

10. Akechi T, Nakano T, Akizuki N, et al.: Somatic symptoms for diagnosing major depression in cancer patients. *Psychosomatics* 2003;44:244–248.
11. Mitchell AJ, Lord K, Symonds P: Which symptoms are indicative of DSMIV depression in cancer settings? An analysis of the diagnostic significance of somatic and non-somatic symptoms. *J Affect Disord* 2012;138:137–148.
12. Chochinov HM, Wilson KG, Enns M, et al.: Prevalence of depression in the terminally ill: Effects of diagnostic criteria and symptom threshold judgments. *Am J Psychiatry* 1994;151:537–540.
13. Ng F, Crawford GB, Chur-Hansen A: Palliative medicine practitioners' views on the concept of depression in the palliative care setting. *J Palliat Med* 2013;16:922–928.
14. Braun V, Clarke V: Interactive data collection I: Interviews. In: Carmichael (ed): *Successful Qualitative Research. A Practical Guide for Beginners*. London: SAGE Publications Ltd., 2013, p. 85.
15. Bowen GA: Naturalistic inquiry and the saturation concept: A research note. *Qualitative research* 2008; 8: 137–152.
16. Morse JM: The significance of saturation. *Qualitat Health Res* 1995;5:147–149.
17. Braun V, Clarke V: Using thematic analysis in psychology. *Qualitat Res Psychol* 2006;3:77–101.
18. NVivo Qualitative Data Analysis Software. Version 9 ed. Doncaster: QSR International Pty Ltd., 2011.
19. Guba EG, Lincoln YS: Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS (eds): *Handbook of Qualitative Research*. Thousand Oaks, CA: SAGE, 1994, pp. 105–117.
20. Burroughs H, Lovell K, Morley M, et al.: "Justifiable depression": How primary care professionals and patients view late-life depression? A qualitative study. *Family Practice* 2006;23:369–377.
21. Murray J, Banerjee S, Byng R, et al.: Primary care professionals' perceptions of depression in older people: A qualitative study. *Soc Sci Med* 2006;63:1363–1373.
22. Schumann I, Schneider A, Kantert C, et al.: Physicians' attitudes, diagnostic process and barriers regarding depression diagnosis in primary care: A systematic review of qualitative studies. *Family Practice* 2012;29:255–263.
23. Thomas-MacLean R, Stoppard JM: Physicians' constructions of depression: Inside/outside the boundaries of medicalization. *Health (London)* 2004;8:275–293.
24. Jablensky A: Categories, dimensions and prototypes: Critical issues for psychiatric classification. *Psychopathology* 2005;38:201–205.
25. Zachar P: Psychiatric disorders are not natural kinds. *Philos Psychiatry Psychol* 2000;7:167–182.
26. Wakefield JC: Are you as smart as a 4th grader? Why the prototype-similarity approach to diagnosis is a step backward for a scientific psychiatry. *World Psychiatry* 2012; 11:27–28.
27. Westen D: Prototype diagnosis of psychiatric syndromes. *World Psychiatry* 2012; 11: 16–21.
28. Hotopf M, Chidgey J, Addington-Hall J, et al.: Depression in advanced disease: A systematic review. Part 1. Prevalence and case finding. *Palliat Med* 2002;16:81–97.
29. Lloyd-Williams M, Friedman T: Depression in palliative care patients—a prospective study. *Eur J Cancer Care (Engl)* 2001;10:270–274.
30. Mitchell AJ, Chan M, Bhatti H, et al.: Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: A meta-analysis of 94 interview-based studies. *Lancet Oncol* 2011;12: 160–174.
31. Wilson KG, Chochinov HM, Skirko MG, et al.: Depression and anxiety disorders in palliative cancer care. *J Pain Symptom Manage* 2007;33:118–129.
32. Jacobsen PB, Donovan KA, Weitzner MA: Distinguishing fatigue and depression in patients with cancer. *Semin Clin Neuropsychiatry* 2003;8:229–240.
33. Reuter K, Harter M: The concepts of fatigue and depression in cancer. *Eur J Cancer Care (Engl)* 2004; 13: 127–134.
34. Farmer A, McGuffin P: The classification of the depressions. Contemporary confusion revisited. *Br J Psychiatry* 1989;155:437–443.
35. Galatzer-Levy IR, Galatzer-Levy RM: The revolution in psychiatric diagnosis: Problems at the foundations. *Perspect Biol Med* 2007;50:161–180.
36. van Praag HM: Nosologomania: A disorder of psychiatry. *World J Biol Psychiatry* 2000;1:151–158.

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Journal of Palliative Medicine reviewers' comments on first submitted manuscript

21-Aug-2013

Dear Dr. Ng:

Thank you for submitting manuscript JPM-2013-0378 entitled "How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study" to Journal of Palliative Medicine. The comments of the reviewer(s) are included at the bottom of this letter.

In light of the reviewer's enthusiasm for the manuscript, I would like to tentatively accept your manuscript for publication pending satisfactory revision. Therefore, I invite you to respond to the reviewer(s)' comments and revise your manuscript.

To revise your manuscript, log into <http://mc.manuscriptcentral.com/palliative> and enter your Author Center, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

Please submit your revision by 20-Oct-2013.

You will be unable to make your revisions on the originally submitted version of the manuscript. Instead, revise your manuscript using a word processing program and save it on your computer. Please also highlight the changes to your manuscript within the document by using the track changes mode in MS Word or by using bold or colored text.

Once the revised manuscript is prepared, you can upload it and submit it through your Author Center.

When submitting your revised manuscript, you will be able to respond to the comments made by the reviewer(s) in the space provided. You can use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the reviewer(s).

IMPORTANT: Your original files are available to you when you upload your revised manuscript. Please delete any redundant files before completing the submission.

NOTE: Original Manuscripts may NOT exceed 3,000 words. Submissions over 3,000 words will be returned to the author.

Because we are trying to facilitate timely publication of manuscripts submitted to Journal of Palliative Medicine, your revised manuscript should be uploaded as soon as possible. If it is not possible for you to submit your revision in a reasonable amount of time, we may have to consider your paper as a new submission.

Once again, thank you for submitting your manuscript to Journal of Palliative Medicine and I look forward to receiving your revision.

Sincerely,
Dr. Charles von Gunten
Editor, Journal of Palliative Medicine
charles@pallmed.us, lpelzek@mcw.edu

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

Thank you very much for submitting this fascinating manuscript for publication. Having read the previous paper from your group I was fascinated to see this extension and further exploration articulated.

From my perspective this is a clear and concise study with findings that should interest clinicians worldwide. I thought it a finely crafted piece of writing that sets out the arguments well. It is easy to follow and overall it just makes sense.

I don't have any specific comments to make or corrections to suggest.

Thank you again.

Reviewer: 2

Comments to the Author

This is an interesting and professional publication which outlines and reflects many areas and sets up aspects for future studies.

One problem of this publication is the low number (9) of studies involved, with an average survey time of 60 minutes.

Ultimately, there are many detail issues that remain unanswered or are not dealt with in sufficient detail (p. 12/19).

Contrary to what the article says (p. 9/14) the subject of the publication was addressed previously by e.g. Ng, Crawford and Chur- Hansen 2013.

Corresponding authors' response to reviewers' comments on first submitted manuscript

24th August 2013

Professor Charles F. von Gunten
Editor-in-Chief
Journal of Palliative Medicine
Hospice and Palliative Medicine for OhioHealth
Columbus, Ohio

Dear Professor von Gunten,

Re: Response to Reviewers' comments for manuscript JPM-2013-0378, entitled "How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study"

Thank you for tentatively accepting the above manuscript for publication. My co-authors and I would like to thank the reviewers for their comments, which we have carefully considered. We have made changes to our manuscript (indicated in tracked changes) in response to the comments, and have necessarily adjusted the word count to comply with the word limit of the journal.

The following is our point-by-point response to the reviewers' comments:

"Reviewer: 1

Comments to the Author

Thank you very much for submitting this fascinating manuscript for publication. Having read the previous paper from your group I was fascinated to see this extension and further exploration articulated.

From my perspective this is a clear and concise study with findings that should interest clinicians worldwide. I thought it a finely crafted piece of writing that sets out the arguments well. It is easy to follow and overall it just makes sense.

I don't have any specific comments to make or corrections to suggest.

Thank you again."

We thank Reviewer 1 for his/her encouraging comments.

"Reviewer: 2

Comments to the Author

This is an interesting and professional publication which outlines and reflects many areas and sets up aspects for future studies."

We are heartened that Reviewer 2 believes our study has identified areas that are worthy of future research.

"One problem of this publication is the low number (9) of studies involved, with an average survey time of 60 minutes."

The number of interviews sufficient in qualitative research is an ongoing topic of active discussion among qualitative researchers, and conventional wisdom considers the quality of the data and the time and care taken in data analysis to be more important than sample size, which is a quantitative research concept.[258] In the qualitative methodology literature, data saturation using purposive sampling is regarded as the gold standard of methodological rigour.[147] We have utilised this principle in the conduct of our study, and have reached data saturation at 9 interviews. Although sample size is not a central consideration in qualitative research, an empirical methodological study suggested that data saturation was reached between 6-12 interviews,[259] which is consistent with our experience in this study. The relatively tightly defined participant group and topic domains would suggest that data saturation could be reached sooner.[147] This was evident in our study, during which we densely coded all interview transcripts, because the data were highly relevant to the research question. Therefore, we are confident that this study satisfies criteria of methodological rigour as recommended in qualitative research guidelines, and we do not consider the number of interviews to be a problem.[142,159] We have added a definition of data saturation and two references that address the issues of constant comparison and data saturation.

“Ultimately, there are many detail issues that remain unanswered or are not dealt with in sufficient detail (p. 12/19).”

We cannot specifically address this comment without knowing the kinds of details that Reviewer 2 has in mind. However, as previously noted, the findings of this study identify further areas for future research, and these areas are discussed in the paper.

“Contrary to what the article says (p. 9/14) the subject of the publication was addressed previously by e.g. Ng, Crawford and Chur- Hansen 2013”

The referenced paper referred to by Reviewer 2 is our previous research on the topic, which we have cited in this paper. Our earlier paper used a different methodology (questionnaire), which was limited in its ability to explore how palliative medicine specialists conceptualised depression. The current paper extends from that earlier paper, and yields new findings that do not exist in the current literature. We are unable to identify any contrary statements relating to this issue in the current paper.

We appreciate the opportunity to submit a revision of our paper, and hope to hear from you in the near future.

Yours sincerely

—

Felicity Ng (Corresponding Author)
Psychiatrist, Northern Mental Health Service & Northern Adelaide Palliative Care Service, Adelaide
Senior Lecturer, Medicine Learning and Teaching Unit, School of Medicine, University of Adelaide

Journal of Palliative Medicine reviewers' comments on revised manuscript

06-Sep-2013

Dear Dr. Ng:

Thank you for submitting manuscript JPM-2013-0378.R1 entitled "How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study" to Journal of Palliative Medicine. The comments of the reviewer(s) are included at the bottom of this letter.

In light of the reviewer's enthusiasm for the manuscript, I would like to tentatively accept your manuscript for publication pending satisfactory revision. Therefore, I invite you to respond to the reviewer(s)' comments and revise your manuscript.

To revise your manuscript, log into <http://mc.manuscriptcentral.com/palliative> and enter your Author Center, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

Please submit your revision by 05-Nov-2013.

You will be unable to make your revisions on the originally submitted version of the manuscript. Instead, revise your manuscript using a word processing program and save it on your computer. Please also highlight the changes to your manuscript within the document by using the track changes mode in MS Word or by using bold or colored text.

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When submitting your revised manuscript, you will be able to respond to the comments made by the reviewer(s) in the space provided. You can use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the reviewer(s).

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NOTE: Original Manuscripts may NOT exceed 3,000 words. Submissions over 3,000 words will be returned to the author.

Because we are trying to facilitate timely publication of manuscripts submitted to Journal of Palliative Medicine, your revised manuscript should be uploaded as soon as possible. If it is not possible for you to submit your revision in a reasonable amount of time, we may have to consider your paper as a new submission.

Once again, thank you for submitting your manuscript to Journal of Palliative Medicine and I look forward to receiving your revision.

Sincerely,
Dr. Charles von Gunten
Editor, Journal of Palliative Medicine
charles@pallmed.us, lpelzek@mcw.edu

Reviewer(s)' Comments to Author:

Reviewer: 2

Comments to the Author

(a) "One problem of this publication is the low number (9) of studies involved, with an average survey time of 60 minutes."

05-Sep-2013--I am satisfied with your solution.

(b) "Ultimately, there are many detail issues that remain unanswered or are not dealt with in sufficient detail (p. 12/19)."

....We cannot specifically address this comment without knowing the kinds of details that Reviewer 2 has in mind.....

05-Sep-2013--

E.g. How should such a consistent system (p. 12) be designed/implemented in concrete terms?

E.g. How and in what form should input from relevant specialties be integrated in concrete terms?

If the matter is not material at this point, it might/should be addressed in detail in another publication. In my opinion, colleagues and experts from all over the world would be highly interested.

(c) "Contrary to what the article says (p. 9/14) the subject of the publication was addressed previously by e.g. Ng, Crawford and Chur- Hansen 2013".

05-Sep-2013--The problem in this case is your use of the term palliative medicine specialists which does not have the same meaning everywhere in the world (consultant, diploma after professional development, etc.).

Corresponding author's response to reviewers' comments on revised manuscript

9th September 2013

Professor Charles F. von Gunten
Editor-in-Chief
Journal of Palliative Medicine
Hospice and Palliative Medicine for OhioHealth
Columbus, Ohio

Dear Professor von Gunten,

Re: Response to Reviewer's comments for manuscript JPM-2013-0378.R1, entitled "How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study"

We are appreciative of Reviewer 2's further thoughtful comments, and are pleased to have the opportunity to respond to them. Reviewer 2 raised two main issues: (1) details of future projects that may stem from this study; and (2) the meaning of the term "palliative medicine specialists". We will address each of these in turn below.

"(b) "Ultimately, there are many detail issues that remain unanswered or are not dealt with in sufficient detail (p. 12/19)."

...We cannot specifically address this comment without knowing the kinds of details that Reviewer 2 has in mind....

05-Sep-2013—

E.g. How should such a consistent system (p. 12) be designed/implemented in concrete terms?

E.g. How and in what form should input from relevant specialties be integrated in concrete terms?

If the matter is not material at this point, it might/should be addressed in detail in another publication. In my opinion, colleagues and experts from all over the world would be highly interested."

We agree with Reviewer 2 that the findings of this study generate multiple lines for potential future research and debates, but detailed discussions about future philosophical and research undertakings are beyond the scope of the current paper. The development of a classification system is a complex process, which will require international and multidisciplinary engagement, as well as refinement through empirical testing of its clinical utility. We hope that this study may stimulate further discussions and research in this field. We have added a sentence in the last paragraph of the discussion section, stating that the design of future projects would benefit from further international discussions.

"05-Sep-2013--The problem in this case is your use of the term palliative medicine specialists which does not have the same meaning everywhere in the world (consultant, diploma after professional development, etc.)."

We thank the Reviewer for pointing out this potential source of confusion for international readers, and have rectified this by clarifying in both the Abstract and in the Methods section that “palliative medicine specialists” in this study means consultants/attending physicians in palliative medicine.

All changes are highlighted using the Word Track Changes function. Because of the addition of text, we have made minor changes to the manuscript in order to comply with the word limit.

Thank you for the opportunity to submit a revision of this paper, and we hope to hear from you in the near future.

Yours sincerely

✍

Felicity Ng (Corresponding Author)

Psychiatrist, Northern Mental Health Service & Northern Adelaide Palliative Care Service, Adelaide

Senior Lecturer, Medicine Learning and Teaching Unit, School of Medicine, University of Adelaide

Journal of Palliative Medicine's decision letter

16-Oct-2013

Dear Dr. Ng:

It is a pleasure to accept your manuscript entitled "How do palliative medicine specialists conceptualise depression? Findings from a qualitative in-depth interview study" in its current form for publication in Journal of Palliative Medicine.

Please be sure to cite this article to ensure maximum exposure of your work.

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Thank you for your fine contribution. On behalf of the Editors of Journal of Palliative Medicine, we look forward to your continued contributions to the Journal.

Sincerely,
Dr. Charles von Gunten
Editor, Journal of Palliative Medicine
charles@pallmed.us, lpelzek@mcw.edu

Appendix J Paper 3: Palliative Medicine Specialists' Causal Explanations for Depression in the Palliative Care Setting: a Qualitative In-depth Interview Study

Citation:

Ng F, Crawford GB, Chur-Hansen A. Palliative medicine specialists' causal explanations for depression: a qualitative in-depth interview study. *BMJ Supportive & Palliative Care* Published Online First: 28 April 2014. DOI: 10.1136/bmjspcare-2013-000626



Palliative medicine specialists' causal explanations for depression in the palliative care setting: a qualitative in-depth interview study

Felicity Ng, Gregory B Crawford and Anna Chur-Hansen

BMJ Support Palliat Care published online April 28, 2014
doi: 10.1136/bmjspcare-2013-000626

Updated information and services can be found at:
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	<i>These include:</i>
References	This article cites 27 articles, 6 of which can be accessed free at: http://spcare.bmj.com/content/early/2014/04/28/bmjspcare-2013-000626.full.html#ref-list-1
P<P	Published online April 28, 2014 in advance of the print journal.
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Ng, F., Crawford, G.B. & Chur-Hansen, A. (2014) Palliative medicine specialists' causal explanations for depression in the palliative care setting: a qualitative in-depth interview study. *BMJ Supportive and Palliative Care*, v. 5(4), pp. 433-456

NOTE:

This publication is included on pages 255-262 in the print copy of the thesis held in the University of Adelaide Library.

BMJ Supportive & Palliative Care reviewers' comments on first submitted manuscript

07-Mar-2014

Dear Dr. Ng,

Manuscript ID bmjpcare-2013-000626 entitled "Palliative medicine specialists' causal explanations for depression in the palliative care setting: A qualitative in-depth interview study" which you submitted to BMJ Supportive & Palliative Care, has been reviewed.

The reviewers have suggested some revisions to your manuscript. Their comments are included at the bottom of this letter. We invite you to respond to the reviewers' comments and make changes recommended by reviewer 2. We would prefer you not to change to major depression indicated by reviewer 1. Please revise your manuscript accordingly.

To revise your manuscript, log into <http://mc.manuscriptcentral.com/bmjpcare> and enter your Author Center, where you will find your manuscript title listed under "Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

Please check that all author names are correctly entered as this will be the name displayed in any PubMed search.

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When submitting your revised manuscript, you will be able to respond to the comments made by the reviewer(s) in the space provided. You can use this space to document any changes you make to the original manuscript. In order to expedite the processing of the revised manuscript, please be as specific as possible in your response to the reviewer(s).

You will receive a proof if your article is accepted, but you will be unable to make substantial changes to your manuscript, please take this opportunity to check the revised submission carefully.

IMPORTANT: Your original files are available to you when you upload your revised manuscript. Please delete any redundant files before completing the submission.

Because we are trying to facilitate timely publication of manuscripts submitted to BMJ Supportive & Palliative Care, your revised manuscript should be submitted by 06-Apr-2014. If it is not possible for you to submit your revision by this date, we may have to consider your paper as a new submission.

We also ask that in addition to the revised paper you provide a point by point response to the reviewer comments, and upload a marked copy of your paper highlighting the changes you have made - preferably 'tracked changes' if using Microsoft word. Please upload this as a supplemental file and label it 'Marked Copy' (your paper will not be able to be processed without this).

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Please list Competing Interests if they exist if not please include the following statement; Competing Interest: None declared.

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I hope you will find the comments useful.

Best wishes,

Bill Noble

Editor in Chief, BMJ Supportive & Palliative Care

bill.noble@sheffield.ac.uk

Reviewers' Comments to Author:

Reviewer: 1

Comments to the Author

This is a nicely written overview of the aetiological theories of major depressive disorder. My reservation is the use of the term 'depression' a term that has a different lay meaning to professional meaning and is frequently used 'loosely' - I would prefer it be altered in the article to 'Major Depression' as this is the disorder they are writing of.

Reviewer: 2

Comments to the Author

This is a really interesting and important addition to the current body of work in this area. It's incredibly useful to develop an understanding of clinicians' causal explanations given the link between conceptualisation and management approaches. It is also interesting to see how

these differ between clinicians and across services.

The only 2 things to note is to elaborate on some methodological areas. Namely:

1) A more detailed explanation of how "co-authors verified themes and coding against data". For example, were all codes and themes generated independently and then verified or did one researcher generate all codes/themes, which were then discussed as a team? How were disagreements or discrepancies managed?

2) Just some further information on the nature of the interview would be helpful. I think the reader would benefit from knowing, for example, whether a topic guide was used or whether just an initial question was asked and the interview was then led entirely by the participant. An example topic guide or prompt questions could be included but this isn't vital.

Those 2 minor points aside I would like to thank the authors for a thoroughly interesting examination of clinicians' views on the causality of depression in their patients, and a very insightful critique of these and implications thereof.

Corresponding author's response to reviewers' comments on first submitted manuscript

10th March 2014

Dr Bill Noble
Editor-in-Chief
BMJ Supportive & Palliative Care
University of Sheffield
Sheffield, UK

Dear Dr Noble,

Re: Response to Reviewers' comments on manuscript ID bmjpscare-2013-000626 entitled "Palliative medicine specialists' causal explanations for depression in the palliative care setting: A qualitative in-depth interview study"

My co-authors and I are appreciative of the reviewers' thoughts on our paper, and are encouraged to receive their feedback on its relevance to the area of depression/palliative care research. Our response to their comments is detailed below.

*Reviewers' Comments to Author:
Reviewer: 1*

Comments to the Author

This is a nicely written overview of the aetiological theories of major depressive disorder. My reservation is the use of the term 'depression' a term that has a different lay meaning to professional meaning and is frequently used 'loosely' - I would prefer it be altered in the article to 'Major Depression' as this is the disorder they are writing of.

We have followed your recommendation not to alter the term "depression" to "Major Depression" in this paper. Major Depression is only one clinical definition of depression according to the DSM classification, and the purpose of this study was to explore how palliative medicine specialists understood the causal mechanisms of depression in general, not only confined to Major Depression. We have therefore deliberately used the term "depression" without further specification other than the clinical usage of the term. This rationale was included in an earlier publication, which we referenced in this paper.[186] However, Reviewer 1's comment has highlighted to us the importance to emphasize this point to readers, and we have accordingly added the following sentence in the Methods section of this manuscript: "As different understandings of depression were assumed, the term "depression" was used in interviews with the only specification being the clinical usage of the term."

Reviewer: 2

Comments to the Author

This is a really interesting and important addition to the current body of work in this area. It's incredibly useful to develop an understanding of clinicians' causal explanations given the link between conceptualisation and management approaches. It is also interesting to see how these differ between clinicians and across services.

*The only 2 things to note is to elaborate on some methodological areas. Namely:
1) A more detailed explanation of how "co-authors verified themes and coding against data". For example, were all codes and themes generated independently and then verified or did one researcher generate all codes/themes, which were then discussed as a team? How were disagreements of discrepancies managed?*

In the Methods sections, we have added the following details in relation to the verification process during data analysis: “To enhance trustworthiness of the findings, both co-authors (ACH and GBC) verified the codes generated from the first fully coded transcript against the raw data, and one co-author (ACH) also verified the final themes against the raw data in all transcripts. Differences arising from this process were discussed among all authors to reach consensus.”

2) Just some further information on the nature of the interview would be helpful. I think the reader would benefit from knowing, for example, whether a topic guide was used or whether just an initial question was asked and the interview was then led entirely by the participant. An example topic guide or prompt questions could be included but this isn't vital.

Those 2 minor points aside I would like to thank the authors for a thoroughly interesting examination of clinicians' views on the causality of depression in their patients, and a very insightful critique of these and implications thereof.

We have added the following two sentences in relation to the interviewing process: “An interview guide was used, which included key content areas of the concepts of depression, its causality and pathogenetic mechanisms, timing and onset of symptoms, course and treatment. Participants were given freedom to speak on these areas as well as other emergent areas relevant to the topic.” As some of this information was described in the earlier published paper,[186] we have emphasised this at the beginning of the Methods section in case readers have other queries about the methodology: “As the methodology has already been described elsewhere,[186] readers are referred to the earlier source for details on recruitment, data collection and analysis. A summary is provided below.”

In addition to the above specific additions, we have also made minor changes to correct misspellings and grammar, and to ensure that all journal references are consistent in format. All changes made to the manuscript are highlighted using the Word Track Changes function.

Thank you very much for the opportunity to submit a revision of this manuscript, and we look forward to your further response.

Yours sincerely

✍

Felicity Ng (Corresponding Author)
Psychiatrist, Northern Mental Health Service & Northern Adelaide Palliative Care Service,
Adelaide
Senior Lecturer, Medicine Learning and Teaching Unit, School of Medicine, University of
Adelaide

BMJ Supportive & Palliative Care's decision letter

06-Apr-2014

Dear Dr. Ng,

Manuscript ID bmjspcare-2013-000626.R1 - Palliative medicine specialists' causal explanations for depression in the palliative care setting: A qualitative in-depth interview study

We are pleased to accept your article for publication in BMJ Supportive & Palliative Care.

Your paper will be now sent for editing and typesetting and you will receive a proof to check in about 10 days; please check your junk mail if you have not received your proof within this time, in case the automatic email goes there.

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If you have any questions, please contact me, quoting the manuscript ID.

Best wishes,

Bill Noble,
Editor-In-Chief
BMJ Supportive & Palliative Care.

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Appendix K List of presentations undertaken during PhD candidature

Oral presentations

Conference

Australian and New Zealand Society of Palliative Medicine (ANZSPM) Conference, Adelaide, 16th September 2010.

Abstract: Ng F. The concept of “depression” in the palliative care setting. *J Palliat Med* 2011; 14: A14

University of Adelaide

Discipline of Psychiatry Postgraduate Research Seminar, University of Adelaide, Adelaide, 16th March 2011

Title of presentation: The concept of depression in palliative care

Health Services

Lyell McEwin Palliative Care Service Education Forum, Lyell McEwin Health Service, SA Health, Adelaide, 20th December 2010

Title of presentation: The concept of depression in the palliative care setting

Older Persons Mental Health Service Education Forum, Glenside Campus, SA Health, Adelaide, 24th June 2011

Title of presentation: The concept of depression in palliative care

Northern Adelaide Palliative Care Service Registrar Education Forum, Modbury Public Hospital, SA Health, Adelaide, 24th January 2014

Title of presentation: The concepts of depression

2014 Palliative Care Week Medical Grand Round, Modbury Public Hospital, SA
Health, Adelaide, 28th May 2014

Title of presentation: “Depression” in the palliative care setting: what does it mean?

Poster presentation

The 18th International Congress on Palliative Care, Montreal, 5-8 October 2010.

Title: What does “depression” mean in the palliative care context?