

UNIVERSITY OF SYDNEY
FACULTY OF MEDICINE

**Enhancing Existential and Spiritual Care for Palliative Care Patients
from both the Patient and Nurse Perspective**

This thesis is submitted in fulfilment of the requirements
for the degree of Doctor of Philosophy



Robyn Marie Keall

RN, Grad. Dip. Palliative Care, Grad. Cert. Oncological Nursing,
Master of Science (Nursing), Master of Nursing (Nurse Practitioner)

Supervisors

Professor Phyllis Butow, Centre for Medical Psychology and Evidence-based
Decision-making, School of Psychology, University of Sydney

Associate Professor Josephine Clayton, Northern Clinical School, University of
Sydney and HammondCare Palliative and Supportive Care Service, Greenwich
Hospital, Sydney.

MAY 2014

ABSTRACT

Existential and spiritual care has been identified as an important but often undertreated area in palliative care patients. Providing holistic care to patients with life limiting illnesses is challenging due to the need to triage symptoms, lack of time, lack of skills and confidence and difficulty assessing and defining concerns. Therapeutic life review interventions are a type of intervention which can assist with addressing existential/spiritual concerns, an example of which is the Outlook intervention. Outlook intervention is conducted over three sessions which focus on; session one- life review, session two- forgiveness for self and others and session three- legacy and heritage for future generations. Traditionally such interventions are carried out by psychosocial health professionals who may not always be available. Nurses may be well placed to deliver interventions such as Outlook. However, the feasibility of this needs to be examined.

The first aim of this thesis was to critically appraise the literature on therapeutic life review interventions in the palliative care setting. A systematic review of the literature was conducted and the following conclusions were drawn: there are few studies evaluating therapeutic life review interventions although the results are promising. These interventions vary in their duration, frequency and complexity, but most can be conducted with patients in their last days to weeks of life with low levels of functioning.

The second aim of the thesis was to explore the efficacy and feasibility of a nurse-facilitated therapeutic life review intervention, Outlook, in the Australian palliative care population. Eleven patients participated in a pilot study; the intervention was found to be feasible and acceptable. Non-significant improvements were found in the domains of finding meaning/peace in life and life completion. The Outlook intervention participant interviews were subjected to qualitative analysis and three overarching themes were identified: 1) life review, 2) current situation and 3) legacy/principles. These results fulfilled the third aim, which was to explore the perceptions that individuals with life-limiting illnesses have about their lives, both positive and negative, and their messages to future generations.

The fourth aim was to understand how Australian palliative care nurses address existential/spiritual concerns with their patients and the fifth aim was to explore the nurses' experiences with and views on existential/spiritual interventions in general and Outlook in particular. These aims were met by conducting semi-structured interviews with twenty Australian palliative care nurses from a variety of backgrounds. Results included identification of facilitators, barriers and strategies that the nurses used in their current practice when providing holistic care. In regards to existential/spiritual intervention usage,

results demonstrated that the nurses had limited or no experience. However, they positively appraised Outlook as providing a framework, being challenging but important, being beneficial for the bereaved and being beneficial for the nurse/team. The nurses also identified potential concerns in implementation and possible modifications to overcome the difficulties so that Outlook may be conducted as part of their practice.

In summary, life review interventions are a promising addition to palliative care practice, requiring a stronger evidence-base before routine implementation can be justified. Nurses may be the most feasible staffing group to deliver these interventions, but would require additional training, support and possibly a different model of care delivery.

PRESENTATION OF THESIS

This thesis is presented as a combination of 1 systematic review and 4 published papers. The review and papers describe the methods, results and discussion of the three research projects undertaken in this candidature. Chapter 1 provides the introduction to the field of palliative care and the concerns of palliative care patients, in particular those in the existential/spiritual domain, interventions to address these concerns and the role of the nurse in providing appropriate care for those concerns. Chapters 2- 6 contain the following manuscripts. The candidate is the principal author for each of the papers.

Chapter 2: 'Therapeutic life review in palliative care: a systematic review of quantitative evaluations.' In press Journal of Pain and Symptom Management.

Chapter 3: 'Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care setting: results from a phase 2 trial' Published in Cancer Nursing (2013; 36 (3) E39-46)

Chapter 4: 'Discussing life story, forgiveness, heritage, and legacy with patients with life-limiting illnesses.' Published in International Journal of Palliative Nursing (2011; 17 (9): 454-460)

Chapter 5: 'Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions.' Published in Journal of Hospice & Palliative Nursing (2014; 16 (2): 105-112)

Chapter 6: 'How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies.' In press Journal of Clinical Nursing

Chapter 7 provides the summary and conclusions of the research undertaken and further research directions.

PUBLICATIONS

Keall, RM, Butow, PN, Steinhauser, KE & Clayton, JM (2011) Discussions with patients with life-limiting illnesses about their life story, forgiveness, heritage and legacy: qualitative results from an acceptability and feasibility study, *International Journal of Palliative Nursing*, 17(9) 454-460.

Keall, RM, Butow, PN, Steinhauser, KE, & Clayton, JM (2012) Nurse facilitated preparation and life completion interventions are acceptable and a phase II trial, *Cancer Nursing*, 36 (3), E39

Keall, RM, Butow, PN, Clayton, JM. (2014) Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions. *Journal of Hospice and Palliative Nursing*, 16(2) 105- 112

Keall, RM, Butow, PN, Clayton, JM. (2014) How do Australian Palliative Care nurses address patients' existential/spiritual concerns? Facilitators, barriers and strategies. *Journal of Clinical Nursing*, in press

Keall, RM, Butow, PN, Clayton, JM. (2014) Therapeutic life review in palliative care: a systematic review of quantitative evaluations. *Journal of Pain and Symptom Management*, in press

PRESENTATIONS

- November, 2013 ‘How do Australian Palliative Care nurses address existential and spiritual concerns? Facilitators, barriers and strategies.’
Oral presentation: IPOS 15th World Congress, Rotterdam, Netherlands
- September, 2013 ‘How do Australian Palliative Care nurses address existential and spiritual concerns? Facilitators, barriers and strategies.’
Oral presentation: 12th Australian Palliative Care conference, Canberra
- August, 2013 ‘How do Australian Palliative Care nurses address existential and spiritual concerns? Facilitators, barriers and strategies.’
Hammond Care, Greenwich
- November, 2012 ‘Enhancing existential and spiritual care for palliative care patients- the use of life stories’
Oral presentation: Making every Moment Matter: Palliative Care Perspectives on Ageing Seminar
- March, 2012 ‘Psychological Concerns in Palliative Care’
Palliative Care Essentials, Hammond Care
- August, 2010 ‘Enhancing existential and spiritual care for patients with life limiting illnesses: results from a phase II trial’
Oral presentation: 3rd Biennial Australian Palliative Care Nurses Australia Conference, Brisbane

STATEMENT OF AUTHENTICATION

This thesis is submitted to the University of Sydney in fulfilment of the requirement is for the Degree of Doctor of Philosophy.

The work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

Signature: ...  Date:23rd May, 2014.....

ACKNOWLEDGMENTS

I would like to express my deepest gratitude to my husband, Paul who has supported me wholeheartedly, encouraging me in my moments of doubt and patiently reading my attempts at academic writing. He has learnt more about existential and spiritual concerns than any physicist should need to know. I am delighted that my wonderful children Naomi, Billy and Rory have not left home before I finished and may be inspired to continue lifelong learning, they have taught me how to truly multi-task. I am inspired by my mum and dad who even in retirement continue to seek new adventures and challenges and I guess that they are pleasantly surprised that their reluctant student has actually completed a PhD. I also wish to thank my gorgeous friends Alison, Gill, Margaret- Ann and Suzette who have dragged me away for girls weekends to make me laugh and to keep my sanity.

I am grateful to the patience, encouragement and generosity of time given to me by my supervisors Professor Phyllis Butow and Associate Professor Josephine Clayton. Together they have guided my research path, edited my manuscripts and provided steady advice about academic writing and procedures. The combination of medicine (JC) and psychology (PB) work well together giving a more rounded approach than a single discipline can provide. Under their guidance I have learnt how to write more clearly, using a 'funnel' approach and to get a good flow. I am still working on the grammar, a work in progress. I feel I can now understand the literature better and to think in a more critical way. I am amazed at my supervisors' ability to focus on my work and see the big picture whilst overseeing so many other projects and commitments.

I have been assisted by several people in my research projects including Judy Hood who transcribed the participant and nurse interviews, most famously mishearing a woman saying to her son 'you are too good for this lowly, rotten world' to be 'you are too good for this slowly, rotting bird'. Thanks to Angela Robl who helped design the recruitment flyers and questionnaires for the Outlook project and to Kelly Arthurs who recruited patients for the Outlook intervention and to Sharon Wiley and Theresa Pot for spreading the word to help with recruitment of the nurse participants. Thank you also to Alison Hession for assisting with the systematic review. I am grateful to the patients and nurses who partook in my research studies and am privileged to have heard their stories, I hope I have reported them correctly.

I have been extremely fortunate in my work life to be identified by Jane Connolly, Nurse Manager of Neringah and Greenwich hospitals who offered me my current position with hours to suit my family and to complete this PhD. I have been surrounded by many nursing role models including Sharon Wiley, Gail Scott, Gerry Dixon, Peta McVey, Kelly Arthurs, Gay Lavery and Karen Eaton who have shown me how to combine compassion, ability, common

sense and humour. I also have Gerry and Peta to thank for introducing me to Associate Professor Clayton when searching for a project and through that meeting to meet Professor Butow and to have collaboration from Associate Professor Steinhauser on her intervention, Outlook. In short starting this whole journey off. I have also been blessed to have the support of Julie Miles, Director of Nursing of Greenwich hospital during this PhD candidature and my Masters in Nursing (Nurse Practitioner) which I completed in 2013 during which I was capably mentored by Drs Ruth Powys, Kat Urban and Melanie Lovell.

Going forward, I hope to be able to combine my research skills with my nursing ability and promote, improve and validate what nurses do so well, provide holistic care.

TABLE OF CONTENTS

ABSTRACT	ii
PRESENTATION OF THESIS	iv
PUBLICATIONS AND PRESENTATIONS.....	v
STATEMENT OF AUTHENTICATION.....	vii
ACKNOWLEDGMENTS.....	viii
TABLE OF CONTENTS.....	x
LIST OF APPENDICES.....	xi
CHAPTER 1: Literature Review and Introduction to Thesis	1
CHAPTER 2: Therapeutic life review in palliative care: a systematic review of quantitative evaluations	29
CHAPTER 3: Nurse-Facilitated Preparation and Life Completion Interventions are Acceptable and Feasible in the Australian Palliative Care Setting: Results from a Phase 2 Trial	56
CHAPTER 4: Discussing Life Story, Forgiveness, Heritage and Legacy with Patients with Life-Limiting Illnesses	65
CHAPTER 5: Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions	73
CHAPTER 6: How do Australian Palliative Care Nurses Address Existential and Spiritual Concerns? Facilitators, Barriers and Strategies	82
CHAPTER 7: Summary and Conclusion	92
APPENDIX I	102
APPENDIX II.....	108
APPENDIX III	119
APPENDIX IV	126
APPENDIX V	139
APPENDIX VI	145

LIST OF APPENDICES

- I Signed statements from the co-authors of the four articles and one manuscript that form part of the body of this thesis, stating each authors' contribution
- II Examples of recruitment flyers, participant information sheets and consent forms for Outlook intervention pilot study
- III Examples of Outlook intervention questions and prompt card information given to participants as part of the Outlook intervention pilot study
- IV Participant questionnaires for the Outlook intervention pilot study
- V Examples of recruitment flyers, participant information sheets and consent forms for nurse interviews
- VI Participant questionnaires for the palliative care nurse interviews

CHAPTER 1

Literature Review and Introduction to Thesis

CHAPTER 1

Introduction and literature review

What is palliative care?

Palliative care 'is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families' (World Health Organisation, 2013). The word 'palliate' means to cloak, in essence covering, embracing and comforting, not delving for the cause but easing the effects of the incurable, underlying disease. Palliative Care Australia explains further that palliative care is 'interdisciplinary care, delivered by coordinated medical, nursing, allied health and social services and integrating the physical, psychological, social and spiritual aspects of care. It recognises the patient and family as the unit of care, and respects the right of each patient to make informed choices about the care they receive. It offers, through a mixture of specialist and primary care providers, as well as community partnerships, a support system to help people live as actively and as well as possible until death. Palliative care also plays an important role in helping the family cope during the patient's illness and in their own bereavement' (Palliative Care Australia, 2003).

The arguments for palliative care.

One difficulty faced by proponents of palliative care is the ability to prove superiority of care through rigorous research. This is in part due to the frailty of the patients and the subsequent high rates of attrition which reduce the power of a study along with methodological errors. Of the few strong quality randomised control trials, there is evidence that palliative care improves family satisfaction with care, increases patients' quality of life and results in cost savings (Zimmermann, Riechelmann, Krzyzanowska, Rodin, & Tannock, 2008).

One recent, robust study of palliative care, in particular early intervention palliative care, has been found to not only improve quality of life and mood but also able to prolong survival. Temel *et al.* randomly assigned 151 recently diagnosed non-small cell lung cancer patients, with an average survival of 1 year, to either usual oncological care or integrated oncological and palliative care. The authors found the patients in the integrated care arm had better quality of life as measured by the Functional Assessment of Cancer Therapy- Lung (intervention group 98.0,

control 91.5, $P= 0.03$), fewer depressive symptoms (intervention group 16%, control 37%, $P= 0.01$) and length of survival (intervention group mean of 11.6 months, control 8.9 months, $P= 0.02$) (Temel et al., 2010).

Besides a strong rationale in terms of patient and caregiver outcomes, palliative care can also contribute to ensuring fiscal responsibility in the delivery of healthcare. Appropriately choosing palliative care over acute care can be both beneficial to the patient and the healthcare budget. Reduction in unnecessary interventions and laboratory tests and shortened acute hospital bed stays provide financial savings to institutions. Inpatient mechanical ventilation, for example, costs \$20 billion per year in the US alone with high rates of mortality, ongoing rehabilitation and re-hospitalization. A study of patients treated by prolonged mechanical ventilation showed that by closer scrutiny to the co-morbidities and advanced age of the patients and the known high morbidity and poor outcomes, savings of up to \$80,000 and savings in quality life years could be obtained by using comfort care instead (Cox, Carson, Govert, Chelluri, & Sanders, 2007).

Who needs palliative care globally?

Palliative care is a global issue; 56 million people die annually worldwide. Many of these deaths are expected and preceded by a chronic debilitating illness, women on average experiencing three years and men two years of an incurable disease. Chronic illness and cancers increase with age and it is estimated that by 2030 in the Western world the old will outnumber the young (Kuebler, 2003). It is not only the 56 million deceased who are affected or in need of palliative care but in addition a conservative estimate of five persons per death, which include children, parents, siblings and friends. This addition brings the amount of people affected annually by death to 300 million or about 5% of the world's population (Singer & Bowman, 2002).

Not all deaths will require palliative care involvement. Expected deaths from cancer and non-malignant illnesses can be sub-divided into 3 groups of care requirement 1) assessment only or no specialist palliative care involvement, with care provided by the patient's general practitioner and/or community nurses 2) sporadic specialist palliative care involvement with majority of care by generalist team or 3) ongoing high levels of need by specialist palliative care services (see table 1). (Palliative Care Australia, 2005).

Table 1: Estimation of palliative care level of involvement

Level of palliative care	Cancer death	Non-Cancer death
Assessment	90%	50%
Ongoing consultation	70%	30%
Direct care	20%	10%

Palliative care in Australia versus the world

The World Health Organization has advised that anyone in need of palliative care should have access to it, and that provision for palliative care should be included in every governmental health policy (World Health Organization, 1990). Furthermore, there are many who believe that palliative care should be a part of public health, along with prevention, screening and early intervention (Faull, Carter, & Daniels, 2005).

It is difficult to ascertain exact numbers for palliative care services as these are dependent on a workforce and sustained support which can vary. However the presence of provision of palliative care within governmental policy and legislation can help understand the acceptance and priority within a country. A recent survey of seven European countries found that all had a national and/or regional health policy plan outlining development and integration of palliative care services, which was either part of a cancer service planning policy or solely regarding palliative care, all had at least one national palliative care organisation and the right to palliative care was an explicit law in Belgium, Germany and France (Van Beek et al., 2013).

Additionally the International Observatory of end-of-life care has been classifying and mapping palliative care provision throughout the world. Countries are classified as having 'no known activity', 'capacity building', 'localized provision' or 'approaching integration'. Of the 234 countries reviewed only 34 were classed as 'approaching integration'. This included Australia and the USA, most Western European and some Asian countries. Eighty countries met the 'localised provision' criteria including many Asian, some smaller European and South American countries. Forty-one countries were classed as 'capacity building', this included many African and some Middle Eastern countries. Seventy-eight countries were found to have 'no known' palliative care services, this included many smaller island nations and the remaining African countries (Clark & Wright, 2007). In a more detailed study of 47 African countries' access to hospice and palliative care services found 21 countries had no services at all, 11 were building up their services, 11 had well-established services often supported by external entities but only

four had integrated services which were supported by the government through funding, policy and legislation (Clark, Wright, Hunt, & Lynch, 2007). These results are quite startling considering that it is the developing world where 80% of the 56 million deaths occur, especially those affected by HIV/AIDS (Singer & Bowman, 2002) and 70% of the estimated 84 million cancer deaths in the next ten years will occur (World Health Organization, 2007).

Closer to home, our neighbour New Zealand has a national palliative care strategy which provides direction for the population which is spread out over the two main islands. The majority of palliative care is provided by community nursing services and general medical practitioners plus or minus support from a hospice based team. There are approximately 37 hospice and palliative care services nationally, 19 of which provide inpatient resulting in between 0.64 -7.73 hospice beds per 100 000 citizens dependent on the variable population density. Whilst these services are open to both malignant and non-malignant diseases, 90% of the patients served have a cancer diagnosis (MacLeod, 2001).

Palliative care services in Australia are guided by a national strategy and there are in excess of 250 specialist services (Australian Government Department of Health, 2000). These specialist services can be provided as 1) a consultancy service e.g. as part of a tertiary hospital, outpatients service, 2) a community out-reach service through a series of networks with general services, residential aged care facilities and patients' homes or 3) as a direct provision service e.g. hospice or dedicated inpatient unit (Carrow, 2002). Ideally palliative care is accessible 24 hours a day, 7 days a week, either face-to-face or more commonly via telephone support. However this is not reality for many areas of Australia, in particular rural and remote areas despite evidence of affordability, feasibility and efficacy (Phillips, Davidson, Newton, & DiGiacomo, 2008).

Despite having in many ways a well-developed palliative care system in Australia, there is still a wide gap between the need for and provision of services. With an estimated 130,000 deaths per annum, palliative care specialist services were involved with only 37.5% of the expected 64,000 deaths (Palliative Care Australia, 2005). Approximately the same amount of people die from cancer as from non-malignant diseases, including end stage organ failure and neurological disorders, yet only 9- 30% of those with non- malignant diseases are referred to palliative care services (Carrow, 2002).

Palliative care as a specialty

Despite people facing incurable diseases and death since time in memoriam, palliative care is a relatively new branch of healthcare, growing out of the work of Dame Cicely Saunders in the United Kingdom at St Christopher's Hospice in the 1960s (Faull et al., 2005). Of course dying patients have always received care but it was this formalisation and inception of palliative care as a specialty requiring education, research and reflection, which gave validity to this important work. Palliative care formal training is available in many countries such as the United Kingdom, the United States of America, New Zealand and Australia where medical physicians can undertake advanced training in palliative care (The Royal Australasian College of Physicians, 2014) and nurses can complete graduate certificates to doctoral studies. There are also many on-line short courses, conferences and day only seminars available to all health care practitioners which can help extend their scope of practice, for example lymphoedema treatment and complex wound care (CareSearch, 2014).

Ideally conceptual understanding of palliative care should be taught at the undergraduate level for all healthcare workers to aid greater acceptance and understanding for the generalist health care practitioner. Increasing the number of generalist practitioners who are confident in providing palliative care in their area also increases the number of patients who can receive palliative care where they live and wish to die, which for most is their own home. Currently only 16% of people die in their own homes, the remainder in palliative care units (17%), residential aged care facilities (8%) and the bulk (59%) in acute hospitals (HammondCare, 2012).

The role of the nurse in palliative care

Palliative care nursing can be delivered by all levels of nursing staff; assistants in nursing, enrolled and registered nurses and advanced practice nurses. Although their professional responsibilities may vary according to their scope of practice, all nurses should share the same motivation- to provide holistic care. Palliative care nurses can practice within hospitals, hospices and community roles where they visit patients in their place of residence, home, nursing home or hostel (Candy, Holman, Leurent, Davis, & Jones, 2011). Palliative care nurses can practice as part of a team or independently if multi-disciplinary team members are not available or affordable within the budget (Rose & Glass, 2006).

The role of the advanced practice nurse (including clinical nurse specialists, nurse consultants and nurse practitioners) incorporates both the compassionate art of nursing and the technical

expertise of a clinician (Coyne, 2003). Advanced practice palliative care nurses utilise many different skills, ranging from therapeutic listening, to symptom assessment and management, resource coordination and case management, and advocacy for patients and their families (Meier & Beresford, 2006).

In addition, some advanced practice nurses are endorsed to order investigations and prescribe medications from a limited formulary of medications and investigations, to make referrals to other medical specialists and to claim reimbursement through governmental or private health care provision. Interestingly the authority to prescribe aspect is not welcomed by all advanced practice nurses. For example, in one extensive postal survey of English specialist nurses, the overwhelming majority did not want prescribing rights, the authors hypothesising that this could take away from patient contact time which is already limited (Ryan-Wooley, McHugh, & Luker, 2007). Lack of time to provide adequate patient care is a major obstacle in most areas of healthcare, but the literature tells us that patients appreciate the time and relationships they share with nurses (Steinhauser, Christakis, et al., 2000) and it is this knowledge that the work they do is valued which provides nurses with job satisfaction and ensures staff retention (Head, Washington, & Myers, 2013).

What are the concerns of people living with a life-limiting illness?

Palliative care aims to provide holistic care for patients with incurable diseases and many scholars have surveyed patients to better understand their needs (Chan & Pang, 2007; Steinhauser, Clipp, et al., 2000). Pain is a major concern as it is often present with a terminal illness. A synthesis of several studies found that between 11 and 84% of those with advanced cancer will experience moderate to severe pain (Franks et al., 2000) as will 65-70% of patients with motor neurone disease (O'Brien, Welsh, & Dunn, 1998). Specific symptoms requiring attention will vary according to the individual, however certain diseases will have a predominant symptom; for example fatigue and weakness is highly represented in the AIDS, cancer and nervous system disorder population. Dyspnoea and cough, are experienced by 10- 70% of advanced cancer and 60-100% of non-malignant terminal diseases such as end stage heart failure and pulmonary diseases (Bausewein & Simon, 2013) and nausea and vomiting combined effect 16- 68% of patients with cancer, end-stage renal disease and AIDS (Solano, Gomes, & Higginson, 2006).

Concerns other than physical symptoms

Patients also have non-physical concerns such as ensuring support for their families and care givers before and after death, continuity of care (not being deserted by their healthcare provider), informed decision making, sustaining function, and emotional disorders such as depression. Depression is a relatively common complaint estimated to affect between 7- 50% of people with advanced cancer (Stagg & Lazenby, 2012; Stiefel, Trill, Berney, Olarte, & Razavi, 2001), along with 82% of those with advanced AIDS, 36% of those with end-stage heart disease, 71% of those with chronic obstructive pulmonary disease and 60% of end-stage renal disease patients (Solano et al., 2006). Some patients become so greatly depressed that they desire hastened death and are suicidal (Breitbart et al., 2000) or request sedation to be rendered unconscious (Cherny, 2006).

Existential/spiritual concerns

An important need reported by patients in palliative care, is for support in sustaining their spiritual health (Boston, Bruce, & Schreiber, 2011; Franks et al., 2000; Steinhauser, Clipp, et al., 2000). Existential/spiritual well-being has been identified as an essential component of a good death per the Institute of Medicine in their report, 'Approaching Death', as one of the six elements of quality end of life care (Singer, Martin, & Kelner, 1999). In addition, Steinhauser *et al.* defined affirmation of the whole person as one of the six elements for a 'good death' in their survey of over seventy five patients, relatives and practitioners in palliative care (Steinhauser, Clipp, et al., 2000). In this study, patient emotional and spiritual well-being was identified as part of two larger domains: end-of-life preparation and completion.

'What bothers you most?' was the question posed by Shah *et al.* in their survey of 286 hospitalized palliative care patients. This survey found 16% of participants responded that it was distress of spiritual, existential and emotional nature which troubled them the most. In the retrospective content analysis of the survey, responses showed high levels of concerns about depression, hopelessness, frustration and being overwhelmed, along with questions about the existence of a higher being, an afterlife and the pointlessness of suffering (Shah et al., 2008). In summary, existential and spiritual distress is unpredictable, may increase with proximity to death, may occur in patients with little or no physical symptoms (Chochinov et al., 2008) and some patients rate existential distress more highly than physical concerns (Kelly, McClement, & Chochinov, 2006).

The unmet existential/spiritual needs of palliative care patients

Despite the advances of palliative care to accommodate the myriad of problems and complications associated with advanced life threatening illnesses, we know that not all needs are met or even addressed. These oversights include existential and spiritual concerns with 25-51% of people diagnosed with cancer considering their spiritual needs are not adequately addressed (Moadel et al., 1999; Rainbird, Perkins, Sanson-Fisher, Rolfe, & Anseline, 2009). Healthcare practitioners tend to focus on physical concerns whilst existential/spiritual concerns are infrequently touched upon (Rodriguez et al., 2010). The fact that palliative care practitioners provide less than ideal existential/spiritual care may be due in part to lack of skills and time (Bailey, Moran, & Graham, 2009), and concern that discussions with patients of their existential/spiritual concerns could be detrimental to either party, (Boston et al., 2011; Leung & Esplen, 2010; Yardley, 2009) as well as the need to triage symptoms (Georgeson & Dungan, 1996). Naturally, patients want to know that their physical symptoms can be controlled so that they are not too exhausted to deal with their existential/spiritual concerns (Coyle, 2006). However, most symptoms do not occur in isolation or predictable order and in many cases, can exacerbate another symptom, for example pain may cause anxiety and fear. Similarly, concerns of an existential or spiritual nature can increase physical pain, and request for painkillers is often for the 'mind-numbing' effect rather than for analgesia. Requests for physician-assisted suicide are also closely linked to existential crises (Breitbart et al., 2000). Pronk noted that spiritual distress can increase pain, reduce therapy compliance and increase requests for active euthanasia (Pronk, 2005).

Defining and measuring existential/spiritual issues

Part of the difficulty of addressing these concerns is in defining the meaning of "spiritual" and "existential". These terms, although technically different, are used interchangeably in the literature, with existential concerns having a more focused emphasis on finding the meaning of one's life (Hench & Danielson, 2009) and spirituality defined more broadly as "...the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred" (Puchalski et al., 2009). It is also important to note that religious observances and spirituality are not identical and some researchers have chosen to divide religiosity into intrinsic (more spiritual part of religious practice) and extrinsic (more ritual and institutional based practice) religiosity. Interestingly, one study found a beneficial effect from

intrinsic religiosity on depression, but little benefit from extrinsic religiosity (Nelson, Rosenfeld, Breitbart, & Galletta, 2002) whilst other researchers have found high levels of religiosity increase the requests for life-prolonging treatments such as cardio-pulmonary resuscitation and intubation during the last week of life (Balboni et al., 2007; Phelps et al., 2009).

Clear identification of existential/spiritual needs may be another barrier to providing holistic care. In response to the need for assessment, and other issues of contention, around existential/spiritual care the National Consensus Project on palliative care have created guidelines (Puchalski et al., 2009). The Project committee, made up of many experts in the field of palliative care, agreed on the several sub-categories for review including assessment of needs, education, models of care and quality improvement. In order to assess spiritual needs questions can be as simple as 'Is your spirituality important in your life? What spiritual resources do you use to help you at these times?' (Puchalski et al., 2009) or a more involved existential/spiritual inventory such as the FICA: – F (Faith or belief), I (Importance of spirituality), C (individual's spiritual Community) and A (interventions to Address the spiritual needs) (Puchalski & Romer, 2000). The FICA tool has been evaluated to be feasible in assisting clinicians to better understand the spirituality of their patients (Borneman, Ferrell, & Puchalski, 2010). Other tools such as the Functional Assessment of Chronic Illness Therapy –spiritual well-being- (FACIT- Sp.) (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002), Quality of Life in the End-of-Life (QUAL-E) (Steinhauser et al., 2004) and the Patient Dignity Inventory (Chochinov et al., 2008) can help to gauge distress related to existential/spiritual concerns. In addition, instruments such as the Memorial Delirium Assessment Scale can assist in the differentiation of existential and spiritual distress from the signs and symptoms of delirium and depression, (Lawlor, 2000), some of which may have a reversible cause. Conversely one author discourages the use of a formal questionnaire to probe the patient as it was felt that these were more likely to intimidate patients, and rather encourages the use of these tools as guidelines for discussions (Pronk, 2005).

Approaches to managing existential/spiritual concerns in the end-of-life

In general, approaches to providing care to those with existential and spiritual concerns in the end-of-life have involved referral to religious practitioners. However, in a secular society such as Australia (Australian Bureau of Statistics, 2011), discussions with a pastoral care worker may not be always welcome. As palliative care practitioners aim to care for the entire person, it is important to understand other treatments and approaches that may be helpful.

Suggestions for effective clinician-patient communication include the tenet that it is more important to listen to patients' existential and spiritual questions than to have the answer. It is helpful to encourage the patient to ask questions and to set the agenda for the conversation. This agenda may include: the patient's past, their story good and bad, their present, their suffering/emotional journey and their future, hope and meaning in death (Pronk, 2005). One study found that a brief (5- 7 minutes) semi-structured patient interview about the patient's existential/spiritual concerns with their oncologist, could reduce depression, and increase levels of quality of life and sense of interpersonal caring (Kristeller, Rhodes, Cripe, & Sheets, 2005). Several authors concur that both good communication and a reliable professional relationship can be beneficial when supporting patients with their concerns (Bailey et al., 2009; Chochinov, 2006; Clayton, Butow, Arnold, & Tattersall, 2005; Okon, 2005; Sinclair, Raffin, Pereira, & Guebert, 2006).

Although in the early stages, the provision of existential/spiritual care at the end-of-life by palliative care practitioners is growing, as is the literature reporting trials of interventions to help assist this care. Therapies like Cognitive Existential Group therapy (20 weekly group sessions) (Kissane, 2003) and Supportive Expressive Group Psychotherapy (1 year of weekly sessions) (Classen et al., 2001; Goodwin et al., 2001) have been found to be effective for patients at an early stage of illness. However, for patients with only a limited time to live and who are already frail and weak such lengthy interventions may be more burdensome than helpful. Patients' time and energy is precious at the end of life, therefore interventions targeting this population likely need to be brief to be feasible.

Current approaches to helping patients with spiritual and existential concerns can be divided into pharmacological and non-pharmacological interventions (Hench & Danielson, 2009; LeMay & Wilson, 2008; Stagg & Lazenby, 2012). Pharmacological approaches can include the use of anti-psychotics, anti-depressants and anxiolytics, medication with a goal of sedation (Cherny, 2006) and/or mood alteration (Campbell et al., 2009). Non-pharmacological interventions can be classed as non-psychotherapeutic and psychotherapeutic interventions (Stagg & Lazenby, 2012). Non-psychotherapeutic interventions can include; aromatherapy (Soden, Vincent, Craske, Lucas, & Ashley, 2004), hypnotherapy (Iglesias, 2004; Rajasekaran, Edmonds, & Higginson, 2005), guided imagery and muscle relaxation (Sloman, 2002). Psychotherapeutic interventions include; therapeutic life review (Chochinov et al., 2005; Steinhauser et al., 2008), psychosocial supportive therapy (Duggleby et al., 2007), narrative therapy (Overcash, 2003), cognitive behavioural therapy (Akechi, Okuyama, Onishi, Morita, &

Furukawa, 2008; Cole & Pargament, 1999), psycho-socio-spiritual education group therapy (Miller, Chibnall, Videen, & Duckro, 2005) and meaning making group therapy (Breitbart et al., 2010).

Therapeutic life review interventions

One non-pharmacological intervention, therapeutic life review, has been adapted for palliative care patients after being used successfully as a treatment for and prevention of depression in the elderly population (Bohlmeijer, Smit, & Cuijpers, 2003; Mastel-Smith et al., 2006).

Therapeutic life review draws on the work of Erikson's stages of psychosocial development, in particular the final two stages: the penultimate developmental dilemma of generativity versus stagnation where one is challenged to formulate a lasting legacy, and the final stage, ego integrity versus despair. It is during the final stage of life that life review is particularly indicated to assist a person understand and accept that their life has been meaningful and worthwhile. If this is not completed, despair in the form of guilt and remorse will dominate (Erikson, 1950). It is through reflection on one's life and the gaining of perspective and meaningfulness that one can see a peaceful and just conclusion to life (Haber, 2006).

Therapeutic life review has been practiced in the palliative care setting in the form of counselling (Linn, Linn, & Harris, 1982), creating biographies (Lichter, Mooney, & Boyd, 1993) and conducting focussed interviews (Lloyd-Williams, Cobb, O'Connor, Dunn, & Shiels, 2013). The efficacy of therapeutic life review has been shown in a small number of studies (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008; Ando, Morita, Akechi, & Okamoto, 2010; Ando, Morita, Okamoto, & Ninosaka, 2008; Ando, Tsuda, & Morita, 2007; Breitbart et al., 2012; Breitbart et al., 2010; Chochinov et al., 2005; Hansen, Enright, Baskin, & Klatt, 2009; Henry et al., 2010; Lee, 2007; Mok, Lau, Lai, & Ching, 2012). The majority of these studies have been undertaken in Asia, the USA or Canada and conducted by a social worker or psychologist/psychiatrist and infrequently a nurse.

A therapeutic life review intervention- Outlook

One life review intervention which has shown promise is the Outlook intervention (Steinhauser et al., 2008). This intervention allows the patient to address their existential/spiritual needs through identifying areas of their lives they would wish to amend, relishing the positives of their journey thus far and setting themselves goals for the future, allowing them to take hold of their situation and re-empower them with decision making. Outlook is conducted by a facilitator over

three sessions of approximately 60 minutes each. Equipment required includes set of questions (see Table 2), prompt cards to be left with the patient at the end of the session (see Appendix III) for further private reflection, and a recording device (optional). The Outlook intervention does not create a legacy product, as some other interventions do. However, if the interview is recorded then the patient can be offered a copy of the interview to keep and or share with their loved ones.

Table 2: Outlook intervention questions (Steinhauser et al., 2008).

Session 1- Life Story	Session 2- Forgiveness	Session 3- Heritage & Legacy
Tell me about your life?	If you were to do things again, what might you do differently?	What are your most valuable lessons learned?
What are your cherished times?	Are there things or times you regret?	What would you like to share with future generations?
Of what are you most proud?	Is there anyone to whom you would like to offer forgiveness?	If you could choose one thing to pass on as your legacy what would that be?
If someone were to make a movie of your life, what would be important to include?	Is there anyone from whom you would like to ask forgiveness?	What things would you like to accomplish?
	Are you at peace?	

The first Outlook session asks the patient to recall their life and highlight the most important aspects, which is a conventional part of life review therapy (Haber, 2006). Prompt cards left with the patient suggest the patient recalls their story, and thinks about their family and early life, remembering the people, places and events which have been important in their lives. The second session focusses on forgiveness, for one's self and for others. This session allows the patient to discuss past disappointments and asks them to consider ways to resolve those regrets. The power of forgiveness as a form of healing has been studied in survivors of incest (Freedman & Enright, 1996) and patients with coronary disease (Waltman et al., 2009) amongst others.

In the third session the patient is asked to identify messages they would like to leave for family or future generations. The prompt cards discuss some options people may consider such as creating a scrapbook or writing letters to be read at loved one's birthdays and celebrations to come. Also in session 3 the patient is invited to consider their future goals.

The utility of facilitating people with a life limiting illness to consider their personal goals and priorities has been highlighted by several authors (Chochinov et al., 2004, 2005; Wright et al.,

2008). While encouraging goal setting is not something usually associated with dying patients, it may both give patients something to aspire to and a renewed sense of hope. In fact, once the goal of cure or remission is removed by advancing disease, patients and practitioners are often left with a feeling of hopelessness and futility, compounding depression and anxiety which is already over-represented in this population (Breitbart et al., 2000). Hope as a form of coping was prioritised by Clayton *et al.* (2005) who found in their descriptive study of fostering coping in palliative care patients, care givers and practitioners three predominant themes; 1) emphasise what can be done, 2) explore realistic goals and 3) discuss day-to-day living (Clayton et al., 2005). The enhancement of hope in end of life care is also supported by Chochinov *et al.* whose therapeutic life review intervention Dignity Therapy was found to be the most helpful in patients with the highest rates of despair and hopelessness (Chochinov et al., 2005).

The Outlook intervention, delivered by a social worker, has been studied in a small (82 enrolled patients) USA-based randomised control pilot study involving three arms, intervention (Outlook), attention (relaxation meditation) group and control (no contact except for pre and post assessments) (Steinhauser et al., 2008). The intervention group showed improvement in measures of activities of daily living ability, anxiety, depression and preparation for end of life. Interestingly, the attention group also showed improvements in activities of daily living ability, but worsening of anxiety and end of life preparation scores and stable depression scores. The control group showed stable activities of daily living ability scores and worsening anxiety, depression and end-of-life preparation scores. Activities of daily living ability, anxiety and depression scores worsened in the control group over time. Improvements were non-significant due to a small sample size and a high attrition rate (>50%). Nonetheless, results are promising.

The role of palliative care nurses in addressing existential/spiritual issues

Life review interventions are not meant to replace formal psychotherapy for which social workers, psychologists and psychiatrists may be the most appropriately skilled. Nevertheless, these specialists are not always available due to financial or resource constraints (Bolmsjo, Hermeren, & Ingvar, 2002) and some patients are reluctant to engage with these health practitioners due to the stigma of mental ill-health (Schomerus, Matschinger, & Angermeyer, 2009). Additionally, rates of referral to these specialists fluctuate as Ellis *et al.* (2009) found in their medical record review of 326 patients with metastatic cancer; with those more likely to be referred for psychological counselling being younger, unmarried and exhibiting more depressive

behaviours. Rates of referrals for psychological interventions declined with advancing age even in patients with documented distress (Ellis et al., 2009).

Nurses are the most numerous member of the healthcare workforce (Australian Institute of Health and Welfare, 2013), practice in almost every healthcare setting and have more contact time with patients than other health professionals (Gaynor et al., 2007). Hence nurses may be very well placed to provide psychological support and interventions. Palliative care nurses wish to provide holistic care (Ronaldson, Hayes, Aggar, Green, & Carey, 2012; Sinclair et al., 2006) and patients have identified nurses as professionals from whom they would like to receive existential/spiritual support (Hermann, 2007; Tan, Braunack-Mayer, & Beilby, 2005). Palliative care nurses, in particular those who provide community care, are often able to provide support over an extended period of time, establishing and building on nurse-patient relationships identified by many as key to continuity of care and assuring the patient that they will not be abandoned (Bolmsjo et al., 2002; Luker, Austin, Caress, & Hallett, 2000; Steinhauser, Clipp, et al., 2000). In turn this relationship may help nurses to increase their confidence and improve their patient care (Bolmsjo et al., 2002).

Despite being eager, nurses know very little about formal existential/spiritual care interventions (Trueman & Parker, 2006). However those who have been included in education around this type of care have found it very satisfying. For example, Morita *et al.* reported on a 5 hour workshop, evaluated with 147 nurses, where participants were instructed in ways to help reduce terminally ill patients' sense of meaninglessness. Approaches included role play and didactic lectures of assessment and care planning. Participants reported high levels of satisfaction with the program which they felt helped them with their understanding of patients' distress, ways to assess and address it and to become more self-aware (Morita et al., 2007).

However, interventions and practices conducted by nurses or to help nurses specifically address existential/spiritual concerns of palliative care patients appear to be limited with few reported in the literature. Of those identified there were three reports of therapeutic life review interventions to have been (partially) conducted by a nurse, in conjunction with another type of psychosocial professional. This included Dignity Therapy (studied twice) which results in a legacy document that can be both time consuming and costly to create. The initial pilot study of Dignity Therapy showed significant improvements in suffering and depressive symptoms (Chochinov et al., 2005), however results from the subsequent larger RCT did not show significant improvements (Chochinov et al., 2011).

Furthermore little is known about how palliative care nurses currently address existential and spiritual concerns in their practice, and what support they require to do so. Improving both the level of nurses' understanding and skill base in the provision of existential/spiritual care for palliative care patients would seem necessary.

Summary of literature review and unmet areas of research

Palliative care is a relatively new field of healthcare which provides care for those with advanced life-limiting illnesses. Palliative care is holistic patient care ideally delivered by multidisciplinary teams, which is practiced throughout the world with varying degrees of specialisation and acceptance, with the need outweighing the supply. Concerns of palliative care patients include those of the physical, existential/spiritual, psychological and social domains, and should include care for patients' loved ones before and after bereavement. Yet not all domains of personhood receive adequate attention, with existential/spiritual care needs often overlooked. Causes for this oversight include the need to triage symptoms, lack of time, skills and confidence and difficulty assessing and defining concerns.

There is a growing interest in this area and some interventions have been developed to address existential/spiritual concerns. One type of intervention is the therapeutic life review, an example of which is the Outlook intervention. This intervention has been studied in an RCT with promising results. It was conducted in the USA by a social worker. The majority of existential/spiritual interventions are conducted by social workers, psychologists or psychiatrists but these practitioners are not as numerous, available or well-represented as nurses. Nurses are eager to provide holistic care though have limited knowledge of formal interventions but are considered by patients to be trustworthy and capable. Research regarding the efficacy of interventions is very important but it is the translation into real world clinical practice that is needed to make a difference to patient care. This of course requires implementation of the interventions that have been found to be effective, in a feasible and cost-effective way, by staff with relevant skills. Nurses are well-placed to deliver interventions such as Outlook.

Currently there is little understanding of the existential/spiritual concerns of Australian palliative care patients, or the feasibility and acceptability of a nurse facilitating the Outlook intervention for palliative care patients. Furthermore, there is a need to explore Australian palliative care nurses' current practice and attitudes towards existential/spiritual care as well as their views on the feasibility of implementing the Outlook intervention into their clinical practice.

Aims of this project

To address these identified knowledge gaps, the aims of thesis are:

1. To critically appraise the literature around therapeutic life review interventions used with palliative care patients.
2. To explore the efficacy and feasibility of a nurse-facilitated therapeutic life review intervention, Outlook, in the Australian palliative care population.
3. To explore the perceptions that individuals with life-limiting illnesses have about their lives, both positive and negative, and their messages to future generations using a therapeutic life review intervention, Outlook.
4. To understand how Australian palliative care nurses address existential/spiritual concerns with their patients.
5. To explore Australian palliative care nurses' experiences with existential/spiritual interventions and their views on the feasibility of implementing a therapeutic life review interventions, Outlook, into their clinical practice.

Presentation of thesis

This thesis is presented as a combination of 1 systematic review and 4 published papers. The review and papers describe the methods, results and discussion of the three research projects undertaken in this candidature. Chapter 1 (this chapter) provides the introduction to the field of palliative care and the concerns of palliative care patients, in particular those in the existential/spiritual domain, interventions to address these concerns and the role of the nurse in providing appropriate care for those concerns.

Chapter 2 reports the results of the systematic review of validated therapeutic life review interventions which have been conducted in the palliative care population, and potentially could be conducted by a nurse (aims 1, 4 and 5).

Chapter 3 reports the quantitative results of a pilot study of a nurse facilitated existential/spiritual questionnaires (aim 1). Chapter 4 describes the qualitative findings of the pilot study, the analysis of patients' interviews, to better understand the perceptions of individuals with life-limiting illnesses (aim 2) and the feasibility of conducting such an intervention (aim 1).

Chapter 5 reports the results of semi-structured interviews with 20 palliative care nurses from a variety of working areas to gain their perceptions on therapeutic life review interventions (aims 1, 3 and 4). Chapter 6 reports the palliative care nurses' current practices, facilitators, barriers and strategies, in regards to providing existential/spiritual care to patients (aim 4).

Chapter 7 provides the summary and conclusions of the research undertaken and further research directions.

REFERENCES

- Akechi, T., Okuyama, T., Onishi, J., Morita, T., & Furukawa, T. A. (2008). Psychotherapy for depression among incurable cancer patients. *Cochrane Database of Systematic Reviews*, 16(2).
- Allen, R. S., Hilgeman, M. M., Ege, M. A., Shuster, J. L., & Burgio, L. D. (2008). Legacy Activities as Interventions Approaching the End of Life. *Journal of Palliative Medicine*, 11(7), 1029-1038.
- Ando, M., Morita, T., Akechi, T., & Okamoto, T. (2010). Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *Journal of Pain & Symptom Management*, 39(6), 993-1002.
- Ando, M., Morita, T., Okamoto, T., & Ninosaka, Y. (2008). One-week Short-Term Life Review interview can improve spiritual well-being of terminally ill cancer patients. *Psychooncology*, 17(9), 885-890.
- Ando, M., Tsuda, A., & Morita, T. (2007). Life review interviews on the spiritual well-being of terminally ill cancer patients. *Supportive Care in Cancer*, 15(2), 225-231.
- Australian Bureau of Statistics. (2011, 28th March 2012). Australian Demographic Statistics. Retrieved 16th May, 2013, from <http://www.abs.gov.au/ausstats/abs@.nsf/featurearticlesbyReleaseDate/AE3CAF747F4751CDC A2579CF000F9ABC?OpenDocument>
- Australian Government Department of Health. (2000). National Palliative Care Strategy. . Canberra Commonwealth Department of Health and Aged Care.
- Australian Institute of Health and Welfare. (2013). AIHW. Retrieved 10th July, 2013, from <http://www.aihw.gov.au/health-workforce>
- Bailey, M. E., Moran, S., & Graham, M. M. (2009). Creating a spiritual tapestry: nurses' experiences of delivering spiritual care to patients in an Irish hospice. *International Journal of Palliative Nursing*, 15(1), 42-48.
- Balboni, T. A., Vanderwerker, L. C., Block, S. D., Paulk, M. E., Lathan, C. S., Peteet, J. R., & Prigerson, H. G. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology*, 25(5), 555-560.
- Bausewein, C., & Simon, S. T. (2013). Shortness of breath and cough in patients in palliative care. *Dtsch Arztebl Int*, 110(33-34), 563-571.
- Bohlmeijer, E., Smit, F., & Cuijpers, P. (2003). Effects of reminiscence and life review on late-life depression: a meta-analysis. *International Journal of Geriatric Psychiatry*, 18(12), 1088-1094.

- Bolmsjo, I., Hermeren, G., & Ingvar, C. (2002). Meeting existential needs in palliative care - Who, when, and why? *Journal of Palliative Care*, *18*(3), 185-191.
- Borneman, T., Ferrell, B., & Puchalski, C. M. (2010). Evaluation of the FICA tool for spiritual assessment. *Journal of Pain and Symptom Management*, *40*(2), 163-173.
- Boston, P., Bruce, A., & Schreiber, R. (2011). Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. *Journal of Pain and Symptom Management*, *41*(3), 604-618.
- Breitbart, W., Poppito, S., Rosenfeld, B., Vickers, A. J., Li, Y., Abbey, J., . . . Cassileth, B. R. (2012). Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *Journal of Clinical Oncology*, *30*(12), 1304-1309.
- Breitbart, W., Rosenfeld, B., Gibson, C., Pessin, H., Poppito, S., Nelson, C., . . . Olden, M. (2010). Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psycho-Oncology*, *19*(1), 21-28.
- Breitbart, W., Rosenfeld, B., Pessin, H., Kaim, M., Funesti-Esch, J., Galiotta, M., . . . Brescia, R. (2000). Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *Jama-Journal of the American Medical Association*, *284*(22), 2907-2911.
- Campbell, N., Boustani, M. A., Ayub, A., Fox, G. C., Munger, S. L., Ott, C., . . . Singh, R. (2009). Pharmacological management of delirium in hospitalized adults--a systematic evidence review. *Journal of General Internal Medicine*, *24*(7), 848-853.
- Candy, B., Holman, A., Leurent, B., Davis, S., & Jones, L. (2011). Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: A systematic review of quantitative and qualitative evidence. *Int J Nurs Stud*, *48*(1), 121-133.
- CareSearch. (2014, 25th February, 2014). University Courses. Retrieved 9th May, 2014, from <http://www.caresearch.com.au/caresearch/tabid/73/Default.aspx#ACU>
- Chan, H. Y., & Pang, S. M. (2007). Quality of life concerns and end-of-life care preferences of aged persons in long-term care facilities. *Journal of Clinical Nursing*, *16*(11), 2158-2166.
- Cherny, N. I. (2006). Sedation for the care of patients with advanced cancer. *Nature Clinical Practice Oncology*, *3*(9), 492-500.
- Chochinov, H. M. (2006). Dying, dignity, and new horizons in palliative end-of-life care. *CA- A cancer journal for clinicians*, *56*(2), 84-103.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2004). Dignity and psychotherapeutic considerations in end-of-life care. *Journal of Palliative Care*, *20*(3), 134-142.

- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Oncology*, 23(24), 5520-5525.
- Chochinov, H. M., Hassard, T., McClement, S., Hack, T., Kristjanson, L. J., Harlos, M., . . . Murray, A. (2008). The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *Journal of Pain and Symptom Management*, 36(6), 559-571.
- Chochinov, H. M., Kristjanson, L. J., Breitbart, W., McClement, S., Hack, T. F., Hassard, T., & Harlos, M. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncology*, 12(8), 753-762.
- Clark, D., & Wright, M. (2007). The International Observatory on End of Life Care: A Global View of Palliative Care Development. *Journal of Pain and Symptom Management*, 33(5), 542-546.
- Clark, D., Wright, M., Hunt, J., & Lynch, T. (2007). Hospice and palliative care development in Africa: a multi-method review of services and experiences. *J Pain Symptom Manage*, 33(6), 698-710.
- Classen, C., Butler, L. D., Koopman, C., Miller, E., DiMiceli, S., Giese-Davis, J., . . . Spiegel, D. (2001). Supportive-expressive group therapy and distress in patients with metastatic breast cancer - A randomized clinical intervention trial. *Archives of General Psychiatry*, 58(5), 494-501.
- Clayton, J. M., Butow, P. N., Arnold, R. M., & Tattersall, M. H. N. (2005). Fostering coping and nurturing hope when discussing the future with terminally cancer patients and their caregivers. *American Cancer Society*, 103, 1965-1975.
- Cole, B., & Pargament, K. (1999). Re-creating your life: A spiritual/psychotherapeutic intervention for people diagnosed with cancer. *Psycho-Oncology*, 8(5), 395-407.
- Cox, C. E., Carson, S. S., Govert, J. A., Chelluri, L., & Sanders, G. D. (2007). An economic evaluation of prolonged mechanical ventilation. *Critical Care Medicine*, 35(8), 1918-1927.
- Coyle, N. (2006). The hard work of living in the face of death. *Journal of Pain and Symptom Management*, 32(3), 266-274.
- Coyne, P. (2003). The Evolution of the Advanced Practice Nurse Within Palliative Care. *Journal of Palliative Medicine*, 6(5), 769-770.
- Currow, D. (2002). Australia: State of palliative service provision 2002. *Journal of Pain and Symptom Management*, 24(2), 170-172.
- Duggleby, W. D., Degner, L., Williams, A., Wright, K., Cooper, D., Popkin, D., & Holtslander, L. (2007). Living with hope: initial evaluation of a psychosocial hope intervention for older palliative home care patients. *Journal of Pain & Symptom Management*, 33(3), 247-257.

- Ellis, J., Lin, J., Walsh, A., Lo, C., Shepherd, F. A., Moore, M., . . . Rodin, G. (Writers). (2009). Predictors of referral for specialized psychosocial oncology care in patients with metastatic cancer: the contributions of age, distress, and marital status, *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*. United States.
- Erikson, E. H. (1950). *Childhood and Society*. New York: Norton.
- Faull, C., Carter, Y., & Daniels, L. (Eds.). (2005). *Handbook of Palliative Care* (2nd ed.). Massachusetts: Blackwell Publishing.
- Franks, P. J., Salisbury, C., Bosanquet, N., Wilkinson, E. K., Lorentzon, M., Kite, S., . . . Higginson, I. J. (2000). The level of need for palliative care: a systematic review of the literature. *Palliative Medicine*, *14*(2), 93-104.
- Freedman, S. R., & Enright, R. D. (1996). Forgiveness as an intervention goal with incest survivors. *Journal of Consulting and Clinical Psychology*, *64*(5), 983-992.
- Gaynor, L., Gallasch, T., Yorkston, E., Stewart, S., Bogossian, F., Fairweather, C., . . . Turner, C. (2007). The future nursing workforce in Australia: baseline data for a prospective study of the profile, attrition rates and graduate outcomes in a contemporary cohort of undergraduates. *Australian Journal of Advanced Nursing*, *25*(2), 11-20.
- Georgeson, J., & Dungan, J. M. (1996). Managing spiritual distress in patients with advanced cancer pain. *Cancer Nursing*, *19*(5), 376-383.
- Goodwin, P. J., Leszcz, M., Ennis, M., Koopmans, J., Vincent, L., Guther, H., . . . Hunter, J. (2001). The effect of group psychosocial support on survival in metastatic breast cancer. *The New England Journal of Medicine*, *345*(24), 1719-1726.
- Haber, D. (2006). Life review: Implementation, theory, research, and therapy. *International Journal of Aging & Human Development*, *63*(2), 153-171.
- HammondCare. (2012). Annual Report. Sydney, Australia.
- Hansen, M. J., Enright, R. D., Baskin, T. W., & Klatt, J. (2009). A Palliative Care Intervention in Forgiveness Therapy for Elderly Terminally Ill Cancer Patients. *Journal of Palliative Care*, *25*(1), 51-60.
- Head, B. A., Washington, K. T., & Myers, J. (2013). Job satisfaction, intent to stay, and recommended job improvements: the palliative nursing assistant speaks. *J Palliat Med*, *16*(11), 1356-1361.
- Hench, I., & Danielson, E. (2009). Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. *Psycho-Oncology*, *18*(3), 225-236.

- Henry, M., Cohen, S. R., Lee, V., Sauthier, P., Provencher, D., Drouin, P., . . . Mayo, N. (2010). The Meaning-Making intervention (MMi) appears to increase meaning in life in advanced ovarian cancer: a randomized controlled pilot study. *Psycho-Oncology*, *19*(12), 1340-1347.
- Hermann, C. P. (2007). The degree to which spiritual needs of patients near the end of life are met. *Oncology Nursing Forum*, *34*(1), 70-78.
- Iglesias, A. (2004). Hypnosis and existential psychotherapy with end-stage terminally ill patients. *American Journal of Clinical Hypnosis*, *46*(3), 201-213.
- Kelly, B., McClement, S., & Chochinov, H. M. (2006). Measurement of psychological distress in palliative care. *Palliative Medicine*, *20*(8), 779-789.
- Kissane, D. W., Bloch, S., Smith, G., Miach, P., Clarke, D. M., Ikin, J., et al (2003). Cognitive-existential group psychotherapy for women with primary breast cancer: a randomised controlled trial. *Psycho-Oncology*, *12*, 532-546.
- Kristeller, J. L., Rhodes, M., Cripe, L. D., & Sheets, V. (2005). Oncologist assisted spiritual intervention study (OASIS): Patient acceptability and initial evidence of effects. *International Journal of Psychiatry in Medicine*, *35*(4), 329-347.
- Kuebler, K. (2003). The Palliative Care Advanced Practice Nurse. *Journal of Palliative Medicine*, *6*(5), 707-714.
- Lawlor, P. G., Nikolaichuk, C., Gagnon, B., Mancini, J. L., Pereira, J. L., Bruera, E. D. (2000). Clinical utility, factor analysis, and further validation of the Memorial Delirium Assessment Scale in patients with advanced cancer: assessing delirium in advanced cancer. *Cancer*, *88*(12), 2859-2867.
- Lee, V. (2007). The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Care Cancer*, *16*, 779-785.
- LeMay, K., & Wilson, K. G. (2008). Treatment of existential distress in life threatening illness: A review of manualized interventions. *Clinical Psychology Review*, *28*(3), 472-493.
- Leung, D., & Esplen, M. J. (2010). Alleviating existential distress of cancer patients: Can relational ethics guide clinicians? *European Journal of Cancer Care*, *19*(1), 30-38.
- Lichter, I., Mooney, J., & Boyd, M. (1993). Biography as therapy. *Palliat Med*, *7*(2), 133-137.
- Linn, M. W., Linn, B. S., & Harris, R. (1982). Effects of counselling for late stage Cancer-patients. *Cancer*, *49*(5), 1048-1055.
- Lloyd-Williams, M., Cobb, M., O'Connor, C., Dunn, L., & Shiels, C. (2013). A pilot randomised controlled trial to reduce suffering and emotional distress in patients with advanced cancer. *J Affect Disord*, *148*(1), 141-145.

- Luker, K., Austin, L., Caress, A., & Hallett, C. E. (2000). The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. *Journal of Advanced Nursing, 31*(4), 775-782.
- MacLeod, R. (2001). A national strategy for palliative care in New Zealand. *Journal of Palliative Medicine, 4*(1).
- Mastel-Smith, B., Binder, B., Malecha, A., Hersch, G., Symes, L., & McFarlane, J. (2006). Testing therapeutic life review offered by home care workers to decrease depression among home-dwelling older women. *Issues in Mental Health Nursing, 27*(10), 1037-1049.
- Meier, D., & Beresford, L. (2006). Advanced Practice Nurses in Palliative Care: A Pivotal Role and Perspective. *Journal of Palliative Medicine, 9*(3), 624-627.
- Miller, D. K., Chibnall, J. T., Videen, S. D., & Duckro, P. N. (2005). Supportive-affective group experience for persons with life-threatening illness: reducing spiritual, psychological, and death-related distress in dying patients. *Journal of Palliative Medicine, 8*(2), 333-343.
- Moadel, A., Morgan, C., Fatone, A., Grennan, J., Carter, J., Laruffa, G., . . . Dutcher, J. (1999). Seeking meaning and hope: Self-reported spiritual and existential needs among an ethnically-diverse cancer patient population. *Psycho-Oncology, 8*(5), 378-385.
- Mok, E., Lau, K.-P., Lai, T., & Ching, S. (2012). The Meaning of Life Intervention for Patients With Advanced-Stage Cancer: Development and Pilot Study. *Oncology Nursing Forum, 39*(6), E480-488.
- Morita, T., Murata, H., Hirai, K., Tamura, K., Kataoka, J., Ohnishi, H., . . . Uchitomi, Y. (2007). Meaninglessness in Terminally Ill Cancer Patients: A Validation Study and Nurse Education Intervention Trial. *Journal of Pain and Symptom Management, 34*(2), 160-170.
- Nelson, C. J., Rosenfeld, B., Breitbart, W., & Galietta, M. (2002). Spirituality, Religion, and Depression in the Terminally Ill. *Psychosomatics, 43*(3), 213-220.
- O'Brien, T., Welsh, J., & Dunn, F. G. (1998). ABC of palliative care - Non-malignant conditions. *British Medical Journal, 316*(7127), 286-289.
- Okon, T. R. (2005). Palliative care review: Spiritual, religious, and existential aspects of palliative care. *Journal of Palliative Medicine, 8*(2), 392-414.
- Overcash, J. A. (2003). Narrative research: a review of methodology and relevance to clinical practice. *Critical Reviews in Oncology/Haematology, 48*, 179-184.
- Palliative Care Australia. (2003). *Palliative Care: Service Provision in Australia: A Planning Guide* (2nd ed.). Canberra, ACT.

- Palliative Care Australia. (2005). *A Guide to Palliative Care Service Development: A population based approach*. Canberra, ACT.
- Peterman, A. H., Fitchett, G., Brady, M. J., Hernandez, L., & Cella, D. (2002). Measuring spiritual well-being in people with cancer: The functional assessment of chronic illness therapy-spiritual well-being scale (FACIT-Sp). *Annals of Behavioral Medicine, 24*(1), 49-58.
- Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, M. E., . . . Prigerson, H. G. (2009). Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA - Journal of the American Medical Association, 301*(11), 1140-1147.
- Phillips, J. L., Davidson, P. M., Newton, P. J., & DiGiacomo, M. (2008). Supporting patients and their caregivers after-hours at the end of life: The role of telephone support. *Journal of Pain and Symptom Management, 36*(1), 11-21.
- Pronk, K. (2005). Role of the doctor in relieving spiritual distress at the end of life. *Am J Hosp Palliat Care, 22*(6), 419-425.
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., . . . Sulmasy, D. (2009). Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference. *Journal of Palliative Medicine, 12*(10), 885-904.
- Puchalski, C., & Romer, A. L. (2000). Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine, 3*(1), 129-137.
- Rainbird, K., Perkins, J., Sanson-Fisher, R., Rolfe, I., & Anseline, P. (2009). The needs of patients with advanced, incurable cancer. *British Journal of Cancer, 101*(5), 759-764.
- Rajasekaran, M., Edmonds, P. M., & Higginson, I. J. (2005). Systematic review of hypnotherapy for treating symptoms in terminally ill cancer patients. *Journal of Palliative Medicine, 19*(5), 418-426.
- Rodriguez, K. L., Bayliss, N., Alexander, S. C., Jeffrey, A. S., Olsen, M. K., Pollak, K. I., . . . Arnold, R. M. (2010). How oncologists and their patients with advanced cancer communicate about health-related quality of life. *Psycho-Oncology, 19*(5), 490-499.
- Ronaldson, S., Hayes, L., Aggar, C., Green, J., & Carey, M. (2012). Spirituality and spiritual caring: nurses' perspectives and practice in palliative and acute care environments. *Journal of Clinical Nursing, 21*(15-16), 2126-2135.
- Rose, J., & Glass, N. (2006). Nurses and palliation in the community: the current discourse. *Int J Palliat Nurs, 12*(12), 588-594.

- Ryan-Wooley, B., McHugh, G., & Luker, K. (2007). Prescribing by specialist nurses in cancer and palliative care: results of a national survey. *Palliative Medicine*, 21, 273-277.
- Schomerus, G., Matschinger, H., & Angermeyer, M. C. (2009). The stigma of psychiatric treatment and help-seeking intentions for depression. *European Archives of Psychiatry and Clinical Neuroscience*, 259(5), 298-306.
- Shah, M., Quill, T., Norton, S., Sada, Y., Buckley, M., & Fridd, C. (2008). "What bothers you the most?" Initial responses from patients receiving palliative care consultation. *Am J Hosp Palliat Care*, 25(2), 88-92.
- Sinclair, S., Raffin, S., Pereira, J., & Guebert, N. (2006). Collective soul: the spirituality of an interdisciplinary palliative care team. *Palliative & supportive care*, 4(1), 13-24.
- Singer, P. A., & Bowman, K. (2002). Quality end-of-life care: A global perspective. *BMC Palliative Care*, 1(1), 4.
- Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: patients' perspectives. *JAMA*, 281(2), 163-168.
- Sloman, R. (2002). Relaxation and imagery for anxiety and depression control in community patients with advanced cancer. *Cancer Nursing*, 25(6), 432-435.
- Soden, K., Vincent, K., Craske, S., Lucas, C., & Ashley, S. (2004). A randomized controlled trial of aromatherapy massage in a hospice setting. *Journal of Palliative Medicine*, 18(2), 87-92.
- Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage*, 31(1), 58-69.
- Stagg, E. K., & Lazenby, M. (2012). Best Practices for the Nonpharmacological Treatment of Depression at the End of Life. *American Journal of Hospice & Palliative Medicine*, 29(3), 183-194.
- Steinhauser, K. E., Alexander, S. C., Byock, I. R., George, L. K., Olsen, M. K., & Tulsky, J. A. (2008). Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *Journal of Palliative Medicine*, 11(9), 1234-1240.
- Steinhauser, K. E., Christakis, N. A., Clipp, E. C., McNeilly, M., McIntyre, L., & Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA (Journal of the American Medical Association)*, 284(19), 2476-2482.
- Steinhauser, K. E., Clipp, E. C., Bosworth, H. B., McNeilly, M., Christakis, N. A., Voils, C. I., & Tulsky, J. A. (2004). Measuring quality of life at the end of life: validation of the QUAL-E. *Palliative & supportive care*, 2(1), 3-14.

- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825-832.
- Stiefel, F., Trill, M. D., Berney, A., Olarte, J. M. N., & Razavi, D. (2001). Depression in palliative care: a pragmatic report from the expert working group of the European Association for Palliative Care. *Supportive Care in Cancer*, 9(7), 477-488.
- Tan, H., Braunack-Mayer, A., & Beilby, J. (2005). The impact of the hospice environment on patient spiritual expression. *Oncol Nurs Forum*, 32, 1049-1055.
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733-742.
- The Royal Australasian College of Physicians. (2014). Australasian chapter of palliative medicine. Retrieved 9th May, 2014, from <http://www.racp.edu.au/page/australasian-chapter-of-palliative-medicine/training-program/>
- Trueman, I., & Parker, J. (2006). Exploring community nurses' perceptions of life review in palliative care. *Journal of Clinical Nursing*, 15(2), 197-207.
- Van Beek, K., Woitha, K., Ahmed, N., Menten, J., Jaspers, B., Engels, Y., . . . Hasselaar, J. (2013). Comparison of legislation, regulations and national health strategies for palliative care in seven European countries (Results from the Europall Research Group): a descriptive study. *Bmc Health Services Research*, 13.
- Waltman, M. A., Russell, D. C., Coyle, C. T., Enright, R. D., Holter, A. C., & M. Swoboda, C. (2009). The effects of a forgiveness intervention on patients with coronary artery disease. *Psychology & Health*, 24(1), 11-27.
- World Health Organisation. (2013). Definition of Palliative Care Retrieved 16th October, 2013, from <http://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (1990). Cancer Pain Relief and Palliative Care (Vol. 804). Geneva: World Health Organization.
- World Health Organization. (2007). Cancer Control: Prevention *Cancer Control- knowledge into action: WHO guides for effective programs*. Geneva: World Health Organization.
- Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., . . . Prigerson, H. G. (2008). Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*, 300(14), 1665-1673.

Yardley, S. J., Walshe, C.E., Parr,A. (2009). Improving training in spiritual care: a qualitative study exploring patient perceptions of professional educational requirements. *Palliative Medicine*, 23(7), 601-607.

Zimmermann, C., Riechelmann, R., Krzyzanowska, M., Rodin, G., & Tannock, I. (2008). Effectiveness of specialized palliative care: a systematic review. *Jama-Journal of the American Medical Association*, 299(14), 1698-1709.

CHAPTER 2

Therapeutic life review in palliative care: a systematic review of quantitative evaluations.

This chapter contains the systematic review titled “Therapeutic life review in palliative care: a systematic review of the quantitative evaluations” which has been accepted for publication in the *Journal of Pain and Symptom Management* and is currently *in press*

CHAPTER 2

Therapeutic Life Review in Palliative Care: A Systematic Review of Quantitative Evaluations

Abstract

Context. There is growing interest in providing non-pharmacological treatments, including therapeutic life review interventions, to enhance palliative care patients' existential/spiritual domains

Objectives. To review quantitative evaluations of therapeutic life review interventions to assist palliative care patients with prognoses of six months or less in addressing existential and spiritual domains.

Methods. Comprehensive searches of Pubmed, Medline, Web of Science, CINAHL, Scopus and PsychINFO were undertaken using a validated palliative care search filter in accordance with PRISMA. Each paper which met the inclusion criteria was read and classified according to the American Heart Association's Disease Management Taxonomy, Consolidated Standards of Reporting Trials, QualSyst and the Task Force on Psychological Interventions. Intervention procedure and outcomes were described.

Results. The searches yielded a total of 1768 articles of which 14 met the inclusion criteria. The articles reported six interventions evaluated once and four interventions evaluated twice resulting in ten distinct interventions. The interventions were evaluated in RCTs ($n= 9$), single arm studies ($n= 3$) and a cohort study ($n= 1$). Interventions were conducted in 1- 8, 15- 160 minute sessions by psychologists, social workers and nurses. Attrition rates were 12-50% due to death and deterioration. Participants lived 28- 110 days after completion. Significant results were reported in 11/14 studies.

Conclusion. There are few studies evaluating therapeutic life review interventions although results are promising. Further studies are required utilising tighter selection criteria to demonstrate efficacy before these are adopted into clinical practice. Further study may include the effect of these interventions on the interventionist and the bereaved family and care givers in long term follow up.

Key words: life review, reminiscence, life completion, story-telling, spiritual well-being.

Running title: Therapeutic Life Review in Palliative Care

Introduction

Palliative care aims to provide whole-person care, by relieving pain and other distressing symptoms, integrating psychological and spiritual aspects of patient care, enhancing quality of life and death while neither hastening nor postponing death (1) and where possible, positively influencing the course of an illness (2). Palliative care, historically the care of the dying, has evolved to include care of those with chronic incurable illnesses and may be referred to as hospice care in some countries. Regardless of the patient's length of prognosis, palliative care practitioners aim to help patients and their families to complete life and prepare for death, and affirm patients as a human with a unique life (3).

Many of these goals are well addressed by the current practice of palliative and supportive care, with for example, growing knowledge and application of pain and other physical symptom control. However, some goals, such as addressing psychological and spiritual/existential concerns, are less well addressed. One needs analysis of more than 250 advanced cancer patients who were not receiving formal palliative care, reported that 40% had unmet psychological/emotional needs (4). Another study found that patient consultations with the treating oncologist focused on psychological or spiritual concerns for less than 1% of the time (5). The oversight of these important domains is thought to be due to health practitioners' feelings of inadequacy (6), lack of time and skills (7), potential for self-exposure for professionals (8, 9) and a perceived need to prioritise unresolved physical symptoms (10). Due to these current deficiencies in care for these domains, interest has grown in specific interventions to address them.

One way of addressing existential/spiritual concerns is the therapeutic life review. Therapeutic life review in the elderly population is thought to bring peace to the individual through review of their life lived, both relishing accomplishments and resolving conflicts (11-13). It is important to clarify that life review differs from reminiscence. Reminiscence is a descriptive activity involving thinking about one's life and recalling memorable events from the past (not recent or current events). Reminiscence may be structured or unstructured, and delivered individually or as a group activity. It is considered pleasurable, improving quality of life and assisting with life adaptation, and has been shown to be effective in the aged population in decreasing depression (11, 14). Life review, on the other hand, is more of an evaluative activity involving examination, addressing and resolving or rectifying conflict if able. Life review takes reminiscence to a deeper level whereby the participant looks for meaning in the events of their life; this may be beneficial in assisting patients facing death with resolution of conflict and completion of life tasks resulting in a sense of peace (15).

Life review interventions have been found to be efficacious in reducing depression in the elderly (16, 17) and those recovering from cerebral vascular accidents (18); improving self-esteem and life satisfaction in elderly veterans (19), improving quality of life in people living with AIDS (20), and preventing despair in those newly relocated to residential aged care facilities (21).

Therapeutic life reviews have been offered and well received by terminally ill patients (22) and are gaining support after several studies (23-27) reported promising results. Therapeutic life reviews were recommended in a recent summary of non-pharmacological treatments for depression in end-of-life care (28). However, to date, there have been no systematic reviews of life review interventions in the context of palliative care, to guide practice. Therefore we aimed to conduct a systematic review of quantitative evaluations of therapeutic life review interventions to assist palliative care patients in addressing existential and spiritual domains.

Methods

This review follows the PRISMA-Statement reporting standard (29). Table 1 presents our research questions in the PICOS approach.

Table 1: PICOS approach to the systematic review following the PRISMA statement

P- patients	Life limiting illnesses e.g. Cancer, AIDS, end-stage organ failure, end stage dementia, prognosis <6 months
I-intervention	Manualized therapeutic life review
C- comparison	None, usual care or attention control
O- outcome	Coping with end-of-life, sense of peace, life completion, mental well-being, quality of life or physical symptoms
S- study design	Quantitative randomized control trials, prospective trials, cohort studies, case series

Inclusion criteria

Publications were included if; 1) they quantitatively evaluated the implementation of a manualized therapeutic life review with palliative care patients or patients identified with life limiting illnesses with a prognosis of 6 months or less, including those with end stage organ failure, end stage AIDS, cancer and dementia; 2) patients were over the age of 18; 3) the paper was reported in the English language and 4) the paper was published in a peer-reviewed journal.

Interventions needed to be manualized, either in a published or un-published form and available to the public for replication, or an adequate description of the intervention needed to be given so that the reader could implement the intervention. Having a manual or a thorough description of the intervention allows translation of the research into practice, whereby others can replicate the intervention or incorporate aspects of it into their clinical practice.

As the literature surrounding this subject was presumed to be small, all quantitative study designs apart from single case studies were allowed, including randomised control trials (RCT), cohort studies or case series.

Exclusion criteria

Publications which fulfilled the above criteria but reported qualitative findings only of therapeutic life reviews were excluded as were study proposals, as these studies did not produce quantitative evidence of efficacy. Also excluded were articles in which the intervention targeted someone other than the patient, e.g. the patient's caregivers or relatives (unless as part of a dyad with the patient), health professionals or the general population.

Search strategy

The following computerized online databases were searched in the second and third weeks in March 2014; Pubmed, Medline, Web of Science CINAHL, Scopus and PsychINFO, including the following filters: article, abstract available, full text available, humans over 18 and in English. Our systematic review was limited to the years 1993- 2014.

The first part of the search strategy was to use a validated palliative care filter to improve accuracy and precision (30) using the terms; advance care planning/OR attitude to death/OR bereavement/OR terminal care/OR hospices/OR life supportive care/OR palliative care/OR terminally ill/OR death/OR palliat*.tw. OR hospice*.tw. OR terminal care*.tw. OR advance care plan*.tw. OR attitude to death*.tw. OR bereavement*.tw. OR terminal care* tw. OR life supportive care* tw. OR terminally ill* tw. OR palliate* tw. OR hospice* tw.

The second part of the search strategy was to use the following terms: life review intervention OR life review OR reminiscence OR life completion OR story telling OR existential OR existential plight OR meaning of life OR meaning OR spiritual well-being OR short term life review OR good death OR forgiveness.

Reference lists of included articles, and repeat authors of included articles, were hand-searched. Although to our knowledge there are no systematic reviews of therapeutic life

interventions alone, these are occasionally discussed in systematic reviews of general psychological interventions and these reviews were also hand-searched. The results were saved to a citation manager, Endnote X6. See figure 1 for a summary of the search results.

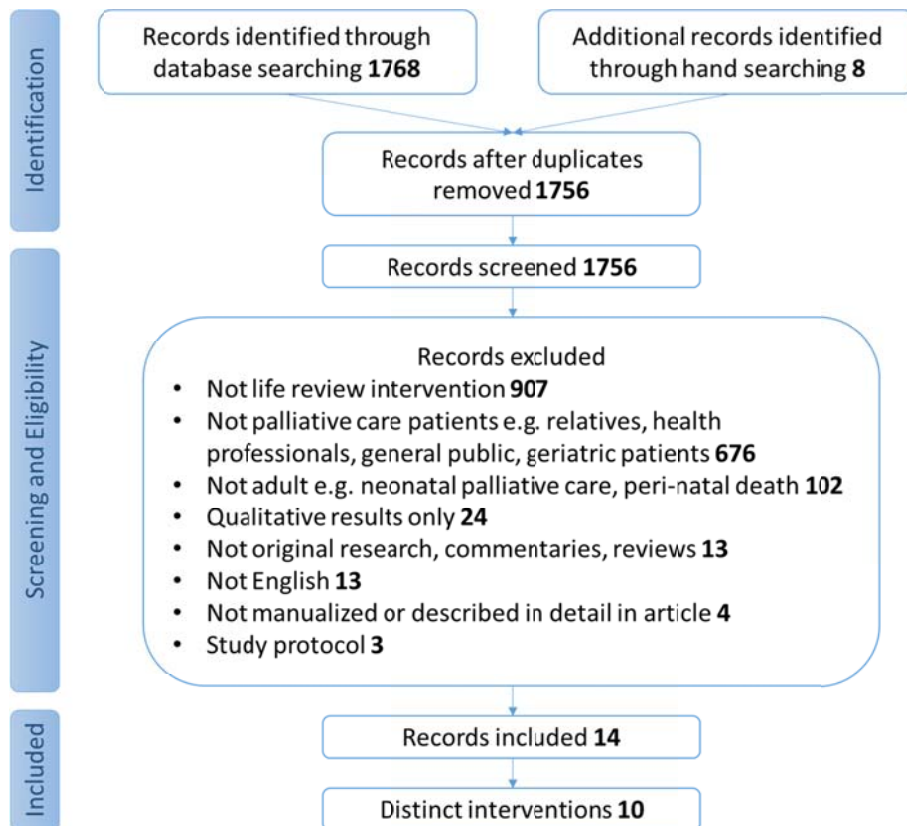


Figure 1: Search strategy results.

Data Extraction

Data were extracted by two reviewers using an electronic (Microsoft Excel 2010) pro forma specifying data items. Where there was disagreement between the reviewers, discussion was undertaken until consensus was reached. The reviewers followed the American Heart Association's Disease Management Taxonomy (31). Data items included 1) patient population, 2) intervention recipient 3) intervention content 4) delivery personnel, 5) method of communication 6) intensity and complexity 7) environment and 8) clinical outcomes. In order to guide the practitioner to apply best supportive care most appropriate to their workplace, we also recorded characteristics of the participants in greater detail (where information was available) using the revised core checklist of the Consolidated Standards of Reporting Trials as adapted for hospice and palliative care research (32). Therefore characteristics of patients recorded included age, gender, socioeconomic indices, ethnicity, life-limiting illness, performance status, days from referral to death, and caregiver availability. Service-descriptors, including setting of study, were also recorded.

Quality assessment

The quality of included studies was based on the standardized QualSyst assessment tool (33). QualSyst consists of two separate scoring systems to evaluate both quantitative and qualitative studies. This assessment tool was selected because it included an extensive manual for quality scoring with definitions and detailed instructions. One author (RK) assessed the quality of all studies and another author (PB) assessed 50% of the studies. Any identified discrepancies were resolved through iterative discussions. For full definitions and instructions for quality scoring, see (33).

Criteria for empirically-validated treatments

A judgement was made as to whether the interventions met the criteria for empirically-validated treatments which are either 'well-established' or 'probably efficacious' as described by the Task Force on Psychological Interventions of the American Psychological Association. An intervention is considered a 'well established' treatment when it shows superiority in two independently researched well-designed studies, it is manualized to treat a specific population and the client sample is well-defined. A 'probably efficacious' treatment is one which meets most of the 'well-established' criteria but has only been researched by one team rather than an independent research team, or has been studied by the same research team but in one or more well-designed studies showing superiority (34).

Results

Utilising the validated search filter and following the described search strategy 1768 articles were identified. Of the articles excluded the majority were because they did not pertain to therapeutic life review interventions ($n= 907$) or were not palliative care study subjects ($n= 676$). Other articles excluded were not adult subjects ($n= 102$), qualitative results only ($n= 24$), not original research ($n= 13$), not in English ($n= 13$), not manualized ($n= 4$) or study protocol only ($n= 3$). This resulted in fourteen articles evaluating ten interventions that met the inclusion criteria and data were extracted following the methods described.

Within the fourteen included articles we found nine RCTs evaluating the following interventions; Legacy Activities, One Week Short Term Life Review, Meaning Centered Group Psychotherapy, Individual Group Psychotherapy, Dignity Therapy, Meaning Making Intervention (two studies), the Meaning of Life intervention and Outlook. The remaining studies were cohort studies (Forgiveness Therapy) and single arm studies (Life Review Intervention, Dignity Therapy and Outlook). The quality of the studies using the QualSyst criteria varied, with scores ranging from 71-80% ($n= 3$), 81-90% ($n= 8$) and 91-100% ($n= 3$).

The studies were conducted in the USA ($n= 5$), Japan ($n= 3$), Canada ($n= 2$), Canada and Australia ($n= 1$), Canada, USA and Australia ($n= 1$), Australia ($n= 1$) and Hong Kong ($n= 1$). Of the ten interventions evaluated, therapeutic life review was a component ($n= 2$) or the entirety of their content ($n= 8$). Interventions were conducted by either a social worker, clinical psychologist or psychiatrist only ($n= 9$), or by these professionals and nurses ($n= 3$) or a nurse alone ($n= 2$). Interventions were implemented in the outpatient clinic ($n= 3$), the inpatient unit only ($n= 2$), the client's home only ($n= 1$) or either the patient's home or inpatient dependent on the patient's need ($n= 8$). All of the interventions were conducted face-to-face either individually ($n= 8$), as part of group therapy ($n= 1$) or as a dyad ($n= 1$). Interventions were delivered in two ($n= 6$), three ($n= 2$), four ($n= 4$), seven ($n= 1$) and eight ($n= 1$) sessions lasting 15 minutes to two and half hours. Patient populations were independent to bed-bound, 28 to 110 days before death.

None of the interventions satisfied the criteria for a well-established treatment. Six had been evaluated in only one study and four, while they had been evaluated in two different studies, had not been evaluated by two unrelated research teams (the 2nd evaluation included a member of the original team). Nor had they shown sustained superiority and thus they are considered to be 'probably efficacious' rather than 'well-established'. Two interventions require more information before being considered probably efficacious (Outlook and Legacy Activities), whilst the remaining 8 met the 'probably efficacious' treatment criteria (34). The fourteen studies are described in more detail below and in table 2 (see table 2).

Insert table 2 about here

Results by intervention

Legacy Activities This intervention is conducted with a patient and carer dyad. The patient-carer dyad is guided by the interventionist to create legacy activities to be enjoyed before and after the patient's death. Examples of legacy activities include creating a scrapbook, cookbook or audiotape of family stories. The intervention lasts for three sessions in which; session 1) the interventionist uses the Legacy Participant Notebook questions to assist the dyad to decide on a legacy activity; session 2) the interventionist coaches the dyads with their project; and session 3) the dyads share their project.

Legacy Activities have been evaluated in one study (35), which was an RCT of the intervention versus Usual Care of 31 dyads of caregivers and patients with multiple co-morbidities, Cancer and Dementia. Participants, both patients and caregivers, were predominantly female, African-Americans with caregivers in self-reported fair to good health and home-based. The interventionist was a social worker or psychologist with access to the treatment manual, the unpublished Legacy Participant Notebook, and supervision by the

intervention developer. There was an attrition rate of 26% due to deteriorating cognitive or physical ability or external stress rather than death. Significant improvements were observed in caregiver stress (intervention group reduced from 49.65 to 48.94 whilst control increased from 43.64 to 46.57, $P= 0.034$), caregivers' report of patients' talkativeness/social interaction (intervention group increased from 3.35 to 4.94 whilst control decreased from 4.14 to 2.64, $P= 0.016$), patients' reported talkativeness/social interaction (intervention group increased from 3.47 to 4.47 whilst control decreased from 3.71 to 2.71, $P= 0.019$) and self-reported breathlessness (intervention group improved 3.00 to 1.43 whilst control worsened from 3.00 to 3.50, $P= 0.026$). Non-significant improvement was shown in pain, however, measures for well-being did not change. It was suggested that volunteers could be trained to improve feasibility of intervention.

Life Review Intervention asks the patients to describe the important events in their lives. It is conducted over four sessions and patients review in chronological order their childhood, adolescence, adulthood and their present situation. The interventionist only takes notes for recording of content; no end product is created.

Life Review Intervention has been evaluated in one single armed, pilot study (36) of 12 inpatients in a Japanese palliative care unit who were predominantly female and either chair or bed-bound. The interventionist was a clinical psychologist and developer of the intervention, as adapted from a previously published author's research (37). There was an attrition rate of 43% due to patients becoming too unwell or dying. Outcome measures of the intervention showed improvements in mood ($z= -2.76$, $P= 0.008$), orientation ($z= -2.05$, $P= 0.041$), spirituality ($z= -2.23$, $P= 0.023$) and overall quality of life ($z= -2.49$, $P= 0.013$). These results were reviewed alongside the interventionist's notes and the authors surmised that the patients who had more positive improvements had been able to evaluate their lives and integrate the bad memories with the good (36).

One Week Short Term Life Review consists of two sessions, and is a condensed version of Life Review Intervention as described above. The interventionist was a clinical psychologist and intervention questions are detailed in the article. In the first session the interventionist helps the patient to review their life, both good and bad memories, in a structured way. The interview is recorded and (between session 1 and 2) the therapist then selects key words from patient responses and creates an album illustrated with representative photos and pictures from books and magazines. At the second session the patient and interventionist review the album and the patient has time to re-evaluate, re-construct and appreciate their lives. The interventionist chooses the pictures and words to go in the patient's album which may not be what the patient would have chosen, however as the patients are all in poor

health and close to death this may be an acceptable way of creating the patient's legacy document.

One Week Short Term Life Review has been studied in both a single arm pilot study of 30 patients (38) and an RCT of 68 patients of a Japanese palliative care unit (23). The single arm study was of mainly female patients with Eastern Cooperative Oncology Group Performance Status Rating (ECOG) of 3 or 4 with an average of 67 days from intervention completion to death resulting in a 14% attrition rate due to deterioration or death. Outcome measures of the single arm study showed significant improvements in: spiritual well-being ($z = -4.2$, $P < 0.001$), anxiety ($z = -3.8$, $P = 0.001$), depression ($z = -3.7$, $P = 0.001$), distress ($z = -4.1$, $P = 0.001$), suffering ($z = -3.5$, $P = 0.001$) and happiness ($z = -3.2$, $P = 0.002$) (38).

The RCT compared One Week short Term Life Review with Usual Care. The study included predominantly female patients with ECOG of 3 or 4 with an average of 28 days from intervention completion to death. The interventionist was a clinical psychologist and developer of the intervention. Intervention questions are included in the article. 12% of patients did not complete the intervention due to death or deterioration. Significant improvements were shown in spiritual well-being (intervention group increased from 17.2 to 25.5 whilst control worsened from 16.7 to 13.8, $P < 0.001$), hope (intervention group increased from 4.4 to 6.0 whilst control worsened from 4.2 to 3.3, $P < 0.001$), life completion (intervention group increased from 4.3 to 5.3 whilst control worsened from 4.1 to 4.0, $P < 0.001$) and suffering ($z = -4.2$, $P = 0.01$). No effect on physical symptoms was demonstrated (23).

Meaning Centered Group Psychotherapy consists of eight group sessions with the participants considering for themselves the following weekly themes; 1) Concepts and sources of meaning, 2) Cancer and meaning, 3) Historical sources of meaning- past, 4) Historical sources of meaning, present and future, 5) Attitudinal sources of meaning, life's limitations, 6) Creative sources of meaning- creativity, 7) Experiential sources of meaning- nature, art, humour and 8) Termination- goodbyes, hopes for future.

Meaning Centered Group Psychotherapy has been studied in an RCT of the intervention versus Supportive Group Therapy in 90 advanced Cancer patients. The patients were 50% female, predominantly Caucasian. The intervention was conducted by a psychiatrist (developer of the intervention) and one to two assistants (39). There was an attrition rate of $> 66\%$, causes not fully recorded, however more participants attended most Meaning Centered Group Psychotherapy sessions compared with the Supportive Group Therapy. Outcome measures for those in the intervention arm of the RCT showed significant improvements in spiritual well-being ($d = 0.72$, $P < 0.0001$) and meaning/peace ($d = 0.74$, $P =$

0.0001) with sustained improvement and improvement over time (2 months). Non-significant improvement was shown in hopelessness, desire for death and anxiety.

Individual Meaning Centered Psychotherapy is adapted from Meaning Centered Group Psychotherapy (see above) and uses didactic and experiential exercises and psychotherapeutic techniques such as reflection, clarification and exploration with participants over seven 1 hour sessions of the following themes; 1) Concepts and sources of meaning, 2) Cancer and meaning- before and after cancer, 3) Historical sources of meaning, 4) Attitudinal sources of meaning, 5) Creative sources of meaning, 6) Experiential sources of meaning and 7) Reflections and hopes for the future. The interventionist meets with patients for an hour to discuss the session and the patient receives readings and completes the activity in their own time.

Individual Meaning Centered Psychotherapy has been studied in an RCT of the intervention versus Therapeutic Massage. The participants of this study were 120 advanced cancer patients with Karnofsky Performance Status scores of > 50. The patients were predominantly female and Caucasian. The interventionist was a psychologist who underwent extensive training, details of the intervention have been published (40). There was an attrition rate of 34% with slightly better attendance at the Individual Meaning Centered Psychotherapy sessions over the Therapeutic Massage group. Outcome measures for the intervention arm showed improvement in; spiritual well-being ($d= 0.60$, $P < 0.001$), meaning/peace ($d= 0.68$, $P= 0.003$), faith ($d= 0.35$, $P= 0.03$), quality of life ($d=0.83$, $P= 0.013$), number of symptoms ($d= -0.36$, $P < 0.001$) and symptom distress ($d= -0.59$, $P < 0.001$). There was no change to hopelessness, anxiety or depression for either arm (24).

Dignity Therapy is conducted over two sessions. At session 1) the interventionist asks patient Dignity Therapy questions including 'Tell me about your life? What are the important roles you have played? What are your hopes and dreams for your loved ones?' The interview is recorded and (between sessions) transcribed. At session 2) the patient is able to review the transcription and make edits as necessary to the 'generativity document' which can then be bound and bequeathed.

Dignity Therapy has been studied in both a single arm study (25) and an RCT (41). The single arm study was conducted in 100 advanced cancer patients, > 50% males with an average of 40 days from end of intervention to death, in two different countries (Canada and Australia). The intervention was conducted by a psychiatrist, psychologist and palliative care nurses who had access to the intervention manual and underwent training with the

intervention developer. Outcome measures for the single arm study with an attrition rate of 22% showed significantly improved suffering ($z = -2.00$, $P = 0.023$), self-reported depressed mood ($z = -1.64$, $P = 0.05$) and non-significant improvement in dignity, hopelessness, desire for death, suicide, anxiety and will to live. There were greater improvements in those who scored higher on pre-test distress (25).

The RCT compared Dignity Therapy to Client-Centered Care or Usual Care of 441 patients with advanced cancer or end organ failure. Forty-nine percent were males with an average Palliative Performance Scale of 44.3% (where 0%= death and 100%= healthy) with an average of 110 days from end of intervention until death. The intervention was conducted in three countries simultaneously, Canada, Australia and the USA. The intervention was conducted by a psychiatrist, psychologist and palliative care nurses who had access to the intervention manual and underwent training with the intervention developer. There was attrition of 25% but these patient's incomplete results were not included in calculations. There were no significant improvements in any of the study arms of the validated measures including the distress specific, Patient Dignity Inventory. This lack of change was thought to be due to low levels of pre-intervention distress. However the patient evaluation at the end of the intervention period found significant differences between groups in likelihood of helpfulness (Dignity Therapy (mean) 4.23, $SD = 0.64$, Client-Centered Care (mean) 3.72, $SD = 0.89$ whilst Usual Care (mean) 3.50, $SD = 1.01$, $P < 0.0001$), ability to increase quality of life (Dignity Therapy (mean) 3.54, $SD = 0.95$, Client-Centered Care (mean) 2.84, $SD = 1.05$ whilst Usual Care (mean) 2.96, $SD = 0.96$, $P = 0.001$) and increasing sense of dignity (Dignity Therapy (mean) 3.52, $SD = 1.04$, Client-Centered Care (mean) 3.11, $SD = 0.97$ and Usual Care (mean) 3.09, $SD = 1.02$, $P = 0.002$) (41).

Forgiveness Therapy involves four sessions during which the interventionist encourages the participant to; 1) Review an issue from their life that needs resolution with the interventionist explaining both positive and negative anger, 2) Expand on the situation from the perspective of offending person, identifying compassion and cognitive reframing from the participant, 3) Give the participant the chance to let go of the associated painful memory and 4) Identify outcomes of forgiveness and a new way of relating to offender. Forgiveness therapy is usually conducted over 10 weeks to 14 months but was truncated to accommodate the poor prognoses of the participants.

Forgiveness therapy was studied in 20 advanced cancer patients, predominantly Caucasian females with ECOG 1-2. The intervention was conducted by a social worker under the guidance of the intervention developer and the treatment manual, which is available on request. There was a 0% attrition rate. The study was a yoked pair design with the initial control group becoming the intervention group after the first intervention group was

complete. Outcome measures of the yoked pair design showed improvements in the intervention group in forgiveness ($t= 7.34, P < 0.001$), anger ($t= -5.10, P < 0.001$), hope ($t= 4.63, P < 0.001$) and quality of life ($t= 3.12, P < 0.01$). There was no difference between the groups after they had both completed the intervention and the initial intervention group maintained their improved levels of forgiveness, anger, hope and quality of life. (42)

Meaning Making Intervention is conducted in one to four sessions during which the participants acknowledge the present, contemplate the past and commit to the present for the future. This is achieved using a 'Life line' timeline to 1) Tell their story starting from the diagnosis, then 2) Add in their life 'turning points' and review how they dealt with those critical events followed by 3) To plan for the future with short and long term goals using their previously recalled strengths.

An RCT of the Meaning Making Intervention versus Usual Care was conducted with 74 patients with either breast or colo-rectal cancer. The majority were female with early stage breast cancer and therefore there was a low attrition rate of 8% due to deterioration or death. The interventionist was either a psychologist or a research nurse who was guided by the intervention developer and the published intervention (43). Improvements were shown in self-esteem (intervention group improved from 17.60 to 15.49 whilst control worsened from 16.56 to 17.15, $P= 0.006$), optimism (intervention group improved from 22.74 to 25.85 whilst control marginally improved from 22.36 to 22.77, $P= 0.019$) and self-efficacy (intervention group improved from 31.71 to 34.49 whilst control worsened from 32.68 to 32.08, $P= 0.002$). Interestingly by the end of the study time participants utilising external psychological support had increased two fold in the control group and three fold in the intervention group despite not being promoted by the investigators. This raises the question of whether this intervention increase vulnerability or proactivity of participants (26).

Adaptation of Meaning Making Intervention as above. One to four (most took three) sessions with therapist who supports self-exploration around three tasks: 1) Review the impact that cancer has made on their lives, 2) Recall other life events and successful coping mechanisms they have used and 3) Review their life goals now they have the cancer diagnosis.

This RCT was of Meaning Making Intervention versus Usual Care in 28 patients with advanced ovarian cancer. The study had an attrition rate of 14% due to patients' deteriorating health rather than death. One patient withdrew from the study as the intervention made her drop her denial coping mechanism. The intervention was conducted by a clinical psychologist with supervision by the intervention's developer and access to the published manual (43). Outcome measures were taken at baseline and 1 month and 3

months post-intervention to observe for changes over time. Significant improvement was shown after three months in spiritual well-being (intervention group improved from 23.3 to 25.3 whilst control worsened from 23.3 to 22.3, $P= 0.04$), and support (intervention group improved from 9.3 to 9.4 whilst control worsened from 8.6 to 7.7, $P= 0.003$). Non-significant improvement was shown in existential well-being at 1 month with improvement to statistical significance after 3 months (intervention group improved from 7.2 to 8.2 whilst control showed no change at 7.0, $P= 0.03$). A similarity between the two studies of Meaning Making Intervention was the observation of increase in use of external counselling by participants from both the intervention and control arms, (intervention arm increased by 3 participants whilst control group increased by 1 participant) although numbers were too small to draw significance (44).

The Meaning of Life Intervention consists of two sessions conducted over two to three days. Session 1) recorded semi-structured interview of the search for personal meaning, questions include 'What do you think about your life? How have you faced adversity in your life? What do you do to love yourself and others? What brings you joy? What do you appreciate in your life? These core questions are followed with other probing questions. In between sessions 1 and 2 the facilitator listens to the recording and extracts significant information into three themes 1) The taste of life 2) The power of love and 3) The meaning of life. At session 2 the interventionist reviews the summary of the interview with the patient.

The Meaning of Life intervention has been studied in an RCT of the intervention versus Usual Care of 84 patients with advanced cancer in Hong Kong. The majority of patients were male with a high level of illiteracy and either requiring physical assistance or chair or bed-bound. The intervention was conducted by a nurse researcher and the authors proposed that it was so simple it could be conducted by any member of the health care team after training. The intervention is described in the unpublished manual potentially available from the author on request. There was an attrition rate of 31% due to death, deterioration or refusal. Significant improvement was shown in quality of life (intervention group improved from 5.1 up to 6.3 whilst control worsened from 6.1 to 6, $P< 0.05$), existential distress (intervention group improved from 4.9 to 7.2 whilst control slightly improved from 5.6 to 5.8, $P< 0.05$) and overall quality of life (intervention group improved from 6.3 to 7.1 whilst control minimally improved from 6.7 to 6.8, $P< 0.05$) (45).

Outlook Intervention Outlook consists of three sessions where the interventionist asks the participant several questions in the following themes; 1) Life story, 2) Forgiveness and 3) Legacy and heritage. Participants are left with prompt cards at the end of each session to encourage further personal reflection about the session they have just completed, they are

also given a handout encouraging development of their own legacy activity e.g. scrapbook, photo album and letter writing. The intervention can be recorded for further analysis or for patient to keep.

Outlook has been studied in both a RCT (27) and a single arm study (46). The RCT of Outlook versus Attention Control versus True Control was in 82 patients with advanced cancer and end stage organ failure, predominantly males. The interventionist was a social worker trained by the intervention's developer with access to the manual (27). There was a greater than 50% attrition rate due to deterioration and death. Non-significant improvements were shown in functional status (intervention group improved from 26.1 to 22.7, attention control improved from 26.3 to 24.8 whilst true control worsened from 28.4 to 28.3), anxiety (intervention group improved from 6.4 to 3.7, attention control worsened from 4.4 to 5.0 whilst true control worsened from 4.4 to 5.6), depression (intervention group improved from 11.8 to 9.1, attention control minimally improved 10.1 to 10.0 whilst true control worsened from 10.7 to 11.9) and end-of life preparation (intervention group improved from 3.4 to 3.7, attention control worsened from 4.0 to 3.8 whilst true control worsened from 4.2 to 3.4). No P values were recorded and the sample size was not large enough to demonstrate significance.

Outcome measures in the single arm study of Outlook with 11 advanced cancer and end stage organ failure patients of which six were female with a 9% attrition rate, showed non-significant improvement in meaning/peace (21.6 improved to 23.9, $P= 0.08$) and end-of-life preparation (2.67 improved to 2.97, $P= 0.07$). Sample size was not large enough to show effect. The interventionist was a palliative care research nurse coached by the intervention developer with access to the manual (46).

Discussion

In this systematic review of 14 articles, reporting 10 distinct therapeutic life review interventions, were identified and data extracted. This small number of results reflected the early stage of development of this literature. However there were a few robust RCTs in which significantly improved patient outcomes were reported. These interventions with further investigation may prove to be 'well-established' empirically-validated treatments, warranting widespread clinical application. Due to the diversity in interventions and measures it is difficult to promote one intervention as the most effective way to conduct therapeutic life review with patients with advanced life threatening illnesses. However it is this diversity that will allow the palliative care practitioner to choose an intervention to suit their clientele, consider conducting their own research study thereby adding to the evidence-

base for the intervention or adding the intervention to their practice to improve patient outcomes and provide truly holistic care.

A weakness of several of the studies was inadequate power due to insufficient sample size and/or high attrition rates. As is the case with many interventions in the palliative care setting, where an attrition rate of 35% is considered common (47), failure to complete the interventions was primarily due to death, fatigue or symptom burden, rather than dissatisfaction. The interventions with the highest attrition rates (Meaning Centered Group Psychotherapy (39), Life Review Intervention (36) and Outlook (27)) were also those with multiple patient-interventionist sessions. Even excluding interventionist time alone creating documents or analysing interviews, these interventions were conducted over the longest period of time and ultimately reported limited or non-significant outcomes.

Shorter interventions fared better. Meaning Centered Group Psychotherapy (39) was re-configured and slightly condensed and resulted in a lower attrition rate and more effective intervention in Individual Meaning-Centered Psychotherapy (24). Similarly, One Week Short Term Life Review therapy, which was adapted from Life Review Intervention, and evaluated in two separate studies, had better than expected attrition rates considering the proximity to death of the participants (67 and 28 days respectively), and positive results on two validated scales, FACIT-Sp. and HADS (23, 38). It would appear that the briefer interventions are more effective in those more proximal to death, a population with high rates of fatigue and symptom burden (48).

Another common deficiency in the literature was failure to screen participants for distress or need, prior to the intervention. Thus several studies which reported negative results noted low or minimal morbidity pre-intervention, leaving little room for improvement (27, 41, 46). Whereas Forgiveness therapy participants were only included if they had a sense 'of being treated unjustly and hurt deeply by another'; this study demonstrated significant improvements in forgiveness, anger and hope (42). Tighter selection criteria might provide a fairer test of these interventions.

Dignity Therapy, in a single arm study of patients with an average of 40 days from intervention until death showed limited but positive results (25) however these were not replicated in the larger RCT which found no significant improvements despite being well reviewed in the participant evaluation (41) and using a validated custom-made tool (49). This was an unfortunate outcome as the study had a large sample size and a good study design. Had the RCT of Dignity Therapy shown significant results, the intervention would be classified as a well-validated intervention (34). The negative results may be in part due to the intervention being simultaneously conducted in three countries, making it difficult to maintain

protocol adherence across large distances. Furthermore, cultural perceptions of such interventions have been shown to differ. One study comparing Korean, Japanese and American palliative care patients undergoing therapeutic life review found differences in perceptions of both the questions asked in the intervention and patients' primary concerns. The authors concluded that interventions need to be tailored to meet the cultural expectations of participants (50).

The Meaning of Life intervention (45) required the least amount of interventionist training, level of patient functioning and education, yet this study still produced statistically significant results. However, study efficacy was measured using a single item quality of life scale which some may argue is not adequate, and a more comprehensive scale which had been validated only in a Chinese population. It is a challenge for researchers in this field to use measures which are neither too burdensome whilst giving adequate detail (51) and are understood by the culture in which it is used. Although translation and validation of tools in different cultures is time-consuming it is an important part of research, allowing for more equitable comparisons and robust results (52).

How generally applicable the intervention is to the palliative care population and the degree of staff training and time required are also all important factors when considering the feasibility and efficacy of these interventions. The importance of adequate staff training was highlighted in an evaluation of the Meaning-Making intervention, in which an unexpected finding was a three-fold increase in participants' use of external psychological support, thought to be due to either increasing vulnerability or proactivity of the participants (26). A subsequent study of the same intervention reported a 12% attrition rate, with one patient withdrawing as her coping mechanism of denial had been removed by the intervention (44). This highlights the need for the interventionist to be adequately trained, and the requirement for contingency psychological care.

Several interventions resulted in an end legacy product (Legacy Activities, Dignity Therapy, Meaning of Life, One Week Short Term Life Review, Outlook (single arm study) and Meaning Making Intervention) which may be helpful to the bereaved carers, as one researcher has studied (53). Legacy Activities specifically created an end product, and positively improved carers' level of stress as well as patients' level of interaction and perceived physical symptoms (35). Carer outcomes should perhaps be explored more extensively in future research.

Of course, creating legacy products are time consuming for the interventionist and possibly costly. The Legacy Activities participants were given US\$25 to buy supplies to create their legacy product and a qualitative study of Dignity Therapy created legacy documents for

around US\$17 each (54). This raises the question of reimbursement by health care insurers for which more robust evidence would be required, or accessing of donated funds to complete the intervention.

Despite being shown to be helpful, therapeutic life review interventions are not widely practiced. This may be in part because these interventions are perceived to be time consuming or the sole domain of the psychologist or social worker (55). A recent study of hospice and palliative care social workers found that although the value of life review was acknowledged, engagement was low due to high case loads, patient length of stay (not enough time) and high patient acuity (56). In the current review, nine of the identified interventions were conducted by a clinical psychologist, psychiatrist or social worker but several had the potential to be conducted by nurses, other healthcare workers such as personal care attendants or trained volunteers. This flexibility may improve uptake of life review interventions as psychosocial professionals may not always be available and patients may be reluctant to engage with them due to the stigma of mental ill-health (57). Nurses may prove to be a viable option as patients want to talk about their lives with nurses (58, 59) and front-line practitioners, including nurses, wish to provide holistic palliative care (60, 61).

Limitations and Future Research Directions

A limitation of this study is that despite using a validated search filter and MeSH terms identified on the publications, there is still potential to have missed or excluded a study which would have contributed to this discussion.

Future research directions could be conducting feasibility studies of the shorter interventions by front line workers without protected research time, for example community palliative care nurses, evaluating the effect on both the participant, the interventionist and their professional relationship. Extension of such a feasibility study could be to examine the long term effects on the grieving family and care-givers of the interventions, in particular those which create legacy products which could potentially reduce complicated bereavement.

Two problems common to the many of the interventions was the high rates of attrition due to death or deterioration of the participant, and ceiling effects on baseline measures which reduced the power of the studies and the potential to show statistical improvement. One approach to address these short comings could be to conduct multi-centre trials to increase the potential number of participants to be recruited, allowing more stringent inclusion criteria of elevated pre-intervention distress. Additionally, ensuring use of the most appropriate tool for measuring pre and post intervention constructs is essential, although this can add a layer of complexity for researchers in non-English speaking countries who must first validate the tool in their language and culture.

Conclusion

In this systematic review ten distinct interventions were identified, evaluated in adequate to good quality studies with some positive, some negative and some unexpected findings. Eight of the interventions were judged to be probably efficacious treatments. The interventions could be conducted with palliative care patients, days to months before their deaths, in one to eight sessions of 15 to 160 minutes per session. The interventions required little to comprehensive training to conduct and all had a manual available or detailed description in the article. Many interventions resulted in creating a legacy product which may be helpful for the bereaved family as well. Therapeutic life review interventions are showing promise as a viable option in helping palliative care patients to address their existential/spiritual domains, an area often under treated.

Disclosure and acknowledgements

The authors acknowledge that their own work was included in this systematic review as it met the inclusion criteria. The authors wish to thank Ms. Alison Hession R.N., M.S. for her assistance with screening the articles for inclusion. The first author wishes to thank both the University of Sydney and Hammond Care for their support of this project. This review was conducted as part of the first author's PhD thesis with no additional funding.

REFERENCES

1. World Health Organisation. Definition of Palliative Care 2013. Available from: <http://www.who.int/cancer/palliative/definition/en/>. Accessed 16th October, 2013.
2. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine* 2010;363:733-742.
3. Steinhauser KE, Clipp EC, McNeilly M, et al. In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine* 2000;132:825-832.
4. Rainbird K, Perkins J, Sanson-Fisher R, Rolfe I, Anseline P. The needs of patients with advanced, incurable cancer. *British Journal of Cancer* 2009;101:759-764.
5. Rodriguez KL, Bayliss N, Alexander SC, et al. How oncologists and their patients with advanced cancer communicate about health-related quality of life. *Psycho-Oncology* 2010;19:490-499.
6. Leung D, Esplen MJ. Alleviating existential distress of cancer patients: Can relational ethics guide clinicians? *European Journal of Cancer Care* 2010;19:30-38.
7. Bailey ME, Moran S, Graham MM. Creating a spiritual tapestry: nurses' experiences of delivering spiritual care to patients in an Irish hospice. *International journal of palliative nursing* 2009;15:42-8.
8. Boston P, Bruce A, Schreiber R. Existential Suffering in the Palliative Care Setting: An Integrated Literature Review. *Journal of Pain and Symptom Management* 2011;41:604-618.
9. LeMay K, Wilson KG. Treatment of existential distress in life threatening illness: A review of manualized interventions. *Clinical Psychology Review* 2008;28:472-493.
10. Georgesen J, Dungan JM. Managing spiritual distress in patients with advanced cancer pain. *Cancer Nursing* 1996;19:376-383.
11. Bohlmeijer E, Smit F, Cuijpers P. Effects of reminiscence and life review on late-life depression: a meta-analysis. *International Journal of Geriatric Psychiatry* 2003;18:1088-1094.
12. King DA, Heisel MJ, Lyness JM. Assessment and psychological treatment of depression in older adults with terminal or life-threatening illness. *Clinical Psychology-Science and Practice* 2005;12:339-353.
13. Eychmueller S. Management of depression in the last month of life. *Current opinion in supportive and palliative care* 2009;3:186-189.
14. Stinson CK, Kirk E. Structured reminiscence: an intervention to decrease depression and increase self-transcendence in older women. *Journal of Clinical Nursing* 2006;15:208-218.
15. Haber D. Life Review: Implementation, Theory, Research, and Therapy. *International Journal of Aging and Human Development* 2006;63:153-171.

16. Mastel-Smith B, Binder B, Malecha A, et al. Testing therapeutic life review offered by home care workers to decrease depression among home-dwelling older women. *Issues in Mental Health Nursing* 2006;27:1037-1049.
17. Binder B, Mastel-Smith,B., Hersch, G., Symes,l.,Maleecha,A. and McFarlane,J. Community-dwelling,Older Women's Perspectives on Therapeutic Life Review: A Qualitative Analysis. *Issues in Mental Health Nursing* 2009;30:288-294.
18. Davis MC. Life review therapy as an intervention to manage depression and enhance life satisfaction in individuals with right hemisphere cerebral vascular accidents. *Issues Ment Health Nurs* 2004;25:503-15.
19. Chiang KJ, Lu RB, Chu H, Chang YC, Chou KR. Evaluation of the effect of a life review group program on self-esteem and life satisfaction in the elderly. *International Journal of Geriatric Psychiatry* 2008;23:7-10.
20. Erlen JA, Mellors MP, Sereika SM, Cook C. The use of life review to enhance quality of life of people living with AIDS: a feasibility study. *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation* 2001;10:453-464.
21. Haight BK, Michel Y, Hendrix S. Life review: preventing despair in newly relocated nursing home residents short- and long-term effects. *International journal of aging & human development* 1998;47:119-142.
22. Lichter I, Mooney J, Boyd M. Biography as therapy. *Palliative medicine* 1993;7:133-7.
23. Ando M, Morita T, Akechi T, Okamoto T. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *Journal of Pain & Symptom Management* 2010;39:993-1002.
24. Breitbart W, Poppito S, Rosenfeld B, et al. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *Journal of Clinical Oncology* 2012;30:1304-1309.
25. Chochinov HM, Hack T, Hassard T, et al. Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Oncology* 2005;23:5520-5525.
26. Lee V, Cohen SR, Edgar L, Laizner AM, Gagnon AJ. Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Social Science & Medicine* 2006;62:3133-3145.
27. Steinhauser KE, Alexander SC, Byock IR, et al. Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *Journal of Palliative Medicine* 2008;11:1234-1240.

28. Stagg EK, Lazenby M. Best practices for the nonpharmacological treatment of depression at the end of life. *Am J Hosp Palliat Care* 2012;29:183-94.
29. Liberati A, Altman DG, Tetzlaff J, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Journal of clinical epidemiology* 2009;62:e1-e34.
30. Sladek R, Tieman J, Fazekas BS, Abernethy AP, Currow DC. Development of a subject search filter to find information relevant to palliative care in the general medical literature. *J Med Libr Assoc* 2006;94:394-401.
31. Krumholz HM, Currie PM, Riegel B, et al. A taxonomy for disease management - A scientific statement from the American Heart Association Disease Management Taxonomy Writing Group. *Circulation* 2006;114:1432-1445.
32. Currow D, Tieman J, Greene A, et al. Refining a Checklist for Reporting Patient Populations and Service Characteristics in Hospice and Palliative Care Research. *Journal of Pain & Symptom Management* 2012;43:902-910.
33. Kmet LM, Lee RC, Cook LS. Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields. In: Edmonton, Alberta: Alberta Heritage Foundation for Medical Research, 2004.
34. Chambless DL, Hollon SD. Defining empirically supported therapies. *Journal of Consulting and Clinical Psychology* 1998;66:7-18.
35. Allen RS, Hilgeman MM, Ege MA, Shuster JL, Burgio LD. Legacy Activities as Interventions Approaching the End of Life. *Journal of Palliative Medicine* 2008;11:1029-1038.
36. Ando M, Tsuda A, Morita T. Life review interviews on the spiritual well-being of terminally ill cancer patients. *Supportive Care in Cancer* 2007;15:225-231.
37. Haight BK, Bahr RT. The therapeutic life review in the the elderly. In: *Academic Psychology Bulletin*, Detroit: Michigan Psychological Association, 1984.
38. Ando M, Morita T, Okamoto T, Ninosaka Y. One-week Short-Term Life Review interview can improve spiritual well-being of terminally ill cancer patients. *Psychooncology* 2008;17:885-90.
39. Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psycho-Oncology* 2010;19:21-28.
40. Breitbart W. Spirituality and meaning in supportive care: Spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Supportive Care in Cancer* 2002;10:272-280.
41. Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncology* 2011;12:753-762.

42. Hansen MJ, Enright RD, Baskin TW, Klatt J. A Palliative Care Intervention in Forgiveness Therapy for Elderly Terminally Ill Cancer Patients. *Journal of Palliative Care* 2009;25:51-60.
43. Lee V. The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Care Cancer* 2008;16:779-85.
44. Henry M, Cohen SR, Lee V, et al. The Meaning-Making intervention (MMi) appears to increase meaning in life in advanced ovarian cancer: a randomized controlled pilot study. *Psycho-Oncology* 2010;19:1340-1347.
45. Mok E, Lau K-P, Lai T, Ching S. The Meaning of Life Intervention for Patients With Advanced-Stage Cancer: Development and Pilot Study. *Oncology Nursing Forum* 2012;39:E480-8.
46. Keall RM, Butow PN, Steinhauser KE, Clayton JM. Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care setting: results from a phase 2 trial. *Cancer Nursing* 2013;36:E39-46.
47. Palmer JL. Analysis of missing data in palliative care studies. *Journal of Pain & Symptom Management* 2004;28:612-618.
48. Oh HS, Seo WS. Systematic review and meta-analysis of the correlates of cancer-related fatigue. *Worldviews Evid Based Nurs* 2011;8:191-201.
49. Chochinov HM, Hassard T, McClement S, et al. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *Journal of pain and symptom management* 2008;36:559-571.
50. Ando M, Morita T, Ahn S, Marquez-Wong F, Ide S. International comparison study on the primary concerns of terminally ill cancer patients in short-term life review interviews among Japanese, Koreans, and Americans. *Palliative & Supportive Care* 2009;7:349-355.
51. Sloan JA, Aaronson N, Cappelleri JC, Fairclough DL, Varricchio C. Assessing the Clinical Significance of Single Items Relative to Summated Scores. *Mayo Clinic Proceedings* 2002;77:479-487.
52. Sperber AD. Translation and validation of study instruments for cross-cultural research. *Gastroenterology* 2004;126:S124-S128.
53. McClement S, Chochinov HM, Hack T, et al. Dignity therapy: family member perspectives. *Journal of palliative medicine* 2007;10:1076-1082.
54. Johns SA. Translating Dignity Therapy into Practice: Effects and Lessons Learned. *Omega: Journal of Death & Dying* 2013;67:135-145.
55. Keall RM, Clayton JM, Butow PN. Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions. *Journal of Hospice & Palliative Nursing* 2014;16:105-112.
56. Csikai EL, Weisenfluh S. Hospice and palliative social workers' engagement in life review interventions. *Am J Hosp Palliat Care* 2013;30:257-63.

57. Schomerus G, Matschinger H, Angermeyer MC. The stigma of psychiatric treatment and help-seeking intentions for depression. *European Archives of Psychiatry and Clinical Neuroscience* 2009;259:298-306.
58. Hermann CP. The degree to which spiritual needs of patients near the end of life are met. *Oncology Nursing Forum* 2007;34:70-78.
59. Tan H, Braunack-Mayer A, Beilby J. The impact of the hospice environment on patient spiritual expression. *Oncol Nurs Forum* 2005;32:1049-1055.
60. Sinclair S, Raffin S, Pereira J, Guebert N. Collective soul: the spirituality of an interdisciplinary palliative care team. *Palliative & supportive care* 2006;4:13-24.
61. Keall RM, Clayton JM, Butow PN. How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies. *Journal of Clinical Nursing* 2014;*in press*.

Author & journal	Patient sample	Intervention/ Study design	Delivery personnel/ Setting	Intervention duration, frequency & complexity	Outcome Measures & follow-up frequency	Results	Qual-syst.
Allen <i>et al.</i> 2008, J. Palliative Medicine.	n= 31 dyads Frail, Cancer, Dementia 75.29 yrs. (av.) Female=71% Ed.=12.6 yrs.(av.) Afro-American= 49 C-g required. AR= 26%	Legacy Activities/ RCT	SW, CP/ Pt.s' home	66-82 mins/ session 3 sessions approx. weekly. Int. training, readings & supervised role play	PSM, ADL, SuWB, ESAS, BMMRS, CES-D, C-GSS. Measures at baseline & 1 week post	Sig. in c-g stress (P= 0.034), c-g report of pt. talkativeness (P= 0.016), pt. talkativeness (P= 0.019), SOB (P= 0.026). NS in pain.	75%
Ando <i>et al.</i> , 2007, Supportive Care in Cancer.	n= 12 Cancer 63 yrs. (av.) Female= 84% Asian= 100% AR= 43%	Life Review Interviews/ Single arm	CP./ Inpatient	Session time not stated 4 sessions over several days Minimal complexity	SELT-M Measures at baseline & post	Sig. in spirituality (P= 0.023), overall qol (P= 0.013), mood (P= 0.008), orientation (P= 0.041). NS in support, physical health	85%
Ando <i>et al.</i> , 2008, Psycho-Oncology	n= 30 Cancer 74 yrs. (av.) Female n= 22 Asian= 100% ECOG 4 n=14 Days= 67 (av.) AR= 14%	One Week Short Term Life Review/ Single arm	CP/ Inpatient or pt.'s home	30-60 mins./session 2 int.-pt. sessions 1 week to create legacy product Training required	FACIT-Sp., HADS, Intensity of psychological suffering. Measures at baseline & post	Sig. in for FACIT-Sp. (P= 0.001), anxiety (P= 0.001), depression (P= 0.001), total HADS (P= 0.001), sufferings (P= 0.001), happiness (P= 0.002)	90%
Ando <i>et al.</i> , 2010, J Pain & Symptom Management	n= 68 Cancer 65 yrs. (av.) Female n=36 Asian= 100% ECOG 4 n=30, Days= 28 (av.) AR= 12%	One Week Short Term Life Review/ RCT	CP/ Inpatient	30-60 mins/ session 2 int.-pt. sessions 1 week to create legacy product Training required	FACIT-Sp., HADS, GDI, Intensity of psychological suffering Measures at baseline & post	Sig. in meaning (P= <0.00), hope (P= <0.00), life completion (P= <0.007), suffering (P= 0.01), HADS (P= <0.00). NC for control or physical symptoms	79%
Breitbart <i>et al.</i> , 2010, Psycho-Oncology	n= 90 Cancer 60.1 yrs. (av.) Female= 50% Ed.= 16.6 yrs. (av.), Caucasian= 77% AR > 66%	Meaning Centered Group Psychotherapy/ RCT	Psych., CP plus 1-2 assistants/ Outpatient	60 mins/session 8 weekly sessions 24-28 hours training for facilitators.	FACIT-Sp., Beck Hopelessness, SATHD, LOT, HADS, KPS. Measures at baseline, post & 2 months post	Sig. in meaning (P= 0.0001), FACIT-Sp total (P= 0.0001). NS in hopelessness, desire for death, anxiety. NC for control	93%

Breitbart <i>et al.</i> , 2012, J. Clinical Oncology	n= 120 Cancer 54.5 yrs. (av.) Female= 55% Ed.= 16.9 yrs. (av.) Caucasian= 82.4% KPS >50 AR= 34%	Individual Meaning Centered Psycho- therapy/ RCT	CP/ Outpatient	60 mins/session 7 weekly sessions Intensive training required	FACIT-Sp., MQOL, HADS, Beck Hopelessness, MSAS, KPS. Measures at baseline, post & 2 months post	Sig. in FACIT-Sp-total (P< 0.001), meaning (P= 0.003), faith (P= 0.03). MQOL (P= 0.013), MSAS-Sx (P< 0.001), MSAS-Di (P= <0.001). NC hopelessness, anxiety or depression	93%
Chochinov <i>et al.</i> , 2005, J. Clinical Oncology	n= 100 Cancer 69.5 yrs. (av.) Female n= 44 HS Ed.= 33% Days= 40 (av.) AR=22%	Dignity Therapy/ Single arm	CP, psych. & nurses/ Inpatients & pt.'s home	60 mins./session 2 int.-pt. sessions 7-10 days to make legacy product. 3 day training	ESAS & single item for; depression, dignity, anxiety, hopelessness, desire for death, suicide & sense of well-being. Baseline & post intervention	Sig. in suffering (P= 0.023), depressed mood (P= 0.05). NS in dignity, hopelessness, desire for death, suicide & will to live. More Sig.in pts. with high pre-test distress	80%
Chochinov <i>et al.</i> , 2011, The Lancet	n= 441 Cancer 64.2 yrs. (av.) Male =52% HS Ed.= 35% Caucasian= 91% PPS= 44.2 (av.) Days=110 (av.) AR= 25%	Dignity Therapy/ RCT	CP, psych. & nurses/ Inpatients & pt.'s home	60 mins./session 2 int.-pt. session 4 days to make the legacy product 3 day training	PPS, FACIT-Sp., PDI, HADS, SISC, qol scale, ESAS Measures at baseline & post	NC in distress, depression or desire for death. Pt evaluated more satisfaction with Dignity Therapy (P< 0.0001). Secondary analysis Sig. spiritual well- being (P= 0.006) & depression than control (P= 0.009)	89%
Hansen <i>et al.</i> , 2009, J. Palliative Care	n=20 Cancer 64-82 yrs. Female n= 18 Middleclass= 100% Caucasian= 95% AR= 0%	Forgive-ness Therapy/ cohort	SW/ Outpatients	60 mins./session 4 weekly sessions Int. training required	MQOL, HHI, State Anger Scale, Enright forgiveness inventory. Measures at baseline post & 4 weeks post	Sig. in forgiveness (P< 0.001), anger (P< 0.001), hope (P< 0.001) & qol (P< 0.01)	82%
Lee <i>et al.</i> , 2006, Social Science & Medicine	n=74 Cancer, 57 yrs. (av.) Female n=28 HS Ed. = 41% AR= 8%	Meaning- Making/ RCT	CP or nurse/ Clinic or pt.'s home	Up to 120 mins./sessions 1-4 sessions Int. training required	RSES, LOT, GSES, Measures at baseline & post	Sig. in self-esteem (P= 0.006), optimism (P= 0.019) & self-efficacy (P= 0.002). 2 fold increase (control), 3 fold increase (int. group) in ext. psych. use	89%
Henry <i>et al.</i> , 2010, Psycho-Oncology	n=24 Ovarian Cancer Female= 100% Caucasian= 96% AR= 14%	Adaptation of Meaning- Making/ RCT	CP/ Clinic or pt.'s home	90 mins (av.)/session 1-4 sessions Int. training required	FACIT-Sp., MQOL, HADS, GSES. Measures at baseline, 1 & 3 months post	Sig. in meaning (P= 0.04), & after 3 months support (P= 0.03). Initial NS in existential well-being (P= 0.08) with improvement over time (P= 0.03)	86%

Mok <i>et al.</i> , 2012, Oncology Nursing Forum	n=84 Cancer Female n= 39 Illiterate n=19 HS Ed. n= 28 Walking n= 36 In bed n=15 AR=31%	The Meaning of Life / RCT	Nurse/ Inpatient	15-60 mins/session 2 int.-pt. sessions 60-120mins.making legacy product Minimal training	QOLC-E, single item qol scale Measures at baseline, one day & two weeks post.	Sig. in existential distress (P< 0.05), QOLC-E total (P< 0.05) & qol (P< 0.05).	89%
Steinhauer <i>et al.</i> , 2008, J. Palliative Medicine	n= 82 Cancer, heart & lung disease Female n= 38 Afro-American=35 HS Ed. =47% AR >50%	Outlook/ RCT	SW or CP/ Inpatient & pt.'s home	45-60 mins/session 3 weekly sessions Int. training required	CESD,POMS, Rosow-Breslau ADL, Daily Spiritual Experience, QUAL-E, MSAS Measures at baseline, 1 & 2 weeks post	NS in end of life preparation sub-scale, depression, anxiety & ADL. NC or Worse for controls	75%
Keall <i>et al.</i> , 2013, Cancer Nursing	n=11 Cancer 50-89 yrs. Female n=6 HS Ed.= 40%, Caucasian = 50% AR= 9%	Outlook / Single arm	Nurse/ Inpatient & pt.'s home	Sessions 40- 160 minutes 3 weekly sessions Minimal training required	CESD,POMS, FACIT-Sp., MSAS QUAL-E, Measures at baseline and 1 week post	NS in FACIT Sp. peace/meaning subscale (P= 0.08) & end-of-life preparation sub scale (P= 0.07)	85%

Patient sample descriptors for available data; life limiting illness, age, gender, socio-economic indices (including Ed. = years of education completed & HS= high school education completed), ethnicity, performance status, days from referral to death (Days), care-giver availability (c-g), attrition rate (AR)

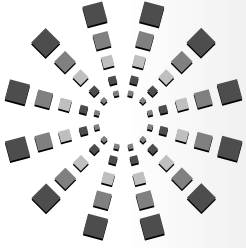
Abbreviations; J.= Journal of, n=number, pt.= patient, int.= interventionist, yrs.= years, mins= minutes, av.= average, Sig.= significant improvement, NS = non-significant improvements, NC= no change, CP= clinical psychologist, SW= social worker, psych. = psychiatrist, qol= quality of life, SOB= shortness of breath, ext. psych.= external psychological support

Abbreviation for measures; PSM= Physical Self-Maintenance, SuWB= Subjective well-being, BMMRS= Brief Multidimensional Measure of Religion and Spirituality, C-GSS= Caregiver Stressors Scale, FACIT-Sp.= Functional Assessment of Cancer Therapy- spirituality well-being, POMS= Profile of Mood States, QUAL-E= qol at End-of-Life, CESD= Center for Epidemiological Depression Scale, MSAS = Memorial Symptom Assessment scale, (MSAS-Sx= symptoms number, MSAS- Di= distress level), ADL= activities of daily living, QOLC-E= qol concerns in the end-of-life, HHI= Herth Hope Index, SELT- M= Skalen zur erfassung von Lebens qualitat bei tumorkranken, HADS= Hospital Anxiety Depression scale, GSES= General Self-Efficacy Scale, RSES= Rosenberg Self-esteem Scale, LOT= Life Orientation Test-Revised, PPS= Palliative Performance Scale, PDI= Patient Dignity Inventory, ESAS= Edmonton Symptom Assessment scale, SISC= Structured Interview of Symptoms and Concerns in Pall Care, KPS= Karnofsky Performance Scale, MQOL= McGill qol scale, SATHD= Schedule of attitudes toward hastened death, GDI= Good Death Inventory

CHAPTER 3

Nurse-Facilitated Preparation and Life Completion Interventions are Acceptable and Feasible in the Australian Palliative Care Setting: Results from a Phase 2 Trial

This chapter contains the systematic review titled “Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care setting: results from a phase 2 trial” Published in *Cancer Nursing* (2013; 36 (3) E39-46)



Robyn M. Keall, MS, RN
Phyllis N. Butow, PhD, M ClinPsych, BA(Hons)
Karen E. Steinhauser, PhD, MA, BA
Josephine M. Clayton, PhD, MBBS(Hons),
FRACP, FACHPM

Nurse-Facilitated Preparation and Life Completion Interventions Are Acceptable and Feasible in the Australian Palliative Care Setting

Results From a Phase 2 Trial

KEY WORDS

Palliative care
Quality of life
Spirituality
Terminal care

Background: Existential/spiritual needs of advanced cancer patients are not always met in healthcare. Potential barriers for health professionals exploring existential concerns include lack of time, training, tools, and confidence. Yet patients with life-threatening illnesses require holistic care, and interest in their existential/spiritual needs is growing. Preparation and life completion interventions have shown positive results in the existential/spiritual care of hospice-eligible patients in the United States. Nurses are in the ideal position to deliver such interventions, but have not been previously evaluated in this context. **Objective:** The objective of this study was to explore the acceptability and feasibility of a nurse-facilitated preparation and life completion intervention (Outlook) in an Australian palliative care patient population. **Methods:** Patients discussed their life story, forgiveness, and heritage and legacy over 3 audiotaped sessions. Preintervention/postintervention outcome measures included the Memorial Symptom Assessment Scale, Functional Assessment of Cancer Therapy–Spirituality Well-being, Profile of Mood States, Quality of Life at End of Life Scale, and Center for Epidemiological Depression Scale. Participant feedback was subjected to thematic analysis to

Author Affiliations: Centre for Medical Psychology and Evidence-Based Decision Making, University of Sydney (Ms Keall and Drs Butow and Clayton), and Hammond Care Palliative and Supportive Care Service, Greenwich Hospital (Ms Keall and Dr Clayton), Sydney, Australia; Center for Health Services Research in Primary Care, Center for Palliative Care Duke University, Durham, North Carolina (Dr Steinhauser); Department of Palliative Care, Royal North Shore Hospital, Sydney, Australia (Dr Clayton).

This study was presented orally at the Biennial Australian Palliative Care Nurses Conference, Brisbane, Australia, in 2010.

This work was supported in part by a Cancer Institute NSW Clinical Research Fellowship for Ms Clayton. The work received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

The authors have no conflicts of interest to disclose.

Correspondence: Robyn M. Keall, MS, RN, Department of Cancer Medicine, Blackburn Bldg, University of Sydney, New South Wales 2060, Australia (robyn.keall@sydney.edu.au).

Accepted for publication June 22, 2012.

DOI: 10.1097/NCC.0b013e3182664c7a

understand the patient experience of receiving the intervention. **Results:** Ten palliative care patients with advanced cancer completed the study. Patients reported the intervention and assessments to be acceptable and feasible and to be overall positively received although with nonsignificant improvements in measures of “meaning and peace” and “preparation for end of life.” **Conclusion:** A nurse-facilitated preparation and life completion intervention is acceptable and feasible for palliative care patients with advanced cancer in Australia. **Implications for Practice:** Outlook is a novel, portable, and feasible tool for use by nurses when addressing existential and spiritual domains of care with patients with advanced cancer.

The goal of palliative care (PC) for patients with advanced cancer is to be holistic, encompassing all the domains of personhood: physical, psychosocial, spiritual, and existential.¹⁻⁴ However, some domains receive more attention than others. For example, a search through Scopus for English-language articles since 2000 about “pain” and “advanced cancer” yielded 4048 results, whereas during the same period, “spiritual care” and “advanced cancer” yielded only 104 articles. Similarly, a recent study of oncologists’ discussion with patients about health-related quality of life documented that oncologists focused on physical concerns 27% of the time, whereas spiritual concerns were rarely touched upon (1%).⁵ For some patients, existential concerns can be more distressing than physical ones.⁶

Lack of attention to spiritual and existential issues in oncology may be multifactorial including inadequate professional preparation and tools⁷ and clinician discomfort associated with discussing emotional issues and potentially exposing one’s inner self.⁸ Existential care is not considered part of the medical model⁹ and thus is not common part of physician or nurse training. The care of the spirit is usually addressed by pastoral care workers, but pastoral care workers are not always available, and for some persons, pastoral care workers may not be acceptable, indicated by fewer individuals who identify themselves as practicing a particular religion.^{10,11} Religion and spirituality are not interchangeable terms; spirituality is defined as “...the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”¹²

In order to address this deficit in the provision of holistic care, interventions that have proven effective in non-life-limiting illnesses, such as depression in the elderly, have been adapted for use in the PC population. For example, life review,^{13,14} which has been shown to be effective as a treatment and prophylaxis of depression in the older person,¹⁵⁻¹⁷ is now proven effective in alleviating depression and anxiety and preparation for end of life, among other measures, in patients with life-threatening illnesses.¹⁸⁻²² Life review draws on Erikson’s²³ stages of psychosocial development especially the developmental stages of “generativity versus stagnation,” where one is challenged to formulate a lasting legacy, and “ego integrity versus despair,” where one can judge the merit of one’s life. It is during these life stages that life review may be particularly useful to assist a person to feel that his/her life

has been meaningful and to see a peaceful and just conclusion to life.¹⁷ If this is not achieved, despair in the form of guilt and remorse may dominate. For those facing premature death from advanced illness, failing to achieve either generativity or ego integrity may lead to existential and spiritual distress.¹⁹

K.E.S. and her colleagues²² tested an intervention that builds on life review called Outlook. This intervention was based in their earlier work that identified emotional and spiritual well-being as integral to quality of life at the end of life.²⁴ Outlook focuses on domains identified as important to patients with life-limiting illnesses, specifically “preparation for end of life” and “life completion.” In their study, Outlook was evaluated in a 3-armed randomized controlled trial with 82 hospice-eligible patients from the United States. Participants randomized to the intervention arm showed improved functional status and end-of-life preparation and decreased anxiety and depression, whereas the true control arm (no intervention vs attention control) had unchanged or worsened results measured using reliable, peer-reviewed psychometrics.²²

In the study of K.E.S. and her colleagues,²² a social worker facilitated the intervention. However, in routine care, oncology nurses may be in an ideal position to deliver such interventions because cancer patients often have years of outpatient treatments or protracted inpatient stays, allowing the building of a nurse-client trustful relationship. The oncology nurse who has delivered the regular chemotherapy or care in the clinic, hospital, or community setting may be more acceptable to some advanced cancer patients than pastoral care or psychosocial health professionals when discussing existential and psychological concerns due to the relationship formulated over the illness trajectory.²⁵ The first aim of our study therefore was to explore the feasibility of a nurse facilitating the Outlook intervention and its potential applicability for use in clinical practice by nursing staff.

A second aim of our study was to explore the acceptability of the intervention in an Australian healthcare context through participant evaluation of the intervention. Factors that may affect the acceptability and efficacy of Outlook in other cultures include the ethnic and religious mix of the population and patterns of PC. Australia, for example, is heterogeneous in its cultural and ethnic demography and has an overall lower religiosity than the United States^{10,11}; thus, an intervention focusing on spirituality may be less accepted. Referral patterns to PC services and possible acknowledgement of advanced illness also follow

different patterns, with the United States having later referrals to PC than Australia.²⁶ Thus, patients in the PC setting in Australia may have longer to live than those in the United States and may find an intervention containing elements of life review and legacy difficult to accept at this earlier stage of the disease trajectory.

■ Methods

We conducted a mixed-methods study to assess acceptability and feasibility of a life-review intervention (Outlook). This study included quantitative preintervention and postintervention psychometrics, quantitative and qualitative measures of participant's evaluation of the intervention (reported here), and qualitative analysis of participants' responses to the intervention questions (results reported elsewhere²⁷). Qualitative measures were subjected to thematic analysis.

Setting and Participants

All patients were recruited from the specialist PC services in Northern Sydney through one of the following arms of the PC service: teaching hospital consultative service, inpatient PC unit, or outpatient community settings. Inclusion criteria for the study were having a diagnosis of life-threatening illness with a prognosis of less than 2 years and being cognitively intact and older than 18 years. Patients who were not fluent in English were excluded as there was no provision to employ interpreters.

Ethics approval was granted by the University of Sydney ethics committee, as well as the ethics committees of participating hospitals/services.

Procedure

Several PC clinicians were invited to enroll their patients in the study after an explanatory presentation. Eligible participants were identified by their clinicians as meeting the study criteria and then approached by the research assistant and given the study sheet. The study was introduced as an opportunity for life review (reflecting on one's life and how one wants to be remembered). Written consent was obtained, and baseline measures were administered immediately afterward. The life-review intervention (Outlook) was then implemented (below). One week following the intervention, the research assistant again met with the participant and administered the final questionnaires and a brief assessment interview.

The Intervention

The preparation and life completion intervention was similar to the Outlook intervention described by K.E.S. and her colleagues²² and included 3 sessions, exploring life story, forgiveness, and legacy. Participants were guided through predetermined questions and were permitted to respond with as much or as little detail as they wished. The session content is shown in Table 1. As

in the US study, sessions were scheduled 1 week apart except when this was inconvenient or not possible because of patient illness. In contrast to the US study, where the intervention was delivered by a social worker, our intervention was delivered by an experienced PC nurse. Prior to commencing the study, the nurse received instruction regarding the Outlook intervention. This involved the nurse reading the Outlook manual and a teleconference support session with K.E.S. (original intervention author), each lasting approximately 30 minutes. As per the original protocol, at the completion of each session, participants were given laminated cards containing information regarding the content of each of the 3 sessions—life story, forgiveness, and heritage and legacy.

In an adaptation of the US Outlook intervention, we offered participants' audiotapes of their interviews, which were easily duplicated to a CD.

Patient Questionnaires, Assessment Interviews, and Research Nurse Observations

Preintervention and postintervention measures with sound psychometric properties, used previously with a PC population, were selected and included the following:

- Depression was assessed with the Center for Epidemiological Depression Scale, short version.²⁸ Patients are asked to rate how true 10 statements regarding mood are for them. Time involved around 2 minutes. Scores range from 0 to 30; scores of 8 or greater indicate depression.
- Symptoms were assessed using the Memorial Symptoms Assessment Scale.²⁹ The Memorial Symptoms Assessment Scale

 **Table 1 • Preparation and Life Completion Intervention Questions²²**

Session 1: Life Story	Session 2: Forgiveness	Session 3: Heritage and Legacy
Tell me about your life.	If you were to do things again, what might you do differently?	What are your most valuable lessons learned?
What are cherished times?	Are there things or times you regret?	What would you like to share with future generations?
Of what are you most proud?	Is there anyone to whom you would like to offer forgiveness?	If you could choose one thing to pass on as your legacy what would that be?
If someone were to make a movie of your life what would be important to include?	Is there anyone from whom you would like to ask forgiveness?	What things would you like to accomplish?

is a comprehensive scale, asking patients if they experience 32 symptoms and if so to rate the frequency, severity, and distress the symptoms cause them. This scale takes up to 10 minutes to complete depending on the amount of symptoms and produces several subscales; we used the Global Distress Index as it is considered more clinically significant. Scores range from 0 to 4. Higher scores indicate greater symptom burden.

- Anxiety was assessed with the Profile of Mood States³⁰ anxiety subscale. This scale includes 5 statements about anxiety, and the patient is asked to rate how true these are for them. This scale takes 2 minutes to complete. Scores range from 0 to 20. Higher scores indicate greater levels of anxiety.
- Quality of life at the end of life was assessed with the Quality of Life at End of Life Scale.³¹ The scale includes 16 statements that are either positively or negatively phrased about end-of-life care, and patients are asked to respond on how true they are for them. This scale generates several subscales including “sense of completion” and “preparation for end of life,” which we focused on. This scale takes 5 to 7 minutes to complete. Subscale scores range from 0 to 5, with higher scores indicating a greater quality of life.
- Spirituality well-being was assessed with the Functional Assessment of Cancer Therapy–Spirituality Well-being.³² This item is made up of 12 statements about faith, and patients are asked to rate how true they are for them. This scale takes 5 minutes to complete. Scores range from 0 to 32 overall and generate 2 subscales: “sense of meaning and peace” (scores 0–32) and “faith in illness” (scores 0–16). Higher scores indicate greater spiritual well-being.

Patient evaluation of the intervention was assessed quantitatively (Table 4) and qualitatively via postintervention evaluation interview (see Appendix for participant evaluation questions).

Research nurse observations were gathered from detailed notes taken after each intervention session and after completing the study.

Analysis

Quantitative data were entered into Predictive Analytics Software version 18.0 and analyzed using 1-tailed paired Student *t* tests. The purpose of this analysis was to evaluate the feasibility of the preintervention–postintervention measures and to examine for trends, to inform a future, larger study.

Thematic content analysis was used to analyze the participants’ evaluation of the intervention. Thematic content analysis portrays the thematic content of interview transcripts by identifying common themes in the texts. The researcher groups quotes and distills a list of common themes from the texts, to portray a shared experience across participants. The themes are named and described to reflect the actual words of participants. Although identifying and naming themes require some level of interpretation, “interpretation” is kept to a minimum.³³ For this analysis, transcripts were read individually (R.K. and P.B.), with each reader identifying discrete themes using the participants’ own words. When analyses of the data were completed and when no new themes were identified, the discrete themes

were grouped into 3 overarching themes. Results were compared and discussed to ensure consistency of interpretation and resolution of discrepancies. A third investigator (J.M.C.) reviewed the transcripts and findings to ensure trustworthiness of the data was maintained.

Results

Participants

Seventeen people receiving PC were invited to join the study: 3 refused, 2 stating “it’s too private,” and a third stating “I’m not dying” (no mention was made of patients’ life expectancy during

 **Table 2 • Demographic Characteristics of the Sample**

Characteristic	n (%)
Gender	
Male	5 (50)
Female	5 (50)
Age, y	
50–59	4 (40)
60–69	1 (10)
70–79	4 (40)
80–89	1 (10)
Marital status	
Married	6 (60)
Widowed/divorced	2 (20)/1 (10)
Single, never married	1 (10)
Ethnicity	
White Australian	5 (50)
White European	4 (40)
White African	1 (10)
Language spoken at home is English	10 (100)
Highest level of education	
Less than school certificate	4 (40)
Higher-school certificate	1 (10)
Trade/diploma	3 (30)
Graduate/professional degree	2 (20)
Cancer type	
Breast	5 (50)
Prostate	4 (40)
Lung	1 (10)
Recruited from	
Hospital	1
Hospice: community	4
Hospice: inpatient	6
Religion	
Protestant	7 (70)
Catholic	1 (10)
None	2 (20)
Are you practicing your religion	
Yes	3 (30)
No	5 (50)
Importance of spirituality or faith	
Very	4 (40)
Somewhat	2 (20)
Not at all	4 (40)

the recruitment process, although, unlike the original study of K.E.S., we did introduce the study as an opportunity to discuss how one wants to be remembered). Fourteen participants consented and completed premeasures: 2 deteriorated before the intervention, and 1 participant deteriorated cognitively during the intervention; as a result, the participation of all 3 was discontinued. Eleven participants completed the intervention, and 10 advanced cancer patients completed the entire intervention and the postintervention measures and intervention evaluation. Demographic characteristics of the final sample are shown in Table 2.

Psychometric Measures

All psychometric measures showed nonsignificant improvements from preintervention to postintervention. Trending to statistical significance ($P < .1$) were the Functional Assessment of Cancer Therapy–Spirituality Well-being “meaning/peace” subscale ($P = .08$) and the QUAL-E “preparation for end of life” ($P = .07$). Changes over time are shown in Table 3.

Participant Evaluation of the Intervention

As participants in this population often had many medical appointments and became unwell and tired easily, scheduling intervention sessions required some flexibility. Sessions for 3 participants were more than a week apart; sessions 2 and 3 were combined for 1 participant at her request (as she felt she could cope with and value the intervention that day, whereas she was not sure if she would feel up to it in a week’s time). The interviews took from 40 minutes to 2½ hours. Four participants accepted an audiotape of their interviews.

Overall, 8 of 10 participants agreed that the intervention was helpful, and 9 participants would recommend the intervention to others. Seven participants felt the intervention helped them to reflect on their life. None of the participants found the printed materials given at the end of each session upsetting. Four participants agreed that some intervention questions were upsetting, in particular for those who had memories of violence or abuse in their lives. However, all of these participants still agreed that the program was helpful and would recommend it to others. Several participants commented that it was very helpful to have the nurse provide the intervention because of the sensitive manner in which the interviews were conducted. Only 1 participant (who had not found the questions upsetting) disagreed that the pro-


 **Table 4 • Participant Quantitative Evaluation of the Program**

Question	Agreed	Unsure	Disagreed
I found the questions during the sessions with the research nurse easy to understand	9	1	
I found the questions during the session with the research nurse upsetting	4		6
I feel the program helped me to reflect on my life	7	2	1
I found the interview sessions with the research nurse to be helpful	7	1	2
It was difficult to find time for the project	2		8
The written materials were distressing to me			10
I found the written materials easy to understand	10		
I found the written materials to be helpful	8		2
Overall I found this program to be helpful	8	1	1
I would recommend this program	9	1	

gram was helpful and would not recommend the intervention to others. This participant had already done extensive journaling/reflection about his life prior to study participation. This person did not feel the program added to the work he had already done by himself. See Table 4 for quantitative evaluation questions and responses.


Participant Qualitative Evaluation

Participants reported that participating in the study was acceptable and meaningful. Participants’ evaluations of the intervention were analyzed using thematic content analysis, which resulted in 3 overarching themes, which are discussed in the following sections. These embraced issues regarding the value of reflection, the occasionally challenging yet therapeutic nature of reflection, and the need for sensitivity in conducting such an intervention. Illustrative participant quotes are shown in Table 5.

 **Table 3 • Preintervention and Postintervention Psychometrics Showing Mean (SD) and P Values**

Intervention	FACIT-Sp Peace/ Meaning Subscale	FACIT-Sp Faith Subscale	QUAL-E End-of-Life Preparation Subscale	QUAL-E Life Completion	POMS Anxiety Subscale	MSAS Global CES-D Distress Index
Preintervention mean (SD)	21.6 (6.23)	8 (5.1)	2.67 (0.67)	3.74 (0.67)	4.8 (3.76)	6.9 (3.07)
Postintervention mean (SD)	23.9 (6.25)	8.4 (6.29)	2.97 (0.54)	3.81 (0.93)	3.8 (3.3)	5.8 (3.42)
<i>t</i> Test <i>P</i>	.08	.36	.07	.37	.26	.20

Abbreviations: CES-D, Center for Epidemiological Depression Scale; FACIT-Sp, Functional Assessment of Cancer Therapy–Spirituality Well-being; MSAS, Memorial Symptoms Assessment Scale; POMS, Profile of Mood States; QUAL-E, Quality of Life at End of Life Scale.

 **Table 5 • Participants' Qualitative Evaluations of the Intervention Analyzed by Thematic Content Analysis Into Overarching Themes**

Enhancing life reflection

"It made me feel good. It made me feel comforting. It made working with someone close like (research nurse) which has been really good for me."

"I think it would be bloody good for a lot of people."

"I liked the fact that I had the little bits of paper, I can go back and read stuff. They precipitated conversations that wouldn't have happened otherwise."

"It's important to have an external person because in the case of my wife, she would have a hard time accepting everything I say and not responding to it."

"I think it's essential to talk with somebody and if it was with a CD-ROM, it's not going to respond to them, they can't see the compassion in your face or the empathy in your eyes."

Challenging yet therapeutic

"I found the natural progression of the programme through childhood, I guess because we go to those early memories through to thinking about death, I actually found that very daunting. Because even though I have a very serious illness, for some reason I've never really thought of it in those terms."

"I found it hard to answer 'valuable lessons learned,' it is hard to pinpoint."

"'Things I'd like to achieve' is hard to answer at my age (86 years), but I'd like to accomplish being sweet and gentle to my family I guess."

"'Are you at peace?' It doesn't mean any difference to me."

"One that I had a struggle with was 'are you at peace?' ... because I thought I should be and I'm not."

Sensitivity to individual variability

"It shouldn't be done too soon after diagnosis because they are still trying to absorb it. But it might be good a bit later, maybe in a group session."

"As long as they're coping, if you can go for more, go for it."

"Good to have some flexibility, some might like to have more sessions and smaller themes."

THEME 1: ENHANCING LIFE REFLECTION

Seven participants made positive comments about the intervention, feeling that it had precipitated reflections and discussions that would not otherwise have occurred and made them feel better about themselves and their lives. Nine participants also felt that it would benefit others in a similar situation to themselves. All participants endorsed the value of having a professional lead the intervention and of the individual, face-to-face format.

THEME 2: CHALLENGING YET THERAPEUTIC

One participant felt that the process of reflecting on their life made them more aware that they had a limited time to live and found this a little confronting. However, this participant stated that she found the opportunity to discuss these issues and express the associated emotion very helpful. In addition, the intervention prompted her to create a photo memoir for her children, for which she and her family were grateful. Some participants found some of the questions conceptually difficult (eg, the use of the word legacy), unsettling (eg, "Are you at peace?"), or not relevant to their time of life (eg, achieving new goals). Others had not previously considered issues raised and struggled to organize their thoughts and feelings. In one case, the interview triggered memories for the participant of past abuse.

THEME 3: SENSITIVITY TO INDIVIDUAL VARIABILITY

Although all the participants liked the program as it is currently formatted, 3 felt that the intervention should not be introduced too close to diagnosis of a life-limiting illness before patients had adapted to their prognosis, as it may be too confronting

and/or patients may be preoccupied with medical appointments. Having flexibility with the timing and number of the sessions was also endorsed by 6 participants.

Nurse Facilitator Field Notes and Reflections

Integral to the intervention was "bearing witness" to the participant's life; probing and interpreting was discouraged, whereas active listening was promoted. The intimacy created by the interviews was overwhelmingly positive. However, some aspects of the intervention were occasionally challenging for the nurse facilitator. As noted above, respondents sometimes reflected on negative or abusive experiences in the past. Several of the questions needed to be repeated or explained when participants were not clear what was required. This required some skill on the nurse's part to reframe and explain and ensure a rich discussion. Thus, adequate training and debriefing for the intervention nurse are important.

Although the intervention was meant to be individual, on one occasion the participant's mother joined, and together they recalled the participant's childhood and fond memories and reflected on important events. Even though the participant has since died, her mother still has the recording of their Outlook intervention discussion, which she greatly values. This suggests that, in at least some instances, allowing family members to join in the intervention may be a positive adaptation.

■ Discussion

In this study, we found that the preparation and life completion intervention, Outlook, was feasible and acceptable in the Australian

PC population. Participants reported that the intervention questions and written materials were easy to understand and enjoyed the opportunity to talk with an empathetic listener outside their family about their lives and to be provided with materials to help them reflect in their own time. Participants appeared to recognize the value of reflecting on regrets, remaining life goals, and past achievements at this time of their lives and finding a way toward resolution and acceptance. Our quantitative data, although preliminary and based on a small sample size, revealed trends to improved psychosocial outcomes following the intervention of a similar magnitude to those reported by K.E.S. and her colleagues.²² Together, these mixed-methods data support Erikson's theory that reflection and resolution are critical tasks for people at the end of their lives.

Furthermore, we found it was feasible and acceptable for a nurse to facilitate the Outlook intervention. The nurse facilitator found it to be a very rewarding and effective way to connect with patients regarding existential and spiritual concerns and allowed him/her to form a deeper and more meaningful relationship with the patients. The training undertaken to facilitate the intervention was relatively straightforward as Outlook is a manualized intervention. The nurse's prior training and experience with counseling in this study were beneficial but not essential, and the only resources required were an audio recorder and time. In some situations, this last component, time, may be the most difficult to secure. Our study has shown that it is possible for nurses to be trained to conduct the intervention and implement it into their clinical practice.

Two participants described the question "Are you at peace?" to be unsettling. Subsequent to this study, the Outlook training manual has been refined (by K.E.S.) to further enhance training of facilitators at a distance and to enable wider implementation of the Outlook intervention. Particular emphasis is given in the new training manual regarding the importance of ensuring that the intervention questions (Table 1) are asked conversationally with a lead-in. For example, although the topic may be "Are you at peace?" the intervention facilitator is taught to introduce this tentatively to avoid imposing an agenda that the patient needs to feel at peace. For example, the intervention facilitator may say, "Some people reflect on the extent to which they are at peace. I'm wondering what your thoughts are about the extent to which you are feeling at peace."

Likewise the term *legacy* did not appear to be easily understood by participants in the current study, with many participants requiring rephrasing of this part of the interview. The notion of legacy has been identified by some other culturally diverse samples as an unclear concept or unimportant to some patients.^{20,34,35} Perhaps, this concept needs further exploration and development in an Australian context with regard to how it is introduced conversationally during the intervention by the nurse. Phrases such as "future accomplishments" and "wisdom shared" may be better understood by Australian PC patients. K.E.S. and her colleagues²² used such phrases in their intervention to describe legacy and did not experience the confusion sometimes apparent in our participants.

There were several limitations to our study, primarily a limited sample size and some dropouts. As a feasibility study, we

did not aim to have sufficient power to demonstrate statistical significance or to include a control arm; thus, we cannot comment on efficacy. Nonetheless, the overall positive findings of this nurse-facilitated intervention merit further investigation with a larger sample utilizing a randomized controlled design. Other directions for future research may include exploring the effect that having an audio recording of a deceased loved one reviewing their life has on caregivers' bereavement experiences, as well as efficacy and feasibility for wider implementation of the intervention by PC nursing staff.

In conclusion, this study showed that a nurse-facilitated preparation and life completion discussion was acceptable and feasible within the Australian PC population. If nurses could be trained to deliver this intervention to advanced cancer patients, this could potentially make this type of care more accessible to patients in situations where a pastoral care or psychosocial health professional is either not available or not acceptable to patients. Wider implementation of the Outlook intervention by nurses would require further evaluation of efficacy and feasibility. For example, the nurse in the current study had protected time to conduct the intervention during the study period. Further studies could explore whether it would be feasible for nurses to incorporate the intervention into routine clinical practice.

ACKNOWLEDGMENTS

The authors thank the patients who gave their time and energy to this study and to the staff of the involved PC services who identified suitable patients.

References

1. Boston PH, Mount BM. The caregiver's perspective on existential and spiritual distress in palliative care. *J Pain Symptom Manage.* 2006;32(1):13–26.
2. Chochinov HM, Hassard T, McClement S, et al. The landscape of distress in the terminally ill. *J Pain Symptom Manage.* 2009;38(5):641–649.
3. Breitbart W. Spirituality and meaning in supportive care: spirituality- and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer.* 2002;10(4):272–280.
4. Highfield MF, Cason C. Spiritual needs of patients: are they recognized? *Cancer Nurs.* 1983;6:187–192.
5. Rodriguez KL, Bayliss N, Alexander SC, et al. How oncologists and their patients with advanced cancer communicate about health-related quality of life. *Psychooncology.* 2010;19(5):490–499.
6. Kelly B, McClement S, Chochinov HM. Measurement of psychological distress in palliative care. *Palliat Med.* 2006;20(8):779–789.
7. Yardley SJ, Walshe CE, Parr A. Improving training in spiritual care: a qualitative study exploring patient perceptions of professional educational requirements. *Palliat Med.* 2009;23(7):601–607.
8. Leung D, Esplen MJ. Alleviating existential distress of cancer patients: can relational ethics guide clinicians? *Eur J Cancer Care.* 2010;19(1):30–38.
9. Rousseau P. Spirituality and the dying patient. *J Clin Oncol.* 2000;18(9):2000–2002.
10. Australian Bureau of Statistics A. 4102.0—Australian Social Trends, March 2011. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4102.0>. Accessed May 3, 2011.
11. US Census Bureau U. 2009—American Community Survey. October 19, 2010. <http://www.census.gov/compendia/statab/2011/tables/11s0075.pdf>. Accessed October 24, 2010.
12. Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. *J Palliat Med.* 2009;12(10):885–904.

13. Bohlmeijer E, Smit F, Cuijpers P. Effects of reminiscence and life review on late-life depression: a meta-analysis. *Int Geriatr Psychiatry*. 2003;18(12):1088–1094.
14. Mastel-Smith B, Binder B, Malecha A, Hersch G, Symes L, McFarlane J. Testing therapeutic life review offered by home care workers to decrease depression among home-dwelling older women. *Issues Ment Health Nurs*. 2006;27(10):1037–1049.
15. Allen RS. The Legacy Project intervention to enhance meaningful family interactions: case examples. *Clin Gerontol*. 2009;32:164–176.
16. Overcash JA. Narrative research: a review of methodology and relevance to clinical practice. *Crit Rev Oncol Haematol*. 2003;48:179–184.
17. Haber D. Life review: implementation, theory, research, and therapy. *Int J Aging Hum Dev*. 2006;63(2):153–171.
18. Lemay K, Wilson KG. Treatment of existential distress in life threatening illness: a review of manualized interventions. *Clin Psychol Rev*. 2008;28(3):472–493.
19. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol*. 2005;23(24):5520–5525.
20. Ando M, Tsuda A, Morita T. Life review interviews on the spiritual well-being of terminally ill cancer patients. *Support Care Cancer*. 2007;15(2):225–231.
21. Lee V. The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Care Cancer*. 2007;16:779–785.
22. Steinhauser KE, Alexander SC, Byock IR, George LK, Olsen MK, Tulsky JA. Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *J Palliat Med*. 2008;11(9):1234–1240.
23. Erikson EH. *The Life Cycle Completed*. New York, NY: Norton; 1982.
24. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med*. 2000;132(10):825–832.
25. Trueman I, Parker J. Exploring community nurses' perceptions of life review in palliative care. *J Clin Nurs*. 2006;15(2):197–207.
26. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med*. 2010;363(8):733–742.
27. Keall RM, Butow PN, Steinhauser KE, Clayton JM. Discussing life story, forgiveness, heritage, and legacy with patients with life-limiting illnesses. *Int J Palliat Nurs*. 2011;17(9):454–460.
28. Radloff L. The CES-D scale: a self-report depression scale for research in the general population. *Appl Psychol Meas*. 1977;1:385–401.
29. Portenoy RK, Thaler HT, Kornblith AB, et al. The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer*. 1994;30A(9):1326–1336.
30. Pollock V, Cho DW, Reker D, Volavka J. Profile of Mood States—factors and their physiological correlates. *J Nerv Ment Dis*. 1979;167(10):612–614.
31. Steinhauser KE, Clipp EC, Bosworth HB, et al. Measuring quality of life at the end of life: validation of the QUAL-E. *Palliat Support Care*. 2004;2(1):3–14.
32. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the Functional Assessment of Chronic Illness Therapy—Spiritual Well-being Scale (FACIT-Sp). *Ann Behav Med*. 2002;24(1):49–58.
33. Creswell JW. *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage; 1998.
34. Blinderman CD, Cherny NI. Existential issues do not necessarily result in existential suffering: lessons from cancer patients in Israel. *Palliat Med*. 2005;19(5):371–380.
35. Morita T, Kawa M, Honke Y, et al. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. *Support Care Cancer*. 2004;12(2):137–140.



Appendix • Participants' Qualitative Evaluation Interview Questions

- 1 The thing/s that I liked most about the program was/were:
- 2 The thing/s that I liked least about the program was/were:
- 3 What suggestions do you have to improve the program (eg, include practical activity)?
- 4 How did the conversations make you feel?
- 5 When is the best time to do this intervention (ie, in the illness experience)?
- 6 Is there anybody we shouldn't do this intervention with?
- 7 Which of these questions did you find most useful/thought provoking?
- 8 Were any of the questions not helpful or concerning?
- 9 How did you find the number of sessions? Could we have covered the same material in fewer sessions? What would be the ideal number of sessions?
- 10 How important was it to have the nurse to talk with?
- 11 Do you think this intervention could be done on your own? Yes/no. Please comment
- 12 Do you think this intervention could be done with your family? Yes/no. Please comment
- 13 Do you think this intervention could be done with a volunteer on your own? Yes/no. Please comment

CHAPTER 4

Discussing Life Story, Forgiveness, Heritage and Legacy with Patients with Life-Limiting Illnesses

This chapter contains the systematic review titled “Discussing life story, forgiveness, heritage and legacy with patients with life-limiting illnesses.” Published in *International Journal of Palliative Nursing* (2011; 17 (9): 454-460)

Discussing life story, forgiveness, heritage, and legacy with patients with life-limiting illnesses

Robyn M Keall, Phyllis N Butow, Karen E Steinhauser, Josephine M Clayton

Abstract

Aim: To explore the perceptions that individuals with life-limiting illnesses have about their lives, both positive and negative, and their messages to future generations. **Methods:** A preparation and life completion intervention (Outlook) was assessed for acceptability and feasibility in an Australian palliative care setting. This paper reports a qualitative analysis of the participants' responses to the intervention. The intervention sessions were audiotaped, transcribed, and analysed using interpretative phenomenological analysis. **Results:** Eleven participants were recruited from inpatient and outpatient hospital and hospice settings. Three overarching themes were identified: life review, current situation, and legacy/principles. **Conclusions:** The intervention provided insights into individual palliative care patients' sense of self, views of their current situation, hopes, and how they would like to be remembered. **Key words:** Life review ● Palliative care ● Existential care ● End-of-life care ● Nursing

RMK is PhD candidate, Centre for Medical Psychology and Evidence-based Decision-Making (CeMPED), University of Sydney, and Clinical Nurse Consultant, Hammond Care Palliative and Supportive Care Service, Greenwich Hospital, Sydney, Australia; **PNB** is Chair of Psychology and Co-Chair, CeMPED; **KES** is Associate Professor, Center for Health Services Research in Primary Care, Center for Palliative Care, Duke University, USA; **JMC** is Associate Professor, CeMPED, Staff Specialist in Palliative Care, Hammond Care Palliative and Supportive Care Service, and Staff Specialist Palliative Care, Royal North Shore Hospital, Sydney, Australia

Correspondence to:
Robyn M Keall
robyn.keall@sydney.edu.au

When curative treatment options have been exhausted and the goal of care is comfort, it is the role of the clinician to attend to the patient in the most effective and holistic manner, which encompasses all human domains of experience and suffering (Coyle, 2006; Mishra et al, 2010). Untreated suffering, in particular existential and spiritual distress, may encourage a patient's desire for death and requests for assisted suicide (Breitbart, 2002). However, the ability of the clinician to provide holistic care is often limited for many reasons, including lack of education, time, practical skills, and confidence, and the fear of exposing one's own human frailty (Yardley et al, 2009; Leung and Esplen, 2010).

Historically, owing to the formalization of the medical model that separated the care of the body from that of the spirit, spiritual care was assigned to the clergy and to pastoral care workers, and therefore the education of doctors and nurses did not include approaches to spiritual care (Rousseau, 2000). However, in many situations

pastoral care workers are not available or not desired by patients, as indicated by the swing away from formal religious practice (US Census Bureau, 2009; Australian Bureau of Statistics, 2011), so it is important that the clinician who is present when the patient requires spiritual support be capable of providing it.

The response to this deficit has seen a call for greater understanding of patients' needs, new approaches to care, and evidence-based practices (American Academy of Hospice and Palliative Medicine et al, 2004; Coyne et al, 2007; Puchalski et al, 2009). Many of these practices have been adapted from the successful treatment and prevention of depression in the aged care population (Mastel-Smith et al, 2006; Pot et al, 2008; Binder et al, 2009), and indeed depression is a common symptom among those with advanced life-threatening illness (Eychmueller, 2009).

One approach to tackling depression is life review (Haber, 2006), in which a patient is asked to look back over their life in order to find meaning, reconcile conflicts and regrets, remember moments of particular happiness, and prepare for the end of life, in the hope that they will come to realize their worth and have the opportunity to leave a lasting legacy. The use of life review and the formulation of a legacy has been reported by various authors (Erlen et al, 2001; Breitbart, 2002; Chochinov et al, 2005; McKeown et al, 2006; Ando et al, 2007; Lee, 2008; Steinhauser et al, 2008). The acceptability of such interventions is influenced by cultural differences, proximity to death, diagnosis, age, and social/emotional support (Steinhauser et al, 2008; Ando et al, 2009; 2010).

This study piloted an intervention, termed Outlook, which builds on life review and aims to facilitate preparation and life completion discussions (Steinhauser et al, 2008). The intervention has been piloted before, but here it was being implemented in a different cultural setting (Australia) from the one in which it was originally tested (the USA). Steinhauser et al (2009) previously explored the issues raised by US

patients in response to the Outlook intervention questions and found that they gave a variety of responses providing a rich narrative. The aim of the analysis presented in this paper was to explore Australian individuals' perceptions of their life, both positive and negative, and their messages to future generations.

Methodology

Design

A trial was conducted to test the acceptability and feasibility of the preparation and life-completion intervention Outlook within an Australian context. Intervention interviews were conducted over a 6-month period by the research nurse and a qualitative analysis was then undertaken.

Sample and setting

Patients were recruited from the specialist palliative care services in Northern Sydney. These include two hospices with a total capacity of 40 beds and an in-house consultative service at a tertiary referral teaching hospital with over 650 referrals per year. Inclusion criteria included having a diagnosis of life-threatening illness with a prognosis of less than 2 years, being English speaking, being cognitively intact, and being over 18. Patients who were not fluent in English were excluded as there was no provision to employ interpreters. Clinicians in the hospital and hospices were asked to identify eligible patients and these patients were invited to participate by a research assistant. The study was introduced as an opportunity for life review (reflecting on one's life and how one wants to be remembered). This contrasts with the US study, in which the intervention was introduced as focusing more on living with a serious illness.

Fourteen participants were initially recruited to the study but two deteriorated after consenting and one deteriorated during the intervention; these three participants were withdrawn. Thus, eleven participants completed the three life review intervention sessions and all of their session transcripts were included in the analysis.

Ethical considerations

Ethical approval was granted by the University of Sydney and the participating hospitals/services. The patients were assured that their responses would be anonymized and that referral to appropriate services would be provided if distress was caused through the intervention.

Procedure and intervention

The intervention was implemented in the manner described by Steinhauer et al (2008), over three

Box 1. Preparation and life completion intervention questions*

Session 1: Life story

- Tell me about your life
- What are your cherished times?
- Of what are you most proud?
- If someone were to make a movie of your life what would be important to include?

Session 2: Forgiveness

- If you were to do things again, what might you do differently?
- Are there things or times you regret?
- Is there anyone to whom you would like to offer forgiveness?
- Is there anyone from whom you would like to ask forgiveness?
- Are you at peace?

Session 3: Heritage and legacy

- What are your most valuable lessons learned?
- What would you like to share with future generations?
- If you could choose one thing to pass on as your legacy what would that be?
- What things would you like to accomplish?

*(Steinhauer et al, 2008)

sessions. Each session consisted of an open discussion guided by four or five broad questions, and there was a different theme for each session: life story, forgiveness, and legacy/heritage (*Box 1*). The sessions were guided by the questions but the participants controlled how much or little they shared. As in Steinhauer et al (2008), sessions were scheduled one week apart except when this was inconvenient or not possible owing to patient illness. The intervention was conducted by an experienced palliative care nurse who had been briefed by the intervention's author, rather than by a social worker who received formal training as in the US study. The interviews were audiotaped and then fully transcribed. The participants were offered a copy of their audiotape, which was another novel aspect of the present study.

Data analysis

The qualitative data from the transcripts of the intervention sessions were analysed, informed by qualitative methodology (Pope and Mays, 2000). Specifically, interpretative phenomenological analysis (IPA) was used to gain an understanding of how the participants had experienced and made meaning of their lives. IPA uses the 'bottom-up' approach to generate data; this allows the analyst to gain understanding of another's lived experience and make their own interpretation of that experience (Reid et al, 2005). In the present study, the participants' transcribed interviews were read by two investigators (RMK and

Table 1. Participants' demographic data (n=11)

Characteristic	Frequency
Sex	
Male	5
Female	6
Age	
50–59	4
60–69	2
70–79	4
80–89	1
Ethnicity	
Caucasian-Australian	6
Caucasian-European	4
Caucasian-African	1
Highest level of education	
Less than year 10	4
Higher school certificate	1
Trade/diploma	4
Graduate/professional degree	2
Marital status	
Married	6
Widowed	2
Divorced	1
Single—never married	2
Household	
Spouse/partner	6
Child	1
Alone	4
Disease	
Breast cancer	5
Prostate cancer	4
Lung cancer	1
End-stage renal disease	1
Religion	
Protestant	8
Catholic	1
None	2
Are you practicing your religion?	
Yes	3
No	6
Importance of spirituality or faith	
Very	4
Somewhat	3
Not at all	4

PNB) and the results were reviewed by a third (JMC) to ensure credibility. Analysis was undertaken on a case-by-case basis, reviewing the three

transcripts of each participant in their entirety. This review generated discrete items using the participants' own language where possible to ensure consistency of interpretation. These discrete items were then clustered into common thread subthemes and these subthemes were then nested into three overarching themes. The three investigators discussed the IPA process to resolve any discrepancies in the analysis.

Results

The participants' ages ranged from 50–86 years. One participant had end-stage renal failure and the other ten had a cancer diagnosis. Demographic characteristics for the participants are shown in *Table 1*.

The data was clustered into eight subthemes, which were then further clustered into three overarching themes: life review, current situation, and legacy/principles. The themes and subthemes are discussed below with illustrative quotations and paraphrasing of the participants' own words. The illustrative examples are identified only by the participant's sex and decade of age, e.g. M80s is a male in his 80s. Potentially identifying facts have been removed.

Life review

This overarching theme includes the ways in which the participants described themselves and their interactions with others, their joyful memories and achievements, and their regrets and unhappy memories.

Self-identity

Throughout the interviews the participants told of how their work, family, and lifestyle choices had helped to shape them. They identified their strengths and roles both in society and in their family structure. The participants described themselves as a 'loyal friend', 'hard worker', 'parent', 'sports player', 'master of their own destiny', and as 'having a positive attitude'.

'Oh I was glad to get married and we had three lovely boys.' (M70s)

'But I made up my mind that I was going make every post a winning post no matter how small it was.' (M80s)

Accomplishments

The participants spoke most frequently of accomplishments resulting from good luck or hard work. These included strong careers, happy relationships, healthy children and grandchildren, meeting their significant other, having supportive

friends and families, and having kept cancer at bay. Most of the participants described their lives in a free-flowing style, recalling their early adulthood then their childhood before coming back to the present. All of the participants spent some time recalling their careers, but the men in particular remembered their careers in a semi-chronological order. Many careers had been adventurous and involved unexpected opportunities. Careers had been important to the women too, but more for the interaction with colleagues. One participant had met her best friend through work and another recalled how after she had retired from work she would continue to catch the train into her workplace and home again for the company.

'And I walked in and I saw this woman and I said "Who's that?" and apparently she said the same thing. And then about a year after that her husband died so I waited and after 9 months I rang her up and I said "Do you want to go out for dinner?" She said "Oh that would be lovely." We went for dinner and went home. We were together for the next 25 years.' (M70s)

'I ended up going back and doing my degree. And I graduated in 2006 and in 2007 everyone expected me to die because the scans were just so bad. Um so I sort of waited around to die for most of 2007. I was incredibly bored!' (F50s)

'You know that fella Julio Iglesias? Reckons he's had a thousand women ... well he's just an apprentice!' (M70s)

'I've landed in nearly every place in [remote country] that you could land. I had good experience and enjoyed it very much.' (M80s)

'Working as a [artistic career] was really the profession which I got hooked into. I mean I just loved it, it was the most interesting period in my life.' (M70s)

Conflict

Five of the participants had lived through times of war, either as children in a war-torn country or as young adults in defence services. One participant shared his experience of being evacuated from war-torn Europe as a child in a terrifying train journey, recalling the feelings, sights, and sounds with great clarity. Another participant recalled witnessing atrocities during civil war in her country. Many of the participants recalled abuse, both physical and mental, from family

members and workmates. While recalling these events, several participants became upset or paused to consider what they had shared. The majority of the stories of abuse came from women but all had found ways of coping with the memories, either by suppressing the thoughts or by understanding how the lives of the abusers had led them to be abusive.

'So we were there during the times of war and we've seen that some of our families have died horrific, just horrific deaths.' (F50s)

Regrets

This subtheme included failings and missed opportunities. Failings included 'not having a good father figure', 'gambling', 'getting tattoos', 'not appreciating my mother', 'marrying the wrong woman', and 'making bad career choices'. Missed opportunities included 'not marrying my first love' and, for two of the participants, not competing nationally in their chosen sport—one owing to lack of finances and the other to lack of discipline. Overall when reflecting on these regrets, the majority expressed some acceptance. As a consequence of the intervention, one participant was prompted to contact some estranged friends, resolve a conflict, and renew that friendship.

'My mother couldn't handle a baby. So I was never wanted, I was always unwanted.' (F70s)

'My sister never accepted me into the family. She was physically abusive to me.' (F60s)

'None of the parents, none of the adults who promised our mother they'd look after us did anything.' (F50s)

'I regret that I didn't have a wonderful father figure but he didn't know any different ... my father was disciplined in the most shocking ways. So he didn't know any other way to behave. But he's left a legacy which is not a nice one.' (F50s)

'I wish that I had a better relationship with my mother.' (F60s, F50s)

'But I never stopped loving her [childhood sweetheart] and you know not a day goes by when I haven't thought of her.' (M60s)

Current situation

This overarching theme contained three sub-themes pertaining to the participants' present life,

'...it is important that the clinician who is present when the patient requires spiritual support be capable of providing it.'

‘Several goals were identified by the participants—some achievable, such as writing a book or memoir, others more fanciful...’

including what contributes to their quality of life and what has a negative effect on them.

Current quality of life

Contributors to this subtheme included having supportive family and friends and, for one participant, a very strong faith in God. For two of the participants who had no family support owing to attrition or choice, their close friendships were essential to their wellbeing.

‘It was a beautiful family I wouldn’t ask for anything better.’ (F50s)

‘[Name] and I’ve known each other for 45 years and her husband for 44. And they form all my family.’ (F60s)

‘My friends are my friends. They mean everything to me.’ (M70s)

Loss as a palliative care patient

This subtheme included loss of physical ability, leading to early retirement and financial concerns, loss of friends, and loss of independence.

‘My grandchildren find it very difficult to deal with it because I cannot play rough house as we used to. I used to lift them to the air, you know and catch them and I was very strong, but that’s not possible.’ (M70s)

‘Sickness is strange ... it puts you in a limbo land ... it shortens your horizon and it doesn’t give you much reason to go on and do things.’ (M60s)

Current goals

Several goals were identified by the participants—some achievable, such as writing a book or memoir, others more fanciful, such as winning money, and others potentially unattainable due to illness, such as travel. One participant wished to continue her charitable work internationally and hoped to start a support group for women in a similar situation to her. Another was prompted by the intervention to complete a photographic memoir for her children. A third wished to share his love and knowledge of music with his fellow patients at a day therapy centre. All of the participants identified goals, some of which had been contemplated before the intervention had taken place.

‘I’m going to win some money somewhere, a big one, at least \$500 000 or so. And I’ll be off to the Whitsundays Passage for two weeks and fish meself stupid. And after that it doesn’t

matter you know. That’s a place I should have gone before and I never did.’ (M70s)

Legacy and principles

This overarching theme included advice for future generations (principles) and how the participants wished to be remembered (legacy).

Principles

These reflected how the participants had lived their lives, for example those who had lived adventurous, travel-filled lives advised others to ‘grab life’, ‘appreciate life’, and ‘be the best you can be’. Those who had endured hardships wanted to encourage others by stating that ‘adversity strengthens’. Some participants warned others not to make the same mistakes that they had, such as prioritizing their careers over their families. Others spoke of ‘the importance of trust’ and advised ‘don’t judge too quickly’. Several participants suggested that their loved ones ‘be responsible for [their] own actions’ and ‘be a good friend’.

‘Don’t go on your days off and play with the grownups, play with your children.’ (M70s)

‘Celebrate what you have in common and respect differences.’ (F50s)

‘People dig your own graves from the day you are born, whether it’s a nice grave or not, is up to you.’ (M70s)

Legacy

Legacy reflected how the participants wanted to be remembered, and included readiness to laugh or see the positive in life and their global views.

‘I try to look for the best in people.’ (M80s)

‘I always said what I wanted but was never rude.’ (M70s)

‘I always look beyond the hills. I don’t see the dirty window just the hills through the window and beyond.’ (F50s)

Discussion

The Outlook intervention was found to be feasible and acceptable in an Australian palliative care population. The participants’ evaluations of the intervention are to be reported in full elsewhere, but eight out of ten of the participants agreed that the intervention was helpful, and nine would recommend it. Seven of the participants felt that the intervention helped them to reflect on their

life. When the participants were offered an audiotape copy of their interviews, four accepted and of those one reported enjoying listening to it with his family. Another participant (who has since died) requested that her mother be included in the interview and the mother still has the audiotape copy as a reminder of her daughter.

The intervention yielded transcripts filled with insights into the individuals' perceptions of their life—both the good and the bad—their principles, and their hopes for the future and for the generations to come. The participants spoke vividly about their self-identity, remembered difficult and joyous times in their lives, and reflected both on their current situation and the wisdom they would like to pass on. All eleven participants were able to engage with the process and speak about their lives.

The analysis was undertaken on a case-by-case basis, with the three transcripts of each participant in their entirety. This method of analysis allowed the life thread running through each individuals' responses to be seen. Although this method of analysis was different to that of Steinhauser et al (2009), who followed the structure set by the three sessions, certain themes were common to the two studies. In particular, there was commonality in the theme of regret and forgiveness, in that despite mistakes or hurt the participants stated that they would not change things, as these events all added up to their lives. Participants from both studies advised future generations to 'be responsible for you own life' and 'be kind to others'. By contrast, only one of the participants in the present study referred to God, whereas the US study had greater religious and spiritual content. Similarly, only one participant in the present study regretted not pursuing their education, whereas this was the most commonly cited regret in the US sample.

The participants appeared to have few regrets in life, and they gave advice to future generations in line with their own approach to life. Ando et al (2007) maintain that life review works best for people who have integrated both good and bad memories to obtain a balanced view of their life. This integration can be indicative of having attained 'ego integrity'. Erikson (1982) proposed that at every developmental stage of one's life there is a challenge to be faced before one can move on. The final stage of man's development is of 'ego integrity' (acceptance of one's life having meaning) versus 'despair' (guilt, resentment, and regret). This age is identified by an experiential rather than a chronological time-frame and the subsequent adjustments. It is thought that inability to maintain ego integrity will lead to existential despair (Haber, 2006).

Reviewing the individual participants' stories as a whole was similar to the analysis undertaken by Hack et al (2010) of 50 transcripts from participants of dignity therapy, which identified 'functions' and 'core values'. Many of the core values identified in that study were shared with the current study, such as 'family', 'a sense of accomplishment', 'true friendship', 'honesty', and 'overcoming adversity'. The end product of dignity therapy is to create a 'generativity' document, a bound, transcribed book containing the story of the patient in their own edited words (Chochinov et al, 2005). However, the concept of committing memories—both good and bad—feelings, and messages for loved ones to paper may restrain participants from revealing their true feelings for fear of upsetting their loved ones (Hack et al, 2010). Yet four of the eleven participants in the current study accepted the offer of an audiotape copy of their interview sessions, which may have included recall of unpleasant memories; one person who shared this openly with his family reported enjoying the experience, and another family member who had been part of the interview also gladly accepted the opportunity to listen to her deceased daughter's voice.

The equipment required to conduct the intervention was minimal (audio recorder, blank CDs, computer with CD-ROM). However, the feasibility of clinicians conducting the intervention in addition to their usual practice is not clear owing to the time requirements: most of the interview sessions took 45–60 minutes to conduct. Modifications to the intervention may increase its feasibility—for example, the three sessions could be condensed into one. The positive patient outcomes justify adequate resources being allocated to enable the practice to be incorporated into standard care.

Limitations

The study was limited by its small sample, and the exclusion of people who were unable to speak fluent English may have reduced its diversity. However, the sample size was comparable to that of similar studies (Ando et al, 2007; Steinhauser et al, 2008). The present study had a lower attrition rate than Steinhauser et al (2008), which may be explained by the early referral to palliative care services that takes place in Australia. A potential bias of the study may be that only those who are comfortable with their life may be willing to discuss it with a stranger.


Future research

Future research could build on these pilot findings by using a larger sample, using a modified

'The Outlook intervention was found to be feasible and acceptable in an Australian palliative care population.'

intervention, and by investigating the effect of the intervention on the client–clinician relationship and patient outcomes such as bereavement.

Conclusion

The life review intervention Outlook allowed patients to remember their lives, make meaning of their current situation, and clarify their hopes for the future. These preliminary findings indicate that Outlook is an effective intervention in Australian palliative care settings, in particular in preparing for the end of life and increasing patients' sense of peace and meaningfulness. This form of communication is worthwhile and begs further investigation of its potentially far-reaching effects. 

Acknowledgments

This work was supported in part by a Cancer Institute NSW Clinical Research Fellowship for JMC. The work received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. We are grateful to the patients who gave their time and energy to this study and to the staff of the involved palliative care services who identified suitable patients.

American Academy of Hospice and Palliative Medicine et al (2004) National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for quality palliative care, executive summary. *J Palliat Med* 7(5): 611–27

Ando M, Tsuda A, Morita T (2007) Life review interviews on the spiritual well-being of terminally ill cancer patients. *Support Care Cancer* 15(2): 225–31

Ando M, Morita T, Ahn SH, Marquez-Wong F, Ide S (2009) International comparison study on the primary concerns of terminally ill cancer patients in short-term life review interviews among Japanese, Koreans and Americans. *Palliat Support Care* 7(3): 349–55

Ando M, Morita T, Akechi I (2010) Factors in short-term life review that affect spiritual well-being in terminally ill cancer patients. *J Hosp Palliat Nurs* 12(5): 305–11

Australian Bureau of Statistics (2011) Australian social trends March 2011 [www.abs.gov.au/ausstats/subscriber.nsf/LookupAttrach/4102.0Publication25.03.111/\\$File/41020_ASTMar2011.pdf](http://www.abs.gov.au/ausstats/subscriber.nsf/LookupAttrach/4102.0Publication25.03.111/$File/41020_ASTMar2011.pdf) (accessed 5 September 2011)

Binder BK, Mastel-Smith B, Hersch G, Symes L, Malecha A, McFarlane J (2009) Community-dwelling, older women's perspectives on Therapeutic Life Review: A qualitative study analysis. *Issues Ment Health Nurs* 30(5): 288–94

Breitbart W (2002) Spirituality and meaning in supportive care: spirituality and meaning-centered group psychotherapy interventions in advanced cancer. *Support Care Cancer* 10(4): 272–80

Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M (2005) Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 23(24): 5520–25

Coyle N (2006) The hard work of living in the face of death. *J Pain Symptom Manage* 32(3): 266–74

Coyne P, Paice JA, Ferrell BR, Malloy P, Virani R, Fennimore LA (2007) Oncology End-Of-Life Nursing Education Consortium training program: improving palliative care in cancer. *Oncol Nurs Forum* 34(4): 801–7

Erikson EH (1982) *The Life Cycle Completed*. Norton, NY

Erlén JA, Mellors MP, Sereika SM, Cook C (2001) The use of life review to enhance quality of life of people living with AIDS: a feasibility study. *Qual Life Res*

10(5): 453–64

Eychmueller S (2009) Management of depression in the last month of life. *Curr Opin Support Palliat Care* 3(3): 186–9

Haber D (2006) Life review: implementation, theory, research and therapy. *Int J Aging Hum Dev* 63(2): 153–71

Hack TF, McClement SE, Chochinov HM et al (2010) Learning from dying patients during their final days: life reflections gleaned from dignity therapy. *Palliat Med* 24(7): 715–23

Lee V (2008) The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Care Cancer* 16(7): 779–85

Leung D, Esplen MJ (2010) Alleviating existential distress of cancer patients: can relational ethics guide clinicians? *Eur J Cancer Care* 19(1): 30–8

Mastel-Smith B, Binder B, Malecha A, Hersch G, Symes L, McFarlane J (2006) Testing therapeutic life review offered by home care workers to decrease depression among home-dwelling older women. *Issues Ment Health Nurs* 27(10): 1037–49

McKeown J, Clarke A, Repper J (2006) Life story work in health and social care: systematic literature review. *J Adv Nurs* 55(2): 237–47

Mishra S, Bhatnagar S, Philip FA et al (2010) Psychological concerns in patients with advanced cancer: an observational study at regional cancer centre, India. *Am J Hosp Palliat Med* 27(5): 316–19

Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D (2002) Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy – Spiritual Well Being Scale (FACIT-Sp). *Ann Behav Med* 24(1): 49–58

Pollock V, Cho DW, Reker D, Volavka J (1979) Profile of Mood States: the factors and their physiological correlates. *J Nerve Ment Dis* 167(10): 612–4

Pope C, Mays N, eds (2000) *Qualitative Research in Health-care*. BMJ Books, London

Portenoy RK, Thaler HT, Kornblith AB et al (1994) The Memorial Symptom Assessment Scale: an instrument for the evaluation of symptom prevalence, characteristics and distress. *Eur J Cancer* 30A(9): 1326–36

Pot AM, Melenhorst AS, Onrust S, Bohlmeijer ET (2008) (Cost) effectiveness of life review for older adults: design of a randomized control trial. *BMC Public Health* 8: 211

Puchalski C, Ferrell B, Virani R et al (2009) Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 12(10): 885–904

Radloff LS (1977) The CES-D scale: a self-report depression scale for research in the general population. *Appl Psych Meas* 1(3): 385–401

Reid K, Flowers P, Larkin M (2005) Exploring lived experience. *Psychologist* 18(1): 20–3

Rousseau P (2000) Spirituality and the dying patient. *J Clin Oncol* 18(9): 2000–2

Steinhauser KE, Alexander SC, Byock IR, George LK, Olsen MK, Tulsky JA (2008) Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *J Palliat Med* 11(9): 1234–40

Steinhauser KE, Alexander SC, Byock IR, George LK, Tulsky JA (2009) Seriously ill patients' discussions of preparation and life completion: an intervention to assist with transition at the end of life. *Palliat Support Care* 7(4): 393–404

Steinhauser KE, Clipp EC, Bosworth HB et al (2004) Measuring quality of life at the end of life: validation of the QUAL-E. *Palliat Support Care* 2(1): 3–14

US Census Bureau (2009) American community survey 2009. www.census.gov/compendia/statab/2011/tables/11s0075.pdf (accessed 5 September 2011)

Yardley SJ, Walshe CE, Parr A (2009) Improving training in spiritual care: a qualitative study exploring patient perceptions of professional educational requirements. *Palliat Med* 23(7): 601–7

CHAPTER 5

Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions

This chapter contains the systematic review titled “Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions.” Published in *Journal of Hospice & Palliative Nursing* (2014; 16 (2): 105-112)

Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions

Robyn Keall, MS, RN ○ Josephine M. Clayton, PhD ○ Phyllis Butow, PhD

The objective of this study was to understand Australian palliative care nurses' experience with existential/spiritual interventions and their critical appraisal of Outlook. Existential/spiritual interventions are showing positive results with palliative care patients. The majority of interventions are conducted by nonnurses, yet nurses are the most populous health care workers and are willing to provide holistic care, and patients are open to their help. A qualitative study through semistructured interviews was conducted. Participants were recruited using purposive sampling of a cross section of 20 palliative care nurses. Questions focused on their experience and review of existential/spiritual interventions in general and a published intervention Outlook. Their responses were transcribed and subjected to thematic analysis. The nurses' responses yielded both a range of experiences with existential/spiritual interventions and a review of Outlook. The review of Outlook identified a further 6 subthemes, including (1) Outlook can provide a framework, (2) session II difficult but valuable, (3) benefit for the bereaved, (4) benefit for the nurse/health care team, (5) potential difficulties in delivering Outlook, and (6) possible modifications. Australian palliative care nurses have limited experience with published existential/spiritual interventions, but many are already including elements of these in their practice, and most welcomed the validated tool. Identified needs included training, experience, dedicated space, and time.

KEYWORDS

end-of-life interventions, existential/spiritual, life review, palliative care nurses

Robyn Keall, MS, RN, is clinical nurse consultant, Palliative Care, University of Sydney, and HammondCare Palliative & Supportive Care Service, Greenwich, New South Wales, Australia.

Josephine M. Clayton, PhD, is associate professor, Central School of Medicine, University of Sydney, and HammondCare Palliative & Supportive Care Service, Greenwich, and Greenwich Hospital, New South Wales, Australia.

Phyllis Butow, PhD, is professor, School of Psychology, University of Sydney, New South Wales, Australia.

Address correspondence to Robyn Keall, MS, RN, Palliative Care, University of Sydney, and HammondCare Palliative & Supportive Care Service, PO Box 5084, Greenwich, New South Wales 2065, Australia (rkeall@sydney.edu.au).

This research was undertaken as part of the first author's PhD study. The authors have no conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000047

Patients with advanced life-limiting illnesses face many challenges including physical changes with troubling symptoms and dependence on others, adjusting to a shortened life expectancy and altered roles and life goals.¹ These challenges can lead to existential/spiritual distress, including depression, anxiety, request for hastened death² and rumination,³ and, for some, the opportunity for personal growth or transcendence.⁴ Interventions tailored to address existential/spiritual concerns are growing in number, the bulk of which have a life review component. Life review interventions have shown positive outcomes in reducing and preventing depression in the elderly⁵⁻⁷ and those with AIDS and dementia^{8,9} and even increasing mental and physical health in the young and healthy.¹⁰ For those with life-limiting illnesses, these interventions are gaining acceptance and are showing some positive results.¹¹⁻¹⁷

The majority of published interventions have been conducted by psychiatrists, psychologists, social workers, or other allied health workers. However, these experts do not always have adequate time or an established relationship with the patient and may not be readily acceptable to patients because of stigma related to mental health services.¹⁸ The nurse (the most populous health professional)¹⁹ may be best placed to have intimate conversations and a therapeutic relationship with the patient and family, better enabling delivery of this type of intervention in routine practice. Yet, there is a dearth of research in the area of nurse-led review interventions.

We recently piloted a life review intervention, using an experienced palliative care nurse as the facilitator.^{17,20} We found that when facilitated by the nurse, the intervention was feasible, acceptable to, and perceived as helpful by patients and potentially efficacious in improving "meaning and peace" and preparation for end of life.¹⁷ This intervention, Outlook, originally grew out of sentinel research of patient, family, and caregiver perceptions of what constitutes a good death.²¹ It focuses on domains identified as important to patients with life-limiting illnesses, specifically "preparation for end of life" and "life completion." Outlook is a portable, affordable, and effective intervention that is conducted by a professional (nurse or social worker) with an individual patient over three 45- to 60-minute sessions, ideally 1 week apart. The sessions consist of several thought-provoking questions that follow the themes of

(1) life review (cherished memories and proud moments), (2) regrets and forgiveness (forgiveness for self for perceived failings and to others for perceived hurt), and (3) heritage and legacy (messages to leave to future generations and goals to achieve prior to death). Patients also receive information pertaining to the session for them to further explore the questions in their own time or to discuss with loved ones. Table 1 shows the intervention questions.

Outlook was initially evaluated in a randomized controlled trial with 82 eligible hospice patients from the United States, with a social worker delivering the intervention. The intervention arm participants showed improved functional status and end-of-life preparation and decreased anxiety and depression at follow-up, whereas the control arm had unchanged or worsened results on these measures. Factors such as socioeconomic status and disease type did not alter acceptability.¹⁵

Although our recent data^{17,20} suggest that Outlook is feasible and acceptable when delivered by an experienced palliative care nurse with dedicated time to deliver the intervention, it is not known how easily this intervention could be implemented into routine palliative care nursing practice. For effective delivery of such interventions, nurses require the appropriate skills and dedicated time and to perceive this as an appropriate part of their role. There have been limited studies of nurses delivering existential/spiritual interventions^{16,17,20,22} or gaining nurses' perspective on such interventions.^{23,24} Therefore, we asked Australian palliative care nurses from a variety of backgrounds how they perceived these types of interventions (in particular, Outlook) and if they perceived it would be feasible for them to incorporate such an intervention into their patients' care.

METHODS

We conducted a qualitative study of palliative care nurses from a variety of professional and geographical settings, using

open-ended questions to define their practice and experience with existential/spiritual interventions with palliative care and to garner their views on the Outlook intervention.

Participants

Eligibility criteria for study participation included being an enrolled or registered nurse working in palliative care. Purposive sampling was by presentation at a research group and dissemination through a palliative care-specific electronic mailing list and subsequent peer referral. Interested nurses were asked to contact the research coordinator who confirmed eligibility and obtained informed consent. Ethics approval was granted by the University of Sydney Ethics Review Board. Recruitment continued until informational redundancy (saturation) was achieved.

Procedure

Participants were interviewed either in person or via telephone, and the interviews were recorded and transcribed. Participants were asked if they had any experience or knowledge of interventions targeted at the existential/spiritual domain of care. They were then either shown (if face to face) or asked to open the attachment that had been sent via e-mail (if via the telephone), a copy of the questions that make up the Outlook intervention (as in Table 1). The process of the intervention was explained, including time taken to conduct the intervention and a brief summary of the results of the previous pilot study of nurse delivery.^{17,20} The nurses were asked to peruse the questions, consider whether it would be feasible to undertake the Outlook intervention in their workplace, and report how they perceived it (see Table 2 for interview questions). These questions were asked as part of a larger suite of questions regarding how Australian palliative care nurses address their patients' existential/spiritual concerns, identifying facilitators, barriers, and strategies to this care and the nurses' self-care practices (results to be discussed elsewhere).

TABLE 1 Outlook Intervention Showing the 3 Sessions of Questions¹⁹

Session 1: Life Story	Session 2: Forgiveness	Session 3: Heritage and Legacy
• Tell me about your life	• If you were to do things again, what might you do differently?	• What are your most valuable lessons learned?
• What are cherished times?	• Are there things or times you regret?	• What would you like to share with future generations?
• Of what are you most proud?	• Is there anyone to whom you would like to offer forgiveness?	• If you could choose one thing to pass on as your legacy, what would that be?
• If someone were to make a movie of your life, what would be important to include?	• Is there anyone from whom you would like to ask forgiveness?	• What things would you like to accomplish?
	• Are you at peace?	



TABLE 2 Questions Posed to Participants About Existential/Spiritual Interventions, in Particular Outlook, Used in Palliative Care	
Do you know or use any treatments or interventions to help with existential and spiritual care?	
If so, tell me about them.	
How well do they work?	
What makes it easier or harder to deliver?	
Please review the questions headed Outlook questions. It involves 3 sessions of approximately 45 min of nurse and patient time.	
Would you consider using this tool?	
Which questions do you think would be most useful to be used in your practice?	
Would it be feasible and acceptable to use in your practice?	
Do you think that this would be feasible in a modified form? If so, what modifications would you suggest?	

Analysis

An inductive approach was taken to analysis, allowing the interviewees’ quotes to form the basis of understanding for the investigator, rather than hypotheses dictating the analyses of the data.²⁵ The number of respondents raising each theme is provided as #/20 to denote frequency of the subthemes.

RESULTS

Participants

Twenty participants were recruited over a 4-month period, April to July 2012; 10 were interviewed via telephone and the remainder face-to-face. Participants were spread between inpatient (palliative care units or hospital consultancy services) and community services, and metropolitan and rural and remote geographical settings and varied in their nursing position, years of experience, identification with a spiritual belief, and importance of spirituality in their lives. Table 2 shows the participants’ demographics.

Demographics of Participants

The interviews took between 21 and 55 minutes to complete. The transcripts of the interviews were subjected to analysis and grouped into 2 overarching themes: (1) current usage/experience with existential/spiritual interventions and (2) the Outlook intervention. The second overarching theme was further grouped into 6 sub-

themes: (i) Outlook can provide a framework, (ii) forgiveness and regrets (session II)—difficult but valuable, (iii) benefit for the grieving relatives, (iv) benefit for the nurse/health care team, (v) potential difficulties in delivering Outlook, and (vi) possible modifications to overcome difficulties (Table 3).

Theme 1: Nurses’ Current Usage of Existential/Spiritual Interventions

Three of 20 nurses had worked in areas that offered patients the opportunity to record their life reviews; none of the nurses had conducted the process, which was completed by volunteers, social workers, or other allied health staff.

Eight of 20 nurses mentioned they often ask patients about their lives in order to get to know them better, to gain their trust, and better understand who they were before their terminal diagnosis, but none of these approaches were from published tools. One nurse who visits nursing home patients said:

The way I tend to bring it up is to talk to people about who they were before they were this person in the nursing home. “What did you do? What interests do you have?” And then from that lead on to “Do you have particular religious beliefs or spiritual beliefs that you’d like us to help you with?”

A hospital-based nurse mentioned that such a spontaneous, conversational approach may help some, but that other patients required a more structured approach:

Certainly there are some (interventions); our psychologist here uses cognitive therapies and stuff like that depending on the patient. Some people, you know are quite open; others actually need a more structured or guided way to actually express themselves.

One nurse commented on the need for adequate time for life review;

In the hospice where I worked, they had a lot of time; both the chaplaincy and social work would be doing life review with patients, like kind of tell their story.

Four of 20 nurses noted observed benefits of life review conducted by other staff. One nurse told of a patient, who had just completed his biography with the help of a hospice volunteer, a program that had just begun to be trialed in her workplace using volunteers to help record hospice patients life stories:

He wanted to tell his story... and he has an estranged granddaughter who had been adopted out because his

TABLE 3 Demographics of Participants

Demographic	n
Age, y	
25-35	2
36-45	4
46-55	8
56-65	6
Gender	
Female	19
Male	1
Nursing position	
Registered nurse	7
Clinical nurse consultant	6
Clinical nurse specialist	4
Nursing unit manager	1
Nurse practitioner	2
Setting of practice	
Community	10
Inpatient unit	6
Acute hospital	4
Location of practice	
Major city	13
Large metropolitan	1
Semirural	5
Remote rural	1
Years of experience	
1-5	2
6-10	3
11-20	4
21-30	6
31+	5
Do you identify with a belief?	
Yes	12
No	8

(continues)

TABLE 3 Demographics of Participants, Continued

Demographic	n
Which belief?	
Christianity	11
Buddhism	1
How important is your belief to you?	
Extremely important	1
Very important	5
Important	5
Not important	1

daughter had mental illness. And so his granddaughter came back on the scene. And he was thrilled and so sort of a legacy for her was telling his story.

Twelve of 20 nurses commented that patients often want to tell their story, to help staff to see them as a real person, to be remembered by, and to pass on wisdom and add meaning to their lives:

They (health care workers) only see a person in a bed, but they've had this journey; they've had this story; they've had these struggles, and I think just to acknowledge that is quite powerful.

Theme 2: Nurses' Reflections of the Outlook Intervention

Subtheme (i): Outlook Can Provide a Framework

Eighteen of 20 nurses were pleased to see the intervention questions; 10 of 20 said that they already asked a few of the questions, and therefore their practice was validated, and others liked the way the questions flowed, forming a framework. Twelve of 20 acknowledged the benefits they could see from such an approach for the patients as well as themselves:

It is a good list of sorts of questions that can open the door that I can see myself doing...

I think having a simple framework from which to operate and practice or get used to having these discussions. I think it's a great idea.

I've never used the words, "Are there times you regret?" And that's a really a really fantastic question because it would get you know people talking. And also "What are



your cherished times?" I think that's a good one too. I think this would give me a bit of structure, more focus.

That looks really good. Not simple questions but not scary questions.

Subtheme (ii): Forgiveness and Regrets—Difficult but Valuable

Seven of 20 nurses commented on the second session that deals with regrets and forgiveness for themselves and others and concludes with the question, "Are you at peace?" For many of the nurses, these were the most valuable and yet the most difficult questions in the intervention:

Like you can't just ask someone outright you know, are you at peace, just randomly, it sort of has to be the right moment.

...waltzing in and saying now "Is there anyone you'd like to offer forgiveness before you die?" would sound really contrived.... I have often asked people "Do you feel at peace?" And even that question gets people talking sometimes.

I think it would take me some time to get comfortable asking patients the forgiveness ones, I'd only really ask those if I had as a kind of follow-on, if they'd mentioned something, "I regret doing that."

Despite the perceived awkwardness that may come with asking some of the more difficult questions, 5 of 20 nurses could see great benefit in these questions:

I think that forgiveness is really valuable, and if people can get through that and explore it a bit and be honest with themselves, it allows for such potential peace, end-of-life peace.

What would give you a degree of peace or greater peace at this stage of your life? It's often really little things too, easily achievable things.

I haven't come out with that question, "Do you have any regrets?" specifically, but that is quite interesting. And that one about forgiveness we're often facilitating reunions. Actually, I think that I would be able to use these questions.

And that encapsulates what people are trying (to do). They want forgiveness, to reconcile with family members.... This is going to give you all the prompts that you need. And often when people are telling you their life story, they are also talking about their disappointments and their regrets and wanting to make peace with people, other family members; a time of reconciliation.

Subtheme (iii): Benefit for the Grieving Relatives

Three of 20 of the nurses who had had experience with patients' undertaking recording of their biographies or life review interventions (either in their current work place or in previous roles) commented on the benefit they have observed for patients' loved ones who were bequeathed the biographies/life reviews:

Our care coordinators recorded life stories with the people over a period of time and they would give the family the recording (after the patient had died), and I spoke to the families afterward, and sometimes and they didn't listen to it for a long time because it was too painful, but a few weeks or months down the track, then they felt strong enough, they were very glad to have it.

It would be good to be able to do that for people because that would be satisfying for them and for us, and it would be great for their, you know, for their families to see them just at that little bit more peace.

Subtheme (iv): Benefit for the Nurse/Team

Two of 20 nurses talked about the benefit to the health practitioner of doing such an intervention, in a way of rounding out the practitioner's holistic care for both themselves and the patients:

I think I could reach a level of comfort to do it fairly easily. I don't think that would be a problem. And I know for me personally that I think that would for want of a better word, would feed that spiritual side of me as well.

(It could) highlight to the team that maybe this person has a potential for having some kind of spiritual crisis or a terminal agitation because they're had all of this in their life that's unresolved.

Subtheme (v): Potential Difficulties in Delivering Outlook

One of the most pressing problems the nurses identified with incorporating Outlook into their work was the amount of time required, with 7 of 20 of the nurses commenting on this:

This is something I would like to do when I retire and volunteer, as my role is very clinical at present, and these look like they may take time.

I guess to me, you know hearing about that particular project in terms of biography, it's staff cumbersome. But if you have volunteers, that would be great. I can't add anything else in my day.

Another potential difficulty was ensuring the nurse-patient relationship was developed enough to enable this conversation. Three of 20 nurses commented on this relationship being integral to allowing a level of comfort for both patient and nurse:

This sort of intervention would be with somebody that I'd probably had a bit of a relationship with already. You know, when you just want to kind of take it that step further.

You probably wouldn't be able to ask all them at once, you'd have to wait for the patient. If they're going to be there a long time, then you could ask these things because I think they would quite like them. It's the matter of the time and if they're going to there long enough and mentally with it.

One nurse commented that experience would be necessary to undertake the intervention:

Things like "Are there things that or times that you regret?" That would be a difficult question to ask somebody that you've only just met. A lot of these things (intervention questions) for a new palliative care nurse would be really difficult, I think.

Subtheme (vi): Potential Modifications to Overcome Difficulties in Delivering Outlook

Six of 20 nurses could see the merit of the intervention while acknowledging time constraint difficulties and made suggestions for modifications that may help the implementation of the intervention in their workplace:

Could you do a question at a time? You know how like, you actually talk to people say when you are giving them a wash or something, and sometimes that's when people open up.

I think it would be good to have that as a part of not necessarily admission because that's a big and arduous kind of thing that happens anyway but to be maybe a week after admission to get to know your patients.

One nurse with both ward and community experience suggested having the questions on a card that could be added to the nurses' identification card (which is worn clipped to their clothes or on a lanyard to identify their name and role) and can accommodate other helpful information cards such as emergency numbers or needle stick injury protocol:

I think it would be really good as, like a prompt for staff to be able to just cast their eyes over this and know that it's

OK to ask these questions and what the result could be if they did ask these questions.

DISCUSSION

This study of palliative care nurses' views has elicited informative perspectives about existential/spiritual interventions in general and the Outlook intervention in particular. The key findings included that palliative care nurses have limited knowledge of existential/spiritual interventions, but are enthusiastic to learn more about them and readily reflected on a published tool (Outlook), giving positives, negatives, and possible adaptations to overcome the negatives.

Nurses' limited knowledge of existential/spiritual interventions has been noted elsewhere²³ and is not surprising, as these targeted interventions were conducted by nonnurses and/or are published in nonnursing journals. Even the few nurses who were familiar with such interventions noted that they had never undertaken such an intervention themselves; this was the domain of the pastoral care worker, the social worker, the psychologist, or the volunteer. The lack of nursing-conducted interventions and research is unfortunate as palliative care nurses want to provide holistic care, palliative care patients want help from nurses for their existential/spiritual concerns,^{26,27} and nurses are the most abundant health care professionals.¹⁹

The nurses' reflections on Outlook were overwhelmingly positive. Some nurses were pleased that they already used some of the Outlook questions, giving validation to their practice and prompting thought for expansion. Many felt the questions were valuable as a framework to keep them on track and, although not necessarily easy to ask, were feasible to include in their practice. The second session (forgiveness and regrets) drew the most comment; some nurses felt patients commonly seek forgiveness and reconciliation and noted that facilitating reunions was already part of their practice.

The nurses felt that using this "framework" would allow them to tease out patients' stories, to allow them to get to know their patients better, and would assist patients to know their life had been valuable. This benefit could potentially reach beyond the patient's life and provide both a legacy and solace for the grieving relatives, as the nurses with patient biography experience noted. One study of an alternate life review/preparation for end-of-life intervention found that the deceased person's completion of the intervention had positive effects on the relatives' grieving process.²⁸

The impact on nurses of conducting existential/spiritual interventions with patients has not been formally studied, although in a previous study of a nurse-led intervention the nurse interventionist did find it a satisfying activity.¹⁷ One of the participants in the current study noted that using

such an approach “would feed the spiritual side of me.” Studies looking at the benefit of existential/spiritual care training on nurses are limited and mixed; 1 study found a moderately positive effect,²⁹ whereas another found none.³⁰ However, in the latter study, patients were not directly involved; therefore, the element of helping others may have been absent.

The nurses in the current study identified potential difficulties in implementing Outlook, such as lack of time (leading to the perceived appropriateness of volunteer delivery), the need for a mature nurse-patient relationship, and the need for experience in palliative care nursing; these barriers have been identified elsewhere.³¹⁻³³ However, the nurses were able to suggest creative modifications to overcome such difficulties, including the use of a prompt card to be attached to their identity badge, using the questions one at a time, conducting the intervention later in the admission when the patient was more comfortable, and sharing this information with the team in order to predict or perhaps diminish symptoms of existential/spiritual distress. These could be usefully considered and evaluated in future trials of nurse-delivered existential/spiritual intervention.

LIMITATIONS

This study was limited by the number of participants (20 participants), but the spread of participants' backgrounds did provide a reasonable cross section of palliative care nurses while not being exhaustive. Also it is acknowledged that qualitative research is influenced by the researchers' position, prior experience, and beliefs.²⁵ In this study, the interviewer and first researcher were also a palliative care nurse.

CONCLUSION

This study found that palliative care nurses want to help their patients holistically and are willing to try existential/spiritual interventions such as Outlook, either as a whole or modified intervention, and that interventions such as Outlook give validation to their own practice. The participants acknowledged challenges to conducting Outlook but also made suggestions that may facilitate usage. The findings of this study justify further research into several areas: (1) implementation of Outlook in both its current and modified version by a range of palliative care nurses; (2) development of measures of patient, family, and nurse satisfaction and spiritual well-being to ensure sensitive evaluation of nurse-delivered interventions such as Outlook; and (3) evaluation of the effect of the Outlook intervention on bereaved loved ones. Results of such investigations could be disseminated via the nursing literature to influence palliative care nurses' knowledge and practice in provision of holistic patient care.

References

1. Saeteren B, Lindstrom UA, Naden D. Latching onto life: living in the area of tension between the possibility of life and the necessity of death. *J Clin Nurs*. 2011;20(5-6):811-818.
2. Lemay K, Wilson KG. Treatment of existential distress in life threatening illness: a review of manualized interventions. *Clin Psychol Rev*. 2008;28(3):472-493.
3. Galfin JM, Watkins ER, Harlow T. Psychological distress and rumination in palliative care patients and their caregivers. *J Palliat Med*. 2010;13(11):1345-1348.
4. Arnold B, Lloyd L. Harnessing complex emergent metaphors for effective communication in palliative care: a multimodal perceptual analysis of hospice patients' reports of transcendence experiences [published online ahead of print May 26, 2013]. *Am J Hosp Palliat Med*. 2013.
5. Binder B, Mastel-Smith B, Hersch G, Symes L, Maleecha A, McFarlane J. Community-dwelling, older women's perspectives on therapeutic life review: a qualitative analysis. *Issues Ment Health Nurs*. 2009;30:288-294.
6. Mastel-Smith B, Binder B, Malecha A, Hersch G, Symes L, McFarlane J. Testing therapeutic life review offered by home care workers to decrease depression among home-dwelling older women. *Issues Ment Health Nurs*. 2006;27(10):1037-1049.
7. Stinson CKKE. Structured reminiscence: an intervention to decrease depression and increase self-transcendence in older women. *J Clin Nurs*. 2006;15:208-218.
8. Kunz JA. Targeted reminiscence interventions for older adults with dementia. *J Geriatr Psychiatry*. 2002;35(1):25-49.
9. Woods B, Spector A, Jones C, Orrell M, Davies S. Reminiscence therapy for dementia. *Cochrane Database Syst Rev*. 2005;(2):1-23.
10. Hudson J, Day MC. Athletes' experiences of expressive writing about sports stressors. *Psychol Sport Exerc*. 2012;13(6):798-806.
11. Allen RS, Hilgeman MM, Ege MA, Shuster JL, Burgio LD. Legacy activities as interventions approaching the end of life. *J Palliat Med*. 2008;11(7):1029-1038.
12. Ando M, Morita T, Akechi T, Okamoto T. Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *J Pain Symptom Manage*. 2010;39(6):993-1002.
13. Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psychooncology*. 2010;19(1):21-28.
14. Henry M, Cohen SR, Lee V, et al. The Meaning-Making intervention (MMi) appears to increase meaning in life in advanced ovarian cancer: a randomized controlled pilot study. *Psychooncology*. 2010;19(12):1340-1347.
15. Steinhauser KE, Alexander SC, Byock IR, George LK, Olsen MK, Tulskey JA. Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *J Palliat Med*. 2008;11(9):1234-1240.
16. Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol*. 2011;12(8):753-762.
17. Keall RM, Butow PN, Steinhauser KE, Clayton JM. Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care setting: results from a phase 2 trial. *Cancer Nurs*. 2013;36(3):E39-E46.
18. Schomerus G, Matschinger H, Angermeyer MC. The stigma of psychiatric treatment and help-seeking intentions for depression. *Eur Arch Psychiatry Clin Neurosci*. 2009;259(5):298-306.
19. Australian Institute of Health and Welfare. Available at <http://www.aihw.gov.au/health-workforce>. Accessed July 10, 2013.
20. Keall RM, Butow PN, Steinhauser KE, Clayton JM. Discussing life story, forgiveness, heritage, and legacy with patients with life-limiting illnesses. *Int J Palliat Nurs*. 2011;17(9):454-460.
21. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulskey JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med*. 2000;132(10):825-832.

22. Symes L, Mastel-Smith B, Hersch G, et al. The feasibility of home care workers delivering an intervention to decrease depression among home-dwelling, older women: a qualitative analysis. *Issues Ment Health Nurs*. 2007;28(7):799-810.
23. Trueman I, Parker J. Exploring community nurses' perceptions of life review in palliative care. *J Clin Nurs*. 2006;15(2):197-207.
24. Morita T, Kawa M, Honke Y, et al. Existential concerns of terminally ill cancer patients receiving specialized palliative care in Japan. *Support Care Cancer*. 2004;12(2):137-140.
25. Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. *Br Med J*. 2008;337:404-409.
26. Hermann CP. The degree to which spiritual needs of patients near the end of life are met. *Oncol Nurs Forum*. 2007;34(1):70-78.
27. Tan H, Braunack-Mayer A, Beilby J. The impact of the hospice environment on patient spiritual expression. *Oncol Nurs Forum*. 2005;32:1049-1055.
28. McClement S, Chochinov HM, Hack T, Hassard T, Kristjanson LJ, Harlos M. Dignity therapy: family member perspectives. *J Palliat Med*. 2007;10(5):1076-1082.
29. Morita T, Murata H, Hirai K, et al. Meaninglessness in terminally ill cancer patients: a validation study and nurse education intervention trial. *J Pain Symptom Manage*. 2007;34(2):160-170.
30. Fillion L, Duval S, Dumont S, et al. Impact of a meaning-centered intervention on job satisfaction and on quality of life among palliative care nurses. *Psychooncology*. 2009;18(12):1300-1310.
31. Bailey ME, Moran S, Graham MM. Creating a spiritual tapestry: nurses' experiences of delivering spiritual care to patients in an Irish hospice. *Int J Palliat Nurs*. 2009;15(1):42-48.
32. Bush T, Bruni N. Spiritual care as a dimension of holistic care: a relational interpretation. *Int J Palliat Nurs*. 2008;14(11):539-545.
33. Boston PH, Mount BM. The caregiver's perspective on existential and spiritual distress in palliative care. *J Pain Symptom Manage*. 2006;32(1):13-26.

CHAPTER 6

How do Australian Palliative Care Nurses Address Existential and Spiritual Concerns? Facilitators, Barriers and Strategies

This chapter contains the systematic review titled “How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies.” In press
Journal of Clinical Nursing

ORIGINAL ARTICLE

How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies

Robyn Keall, Josephine M Clayton and Phyllis Butow

Aims and objectives. To investigate the facilitators, barriers and strategies that Australian palliative care nurses identify in providing existential and spiritual care for patients with life-limiting illnesses.

Background. Palliative care aims to be holistic, incorporating all domains of personhood, but spiritual/existential domain issues are often undertreated. Lack of time and skills and concerns for what you may uncover hamper care provision.

Design. A qualitative study through semistructured interviews.

Methods. We interviewed 20 palliative care nurses from a cross section of area of work, place of work, years of experience, spiritual beliefs and importance of those beliefs within their lives. Questions focused on their current practices of existential and spiritual care, identification of facilitators of, barriers to and strategies for provision of that care. Their responses were transcribed and subjected to thematic analysis.

Results. The nurses' interviews yielded several themes including development of the nurse–patient relationship (14/20 nurses), good communication skills and examples of questions they use to 'create openings' to facilitate care. Barriers were identified as follows: lack of time (11/20 nurses), skills, privacy and fear of what you may uncover, unresolved symptoms and differences in culture or belief. Novel to our study, the nurses offered strategies that included the following: undertaking further education in this area, being self-aware and ensuring the setting is conducive to in-depth conversations and interactions and documentation and/or interdisciplinary sharing for continuity of care.

Conclusion. Palliative care nurses are well placed to provide existential and spiritual care to patients with the primary facilitator being the nurse–patient relationship, the primary barrier being lack of time and the primary strategy being undertaking further education in this area.

Relevance to clinical practice. These findings could be used for nurse-support programmes, undergraduate or graduate studies or communication workshop for nurses.

Key words: communication skills, end-of-life care, existential care, nurse education, nurse–patient relationships, nursing care, nursing interventions, palliative care, spiritual care

Accepted for publication: 6 January 2014

Authors: *Robyn Keall*, MS, RN, PhD Candidate and Clinical Nurse Consultant (Palliative Care), University of Sydney & HammondCare Palliative & Supportive Care Service, Sydney; *Josephine M Clayton*, PhD, Associate Professor, University of Sydney & HammondCare Palliative & Supportive Care Service, Greenwich Hospital, Greenwich; *Phyllis Butow*, PhD, Professor, Chair of Psychology, The University of Sydney, Sydney, NSW, Australia

Correspondence: Robyn Keall, MS, PhD Candidate, University of Sydney & HammondCare Palliative & Supportive Care Service, The University of Sydney, Rm 164, CeMPED, Transient Building F12, NSW 2006, Australia. Telephone: +61 299038333. E-mail: rkeall@sydney.edu.au

What does this paper contribute to the wider global clinical community?

- Identification of facilitators and barriers to existential/spiritual care.
- Strategies to assist nurses in overcoming barriers to existential/spiritual care.
- Future research considerations of these findings.

Introduction

Palliative care aims to provide support and symptom control, improving quality rather than quantity of life, for those with life-threatening illnesses throughout their illness trajectory (Puchalski *et al.* 2009). This approach is holistic, treating the entire person not just the disease, taking into account that person's physical, social, psychological and spiritual needs and addressing each component with equal consideration. However, provision of care is not always adequate in the spiritual domain (Rainbird *et al.* 2009, Yardley *et al.* 2009).

Interest in provision of spiritual care as part of healthcare delivery is growing. Guidelines to providing spiritual care for palliative care patients have been formulated. Recommendations include the following: the regular assessment of spiritual concerns using a reputable tool (enabling identification of a patient's hopes, dreams, fears and beliefs), assisting patients to incorporate these spiritual concerns into their daily care and life completion activities including life review. This care is ideally provided by appropriately educated, interdisciplinary and in particular pastoral care staff (National Consensus Project for Quality Palliative Care 2004).

Background

In a well-funded, professionally resourced area, there may be a variety of amply qualified spiritual practitioners, but this is not the reality for all palliative care services (Bolsjo *et al.* 2002). Nurses make up the largest percentage of the healthcare workforce. They are present in almost every palliative care setting and have the greatest amount of contact with patients (Gaynor *et al.* 2007). In Australia, palliative care nurses practise in hospitals as consultants or within dedicated wards as bedside nurses, in hospices and in community roles in which they visit patients in their home, nursing home, hostel or institution (Candy *et al.* 2011). The palliative care nurse's geographical area of service may be up to several hundreds of square kilometres, providing support either directly to patients or to local generalist practitioners via telephone or computer link-up. The palliative care nurse's interaction may be as brief as once or as long as several years with almost daily support. Thus, they are potentially the staff member most likely to be present and able to provide spiritual care. Importantly, palliative care patients have identified nurses as providing them with much needed spiritual support (Tan *et al.* 2005, Hermann 2007).

Previous studies specifically about palliative care nurses and the provision of spiritual/existential care are limited,

with results for nurses usually not presented separately to those for other members of the palliative care practitioner team (Wright 2002). The limited research available suggests that (1) nurses view this care as part of their holistic care role (Sinclair *et al.* 2006); (2) there are inherent challenges to provision of spiritual care, such as lack of time and difficulty in documentation (Bailey *et al.* 2009); (3) nurse-patient relationships, therapeutic touch, active listening, communication and being spiritually self-aware (Boston & Mount 2006, Bush & Bruni 2008), being present and co-creating fluid relationships with patients and families (Daaleman *et al.* 2008) can all be beneficial.

Few of the published studies have been entirely about palliative care nurses' perspectives, and of those, none to our knowledge have included palliative care nurses from different geographical and workplace settings. Therefore, the aim of this study was to explore (from a variety of settings) Australian palliative care nurses' perceptions of the facilitators, barriers and strategies to provision of spiritual/existential care to their patients.

Methods

Design and data collection

In this qualitative study, structured interviews were conducted with palliative care nurses from the State of New South Wales, Australia. Recruitment involved several approaches: an advertisement disseminated via the New South Wales Palliative Care Association and a brief presentation to colleagues at a research meeting with recruitment flyers, which in turn was disseminated through the Rural and Remote Palliative Care Nurses Association. Interested participants were asked to contact the researcher to discuss the study further and provide informed consent. Consented participants were also invited to mention the study to eligible colleagues, who in turn could contact the researcher for further information.

Once consented, participants were invited to complete an interview either face-to-face or over the phone, at a time convenient to them, which was recorded using a hand-held digital recorder. The semistructured interviews began with gathering of demographics and followed with open questions concerning the nurse's current approach to spiritual care for palliative care patients, facilitators and barriers to providing spiritual care and strategies they use in discussing spiritual concerns. Interviews took between 21–55 minutes to complete. The recorded interviews were then transcribed and subjected to thematic analysis.

Analysis

An inductive approach was taken to analysis, allowing the interviewees' quotes to form the basis of understanding for the investigator, rather than hypotheses dictating the analyses of the data (Kuper *et al.* 2008). The number of respondents raising each theme is provided, and the words 'a few' (0–5), 'some' (6–10), 'many' (11–15) and 'most' (16–20) have been used to denote frequency of the subthemes.

The quotations used have been de-identified, however, the following system has been used to enable comparison of responses. This includes place of practice: community (C) or acute (A); setting: rural/remote (R) or urban (U); years of experience: (number); and self-reported importance of spirituality: not important (NI), important (I), very important (VI) or extremely important (EI) to the nurse. Therefore, a community nurse in a rural setting with 12 years of experience, to whom spirituality is VI, would be identified as (C/R/12/VI).

Ethics approval was granted by the University of Sydney Human Research Ethics committee. All participants provided informed written consent.

Results

Participants

Recruitment took place over four months, April to June, 2012, with 20 eligible participants volunteering to take part. Ten interviews were conducted via telephone and 10 in person. Demographic details of participants are shown in Table 1. Twelve of the 20 nurses identified with a spiritual or religious belief, 11 of those with Christianity and one with Buddhism; of these, they considered their beliefs to be NI (2), important (4), VI (5) and EI (1) in their lives. Interestingly, two of the participants who said they did not identify with any particular spiritual belief still felt that spirituality was important in their lives.

Facilitators

The nurses identified facilitators to talking with patients about spiritual and existential concerns, as outlined below.

1. Development of nurse–patient relationship (14/20)

Many participants felt that nurse–patient relationships are essential to allowing conversations on a deeper level. The majority of the nurses identified that whether they saw the patient once or many times, rapport and trust allowed conversations of a deeper level to take place:

The initial part is about rapport building.... and people can open up a little bit more each time...slowly over a number of visits you'll get to know who that person is. (C/R/31)

The concept of fostering the nurse–patient relationship was more frequently mentioned by the community nurses who also spoke of the benefits of continuity of care:

I find it easier when I see the patient for the first time and go through the whole admission process..... it's much easier to continue on with their spiritual care than it is to come in cold. (C/U/12/I)

Factors that aided the development of the nurse–patient relationship included the following:

Table 1 Demographics of participants

Age	
25–35	2
36–45	4
46–55	8
56–65	6
Sex	
Female	19
Male	1
Nursing position	
Registered nurse	7
Clinical nurse consultant	6
Clinical nurse specialist	4
Nursing unit manager	1
Nurse practitioner	2
Area of practice	
Community	9
Inpatient unit	6
Acute hospital	4
Area	1
Location of practice	
Major city	13
Large metropolitan	1
Semirural	5
Remote rural	1
Years of experience	
1–5 years	2
6–10 years	3
11–20 years	4
21–30 years	6
31–40 years	5
Do you identify with a belief?	
Yes	12
No	8
Which one?	
Christianity	11
Buddhism	1
How important is it to you?	
Important	6
Very important	5
Not important	2
Extremely important	1

1a. *Confidence and experience*

For many nurses, confidence and experience enhanced their ability to provide care. Several nurses could remember feeling inadequate or uncomfortable discussing sensitive issues with patients earlier in their careers:

Once I became more confident...my approach...is to be completely open-minded and treat everybody as unique. (C/U/12/I)

It's about your own clinical skills and your intuition about how much further you can take conversations or whether you are just planting seeds and then you come back. (A/R/20/NI)

1b. *Walking alongside the patient*

Some participants used the phrase 'walking alongside the patient' to describe an approach in which they did not try to change things but tried to support the patient in their decisions and listen when the patient was ready to talk about spiritual issues:

You might see that moment where you got in and they've opened themselves up a little and you can sit down and talk to them for half an hour and really kind of figure out what's going on. (A/U/2)

So there is only so much I can do. I can only walk beside it, I can't change it. (C/R/32/VI)

1c. *Patient openness*

While patient openness was out of the control of the nurse, a few identified that a patient's demeanour can assist in the development of the nurse-patient relationship:

It's definitely easier when the patients are very aware of themselves, aware of what might happen along the course of their illness. You can have a more open discussion. (A/U/2)

2. *Communication skills (13/20)*

Many nurses responded that good communication skills are essential to the provision of spiritual care; one hospital-based nurse reflected on how poor communication can make a difficult situation worse:

We've got a clinical complaints unit here and I would say that 95% of the complaints that come through there are about our poor communication. Even things like, 'We didn't understand that mum was going to die, we weren't given information.' I think communication is the key to all of this. (A/U/25/I)

Different components of good communication skills were identified as follows:

2a. *Active listening*: Some nurses spoke about the importance of giving the patient 100% of your attention and showing them you have heard what they have to say by paraphrasing their words:

Being open yourself, either maybe noting inflections of what they're saying or specific words that (you) may use at another time which may lead you to may be open up that discussion again. (C/R/31)

2b. *Be genuine/human/know your limitations*: Some of the nurses talked about being open and honest and that patients can sense whether you are genuine or not. A few participants spoke of being self-aware and avoiding a situation if you cannot give 100% of your attention:

You need to respect people...I think people can pick up that respect and they can pick up if you genuinely care, that's a connection with humanity. And if they feel that you are very human and caring... then they are probably more likely to open up to you. (C/R/31)

Some also noted that it is not essential to know all the answers and that patients do not expect it, being genuine and listening as another human was adequate:

I try and really engage with someone like a 100% when they're telling me something... even if I don't really have the answers... because I mean I don't have the answers but people seem to appreciate when you just listen without judgement. (A/U/1.5/I)

2c. Some of the nurses noted *that allowing silence*, rather than filling the void with questions or comments, gives patients the opportunity to elaborate on their thoughts in an unhurried or directed way:

Allowing people to talk or allowing silences. One of my mentors told me that you should sit on your hands or if you feel like you should leave don't- stay a bit longer. (C/R/30/VI)

2d. *Compassion*: Some nurses identified having and showing compassion and empathy for the patient's circumstances allows the deepening of the therapeutic relationship:

Acknowledging what a tough time people are having....that it must be frightening and that they must be concerned is a good way of opening up those lines of communication. (A/U/25/I)

2e. *Body language/reading clues*: A few nurses spoke of being aware of nonverbal cues from the patient and of their own nonverbal behaviour, to fully engage with the patient and put them at ease:

And you can connect too with people with just even how you are sitting, how you're looking, the care in your face, the tone in your voice, the spaces that you put between words. (C/R/31)

3. *Examples of questions palliative care nurses use to facilitate conversations*

Many experienced participants gave examples of questions they typically used to facilitate spiritual discussion, for example (Table 2):

Table 2 Participant quotes regarding questions used by palliative care nurses to facilitate spiritual conversations

'Are you peaceful inside do you feel peaceful or what about the family? 'How's all that happening for you?' How's the illness affecting them and their place in the family? (C/U/40/EI)

I'm really sorry we haven't had time to... get to know each other but is there anything much deeper that I can help you with? (A/R/ 20/NI)

I always introduce myself and give them a little bit of my back ground.... Can I just get a bit of your back ground....where you were born and your family, how and where you grew up and kind of just bring it in to the picture then focus more on symptoms and what it is they would actually like to from me. (A/U/40/I)

What are the three biggest problems? (C/R/20)

What's the thing that troubles you the most? (A/U/25/I)

Have you got any hopes, dreams or wishes at the moment? (A/U/25)

Are you part of a spiritual or religious community? (C/R/31)

A patient says 'I just wish it was all over'. And I will ask 'Why is that? What's causing you to say that?' (C/U/16/VI)

I use Hope a lot because... hope is dynamic and it's changing.

It's a word that can be used as a verb. I can hope, I will hope, I shall hope and in life our hopes can change. And in death or in the lead up to death, our hopes can change and those changing hopes can help support us. For example, you can go from 'I hope I don't die' to 'I hope the pain is a little bit less' 'I hope my family are going to cope better', 'I hope I am going to die peacefully'. 'I hope I am going to have a few more days'. 'I hope I am going to find something after death'. (C/R/31)

Barriers

Various barriers to discussing spiritual and existential concerns were identified.

(1) *Time* (11/20) was the most prevalent barrier. Many nurses spoke about not having enough time to discuss their patients' concerns due their concurrent workload:

You might see that moment where they've opened themselves up a little...but you've got to go and do six other things, finding that balance in a busy ward can be hard. (A/U/2)

Some nurses mentioned the need to triage and address symptoms in order of severity, knowing that sometimes one uncontrolled symptom can exacerbate another:

You can't talk about someone's spiritual stuff if they're hanging off the end of the bed in agony. You've still got to address what needs to be done first. (C/U/40)

Some nurses spoke about the difficulty of patients being referred too late to palliative care or noted that patients sometimes deteriorate and die before they or their families are psychologically ready for death. This situation causes distress for the patient, their family and the nurse:

It's particularly difficult when there's a young family and it's happened too quickly. You're doing an awful lot of work at the eleventh hour when it's all too late really to prepare anyone. (C/U/40)

(2) *Fear of what you may uncover* or that you may make a bad situation worse was identified by 7/20 nurses who spoke of their perceived inadequacies:

We need to be treating the whole person... although I don't know that I'm the greatest at doing that because I don't feel confident enough...because I am afraid if they come up with something and I don't how to answer. (A/U/10/NI)

(3) *Unresolved symptoms*: (4/20) nurses identified that spiritual and psychological concerns can be mistaken for physical ones and treated inappropriately; one respondent gave a particularly vivid example of this:

A young single father went to theatre, open and close. He was riddled with cancer. His pain relief kept escalating without any effect. We sat down and talked.... and got him to tell his life story. ... and his needs for opiates actually decreased significantly. (A/U/40/I)

(4) *Lack of privacy* due to the presence of family members or other team members, which can stifle meaningful conversation, was noted by (4/20) nurses. This could be a problem both in the patient's home and in the inpatient unit:

If it's a husband they won't talk in front of their wife or vice versa. And not having other people there.... the Registrar, the Consultant and we (have) had a student attached with us lately. So it's really difficult. (C/U/30/VI)

(5) *Lack of skills in others*: Three of the twenty nurses expressed concerns about lack of skills and gave examples of other nurses with whom they had worked who had been reluctant to undertake deep and sensitive conversations with patients:

Some of the nurses particularly feel very uncomfortable asking questions around those sorts of areas. They feel that they're not really sufficiently trained. (C/U/40)

(6) *Differences of belief*: One nurse who identified herself as a Christian noted that she felt more comfortable helping Christian patients as she was concerned that she may offend someone of another faith:

I (worry that I) would offend them... because I don't know enough about their faith to provide them with things that could be comforting.... I can tell them about my faith but that's not what it's about. (A/U/10/NI)

Strategies

The nurses identified several different strategies to assist in the provision of existential and spiritual support to patients, as outlined below.

(1) *Making appropriate referrals*: A key role of the nurse included knowing when to refer a patient on to other members of the multidisciplinary team. Thirteen of the twenty nurses responded that they would refer a patient on to a social worker, pastoral care worker or psychologist:

It's about identifying them and acknowledging them as being important and then making sure that people have access to the supports that they need. (A/U/25/I)

(2) *Maintain realistic expectations*: Seven of the twenty nurses commented about the importance of maintaining realistic expectations regarding the amount of help you can provide:

So there is only so much I can do. (C/R/32/VI)

Keeping a realistic perspective is the biggest thing. You can't fix everything and you can't deal with everything. Sometimes you've just got to go, well that's the way the world is and you take a step back from it all. (A/U/2)

(3) *Setting the scene*: Several (7/20) of the nurses touched on ensuring the setting was conducive to a deeper-level conversation; this may be accepting the offer of an unwanted cup of tea *to show you mean to stay awhile* (A/R/20/NI), trying to blend in with the surroundings *I often sit on the floor at people's houses....trying to mould yourself into that environment* (C/R/31), using prompts to start the conversation *I'll look around the room and...discuss who's in the photos...breaks the barrier down a bit.* (C/U/40/EI) or asking close family for insights into the patient:

You have to work through the family as well... You talk to wives of you know 50 years or more and you get an idea of what that person has been like. (A/R/20/NI)

(4) *Undertake counselling courses*: Several of the nurses (6/20) had (of their own volition or with work support)

undertaken either counselling courses or courses in self-awareness which they felt had improved their communication skills and changed the way they viewed their role and interactions with others:

I did a 3 day (an expert in grief counselling) course that really opened my eyes. I went from a nurse that wanted to fix things to letting things unfold. (C/U/12/I)

(5) *Documenting*: Participants felt that discussions of existential/spiritual concerns with patients can reveal sensitive issues, but the need for good team communication and continuity of care needs to be balanced against maintaining patient confidentiality and the burden of paperwork. Many nurses said that they *would not document the details* of the discussion, rather simply noting that an in-depth conversation had occurred:

No we wouldn't document.... We might pass it on to some extent... we (might) discuss in the office (for continuity of care) but probably not documented. (C/R/8/I)

Some would use the patient's words in inverted commas in their documentation to describe their distress, for example 'I can't go on!', but not the detail of the distress. For one nurse, this raised the question of not treating spiritual concerns with the same attention as physical issues:

I would hesitate to sort of verbatim write things down. I don't know if that's good or bad because I would write verbatim what someone said about pain. (C/U/16/VI)

A few nurses identified that it is easier to record tangible things like bowel movements and response to medications than to quantify those of a spiritual nature:

You always write down the easy things to measure but spiritual concerns aren't quite as easy to put a number on. (A/U/1.5/I)

In addition, two nurses raised concerns that documenting may breach patient confidentiality boundaries; one nurse makes a point of getting the patient's permission first:

I ask 'do you mind if I document our conversation?' And sometimes they say 'no, I don't mind' and sometimes they say, 'of course I don't want anyone else to every hear this'. So in that case I would just document that a discussion was had about the person's concerns or the person's beliefs or whatever it was. (A/U/25)

Some nurses who *would document details* felt it was important for the team to understand what was troubling the patient to give appropriate care:

I try to document as much as possible when writing in the Progress Notes. If somebody's upset for whatever reason I just plainly write it down. (C/U/12/I)

One nurse expressed frustration working in a setting when spiritual concerns were discussed but were not documented:

They'd never write anything in the notes and it felt like we're missing out on something. (A/U/30/VI)

Discussion

This study identified facilitators, barriers and strategies to provision of spiritual care as perceived by palliative care nurses. Our key findings were as follows: (1) facilitators include therapeutic nurse–patient relationships, good communication skills and helpful questions, (2) barriers include time, fear of what you may uncover, lack of skills and unresolved symptoms, and (3) strategies include appropriate referrals, setting the scene, ongoing nurse education and documentation.

The collection of questions that the nurses have used with success is novel to this study, and it is hoped that these may be of help to the reader. These lines of questioning have been described as ‘creating openings’ to conversation and that this is central to the provision of holistic care (Boston & Mount 2006).

Many of the nurse-identified facilitators echoed findings of other studies, including that an open and aware nurse–patient relationship allows for continuity of care and ensures patients do not feel abandoned (Luker *et al.* 2000, Steinhauer *et al.* 2000, Bolmsjo *et al.* 2002). Conversely, lack of continuity has been identified as an impediment to providing spiritual support (Daaleman *et al.* 2008). Therapeutic nurse–patient relationship building is therefore an avenue worth exploring to enhance nurses’ confidence, skills and abilities and ultimately patient care (Bolmsjo *et al.* 2002). In our study, community nurses spoke about how they developed nurse–patient relationships and this helped their care. Taking this practice into the acute setting would be most easily replicated with the primary nurse model whereby one nurse acts a ‘case manager’ for the patient, developing an intimate relationship which will help guide care (Pontin 1999, Bolmsjo *et al.* 2002).

Good communication skills were unsurprisingly highlighted, as they feature in the bulk of research about spiritual and existential support (Puchalski & Romer 2000, Clayton *et al.* 2005, Okon 2005, Chochinov 2006, Sinclair *et al.* 2006, Bailey *et al.* 2009). Some authors have noted that communication is not always about what or how you say it but also how you do not say anything but offer human and silent presence (Dettmore 2011).

A recent study comparing palliative care nurses with acute care nurses found that the palliative care nurses had higher levels of spiritual awareness, which enabled them to provide spiritual/existential care, which was attributed to advanced experience and career progression (Ronaldson *et al.* 2012). In contrast, our findings suggest that the degree of importance of spirituality to participants and identification with a particular belief did not correlate with years of nursing experience, suggesting perhaps that nurses who are drawn to palliative care are more interested in spirituality for themselves and their patients.

The bulk of the nurse-identified barriers in this study have been previously discussed in the literature, in particular the barriers of lack of time, lack of skills, lack of privacy and fear of what you may uncover (Boston & Mount 2006, Sinclair *et al.* 2006, Bush & Bruni 2008, Daaleman *et al.* 2008, Bailey *et al.* 2009, Leung & Esplen 2010, Ronaldson *et al.* 2012). Other writers have also described an imperative to resolve symptoms such as pain and breathlessness (Georgesén & Dungan 1996), which may take precedence over spiritual suffering, while others describe how unresolved symptoms can exacerbate spiritual distress (Chochinov 2006) and vice versa. Differences of cultural and spiritual background/beliefs between the professional and the patient have also been previously identified as a possible barrier (Sinclair *et al.* 2006) warning of the dangers of overstepping of the boundary into proselytising one’s faith or belief (Daaleman *et al.* 2008).

The nurses noted that a conducive setting, ongoing education and development of self-awareness allow in-depth conversations of issues of spiritual/existential concern to take place and in turn enable ‘a nurse who wanted to fix things to letting things unfold’. Also of interest are the findings about documenting spiritual concerns; they are difficult to quantify, they might breach patient confidentiality, and yet, the nurses felt that it was important to note that the patients had concerns of a spiritual nature and for some verbal handover to colleagues to ensure continuity of care. One study agreed that it is essential for nurses to document their care of this domain to both acknowledge the interaction and raise awareness of the importance of this care (Ronaldson *et al.* 2012).

Limitations

The limitations of this study were the moderate sample size and the single-state sample. The respondents were not directly asked about their personal experience of loss or caring for a loved one which has been identified as a facilitator

to spiritual discussion (Boston & Mount 2006, Daaleman et al. 2008), with one author going so far as to say that only the wounded healer can truly heal (Boston & Mount 2006). In addition, participants were self-selected and therefore a potentially biased sample.

Conclusion

To meet the clinical practice guidelines for quality care in palliative care (National Consensus Project for Quality Palliative Care 2004) and to truly provide holistic care, 'spiritual, religious and existential aspects of care' must be addressed. Palliative care nurses are well placed and willing to provide such care, but are not always skilled and are most often time-poor. Therefore, attention must be given to ongoing education and organisational commitment to moving nursing from task-oriented care provision to holistic care, including adequate time to deliver this care. This may be achievable with investigation of alternative models of nursing care and support of evidence-based education programmes to enhance skills in this important aspect of care.

Relevance to practice

It is proposed that these findings could form part of a communications education programme for nurses, building on the concept of the therapeutic nurse-patient relationships

and the role of models of nursing, and used in both the palliative and the nonpalliative care setting. Further research into nursing models of care to enhance palliative care patients' care in all domains of care should be undertaken.

Acknowledgements

The authors would like to thank the Palliative Care Rural and Remote Nurses network, the NSW Palliative Care Association and the dedicated palliative care nurses who willingly gave up their time to talk with us.

Disclosure

The authors have confirmed that all authors meet the ICMJE criteria for authorship credit (www.icmje.org/ethical_1author.html), as follows: (1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content and (3) final approval of the version to be published.

Conflict of interest

The authors have no conflict of interest in this article. The research was undertaken as part of the first author's PhD work with no additional funding.

References

- Bailey ME, Moran S & Graham MM (2009) Creating a spiritual tapestry: nurses' experiences of delivering spiritual care to patients in an Irish hospice. *International Journal of Palliative Nursing* 15, 42–48.
- Bolmsjo I, Hermeren G & Ingvar C (2002) Meeting existential needs in palliative care – who, when, and why? *Journal of Palliative Care* 18, 185–191.
- Boston PH & Mount BM (2006) The caregiver's perspective on existential and spiritual distress in palliative care. *Journal of Pain and Symptom Management* 32, 13–26.
- Bush T & Bruni N (2008) Spiritual care as a dimension of holistic care: a relational interpretation. *International Journal of Palliative Nursing* 14, 539–545.
- Candy B, Holman A, Leurent B, Davis S & Jones L (2011) Hospice care delivered at home, in nursing homes and in dedicated hospice facilities: a systematic review of quantitative and qualitative evidence. *International Journal of Nursing Studies* 48, 121–133.
- Chochinov HM (2006) Dying, dignity, and new horizons in palliative end-of-life care. *CA: A Cancer Journal for Clinicians* 56, 84–103.
- Clayton JM, Butow PN, Arnold RM & Tattersall MHN (2005) Fostering coping and nurturing hope when discussing the future with terminally cancer patients and their caregivers. *American Cancer Society* 103, 1965–1975.
- Daaleman TP, Usher BM, Williams SW, Rawlings J & Hanson LC (2008) An exploratory study of spiritual care at the end of life. *Annals of Family Medicine* 6, 406–411.
- Dettmore D (2011) Don't just do something, stand there: responding to unrelieved patient suffering. *Journal of Psychosocial Nursing and Mental Health Services* 49, 34–38.
- Gaynor L, Gallasch T, Yorkston E, Stewart S, Bogossian F, Fairweather C, Foley D, Nutter H, Thompson J, Stewart L, Anastasi J, Kelly J, Barnes L, Glover P & Turner C (2007) The future nursing workforce in Australia: baseline data for a prospective study of the profile, attrition rates and graduate outcomes in a contemporary cohort of undergraduates. *Australian Journal of Advanced Nursing* 25, 11–20.
- Georgeson J & Dungan JM (1996) Managing spiritual distress in patients with advanced cancer pain. *Cancer Nursing* 19, 376–383.
- Hermann CP (2007) The degree to which spiritual needs of patients near the end of life are met. *Oncology Nursing Forum* 34, 70–78.
- Kuper A, Reeves S & Levinson W (2008) An introduction to reading and

- appraising qualitative research. *British Medical Journal* 337, 404–409.
- Leung D & Esplen MJ (2010) Alleviating existential distress of cancer patients: can relational ethics guide clinicians? *European Journal of Cancer Care* 19, 30–38.
- Luker KA, Austin L, Caress A & Hallett CE (2000) The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. *Journal of Advanced Nursing* 31, 775–782.
- National Consensus Project for Quality Palliative Care (2004) Clinical Practice Guidelines for quality palliative care: executive summary. *Journal of Palliative Medicine* 7, 611–627.
- Okon TR (2005) Palliative care review: spiritual, religious, and existential aspects of palliative care. *Journal of Palliative Medicine* 8, 392–414.
- Pontin D (1999) Primary nursing: a mode of care or a philosophy of nursing? *Journal of Advanced Nursing* 29, 584–591.
- Puchalski C & Romer AL (2000) Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine* 3, 129–137.
- Puchalski C, Ferrell B, Otis-Green S, Baird P, Bull J, Chochinov H, Handzo G, Nelson-Becker H, Prince-Paul M, Puggliese K & Sulmasy D (2009) Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. *Journal of Palliative Medicine* 12, 885–904.
- Rainbird K, Perkins J, Sanson-Fisher R, Rolfe I & Anseline P (2009) The needs of patients with advanced, incurable cancer. *British Journal of Cancer* 101, 759–764.
- Ronaldson S, Hayes L, Aggar C, Green J & Carey M (2012) Spirituality and spiritual caring: nurses' perspectives and practice in palliative and acute care environments. *Journal of Clinical Nursing* 21, 2126–2135.
- Sinclair S, Raffin S, Pereira J & Guebert N (2006) Collective soul: the spirituality of an interdisciplinary palliative care team. *Palliative & Supportive Care* 4, 13–24.
- Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM & Tulsky JA (2000) In search of a good death: observations of patients, families, and providers. *Annals of Internal Medicine* 132, 825–832.
- Tan H, Braunack-Mayer A & Beilby J (2005) The impact of the hospice environment on patient spiritual expression. *Oncology Nursing Forum* 32, 1049–1055.
- Wright MC (2002) The essence of spiritual care: a phenomenological enquiry. *Palliative Medicine* 16, 125–132.
- Yardley SJ, Walshe CE & Parr A (2009) Improving training in spiritual care: a qualitative study exploring patient perceptions of professional educational requirements. *Palliative Medicine* 23, 601–607.

The Journal of Clinical Nursing (JCN) is an international, peer reviewed journal that aims to promote a high standard of clinically related scholarship which supports the practice and discipline of nursing.

For further information and full author guidelines, please visit JCN on the Wiley Online Library website: <http://wileyonlinelibrary.com/journal/jcn>

Reasons to submit your paper to JCN:

High-impact forum: one of the world's most cited nursing journals, with an impact factor of 1.316 – ranked 21/101 (Nursing (Social Science)) and 25/103 Nursing (Science) in the 2012 Journal Citation Reports® (Thomson Reuters, 2012).

One of the most read nursing journals in the world: over 1.9 million full text accesses in 2011 and accessible in over 8000 libraries worldwide (including over 3500 in developing countries with free or low cost access).

Early View: fully citable online publication ahead of inclusion in an issue.

Fast and easy online submission: online submission at <http://mc.manuscriptcentral.com/jcnur>.

Positive publishing experience: rapid double-blind peer review with constructive feedback.

Online Open: the option to make your article freely and openly accessible to non-subscribers upon publication in Wiley Online Library, as well as the option to deposit the article in your preferred archive.

CHAPTER 7

Summary and Conclusions

CHAPTER 7

Summary and Conclusion

Summary of systematic review findings

The first aim of this thesis was to critically appraise the literature around therapeutic life review interventions used with palliative care patients. A thorough systematic search of several databases was conducted using a validated search filter and strict inclusion criteria. Subsequently identified articles were subject to scrutiny using several validated tools as described in the methods section of Chapter 2. Of the fourteen articles identified, describing 10 distinct therapeutic life review interventions, there were nine randomised control trials evaluating the following interventions; Legacy Activities (Allen, Hilgeman, Ege, Shuster, & Burgio, 2008), One Week Short Term Life Review (Ando, Morita, Akechi, & Okamoto, 2010; Ando, Morita, Okamoto, & Ninosaka, 2008), Meaning Centered Group Psychotherapy (Breitbart et al., 2010), Individual Group Psychotherapy (Breitbart et al., 2012), Dignity Therapy (Chochinov et al., 2011), Meaning Making Intervention (Henry et al., 2010; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006), the Meaning of Life intervention (Mok, Lau, Lai, & Ching, 2012) and Outlook intervention (Steinhauser et al., 2008). The remaining studies were either cohort studies evaluating Forgiveness Therapy (Hansen, Enright, Baskin, & Klatt, 2009) or single arm studies evaluating the following interventions: Life Review Intervention (Ando, Tsuda, & Morita, 2007), Dignity Therapy (Chochinov et al., 2005) and Outlook (Keall, Butow, Steinhauser, & Clayton, 2013). The quality of the studies using the QualSyst criteria varied, with scores ranging from 71-80% (n= 3), 81-90% (n= 8) and 91-100% (n= 3). Eleven of the fourteen studies reported significant improvements in measures of constructs such as depression, sense of peace and preparation for end of life and quality of life. The interventions were conducted in 5 different countries by either a social worker, clinical psychologist or psychiatrist only (n= 9), or by these professionals and nurses (n= 3) or a nurse alone (n= 2). All of the interventions were conducted face-to-face but varied in their duration, frequency and complexity. They were all conducted with patients in their last days to months of life with levels of functioning from independent (least amount of participants) to semi or totally dependent (most participants).

None of the interventions satisfied the criteria for a well-established treatment. Six had been evaluated in only one study and four, while they had been evaluated in two different studies, had not been evaluated by two unrelated research teams (the second evaluation included a member of the original team). Nor had they shown sustained superiority and thus they are

considered to be 'probably efficacious' rather than 'well-established'. Two interventions require more information before being considered probably efficacious (Outlook and Legacy Activities), whilst the remaining 8 met the 'probably efficacious' treatment criteria (Chambless & Hollon, 1998). In summary there are few studies evaluating therapeutic life review interventions, although results are promising.

Summary of Outlook intervention pilot

The second and third aims of this thesis were to explore the efficacy and feasibility of a nurse-facilitated therapeutic life review intervention in the Australian palliative care population and to explore the perceptions that individuals who underwent the therapeutic life review have about their lives, both positive and negative, and their messages to future generations. The results were presented, discussed and compared with previous literature in two related papers (Chapters 3 and 4).

Chapter 3 reports the efficacy and feasibility results of the Outlook intervention when conducted by a palliative care nurse with 11 Australian palliative care patients. One participant died after completing the intervention but before post intervention measures, so only their interviews were subjected to qualitative analysis in Chapter 4. Patients with advanced cancer (n= 10) and one end-stage organ failure (n= 1) participated in the study and were assessed pre (n= 11) and post (n= 10) intervention using a battery of validated scales.

The Outlook intervention comprises three face-to-face sessions focusing on: a) their life history- asking the patient to talk about their life, their cherished moments, the important parts to be included if a movie were to be made of their life, b) forgiveness and regrets- asks the patient to consider the things they would do differently if they had the time over, things they like to forgive themselves about, things they would like to forgive others about and c) heritage and legacy- asks the patients to consider messages they would like to leave for future generations, how they would like to be remembered, their principles- what they stood for and to think of goals they would like to achieve in their remaining time. Patients are offered a copy of the recorded sessions at the end of the intervention to keep.

Quantitative results showed non- significant changes in the constructs of meaning of life/sense of peace ($p= 0.07$) and end-of-life preparation ($p= 0.07$). Quantitative participant evaluation of the intervention found 8/10 considered it to be helpful and 9/10 would recommend the intervention. Four out of 10 patients accepted the recording of the interviews to keep and show to their family. Thematic analysis of the participants' evaluations of Outlook intervention resulted in three themes 1) the intervention Outlook enabled them to

reflect on their lives 2) they found the second session of Outlook (regrets and forgiveness) to be challenging yet therapeutic and 3) they appreciated the sensitivity to individual variability that was shown by the interventionist.

Chapter 4 reports the qualitative results of the Outlook intervention. The recorded intervention interviews were transcribed and subjected to qualitative examination using Interpretative Phenomenological Analysis (Reid, Flowers, & Larkin, 2005). This resulted in the identification of three overarching themes: 1) life review, 2) current situation and 3) legacy and principles. Within these themes there were several sub-themes. Within the first theme of life review were: self-identity, accomplishments, conflict and regrets. The second theme of current situation included: current quality of life, loss as a palliative care patient and current goals. The final overarching theme was legacy and principles which included: participants' messages for future generations and their families. The Outlook intervention yielded both good and bad memories for patients and offered for those who wished to accept it, a legacy product which may provide comfort for the patient's bereaved loved ones. The Outlook intervention was feasible, acceptable and effective (with non-significant improvements) and offered insights into the concerns of terminally ill patients. However, finding the time for both the patient and the healthcare practitioner was challenging. Suggestions which would shorten the time involved were considered, including combining the three sessions, giving patients a work book or training volunteers to conduct the intervention.

Summary of palliative care nurse interviews

The fourth and fifth aims of the thesis were to understand how Australian palliative care nurses address existential/spiritual concerns with their patients and to explore the nurses' experiences with existential/spiritual interventions and their views on the feasibility of implementing a therapeutic life review intervention, Outlook, in their clinical practice. Twenty Australian palliative care nurses from a variety of areas: inpatient specialist palliative care units, community palliative care teams and acute hospital consultancy teams and geographic settings: urban, metropolitan and rural and remote were interviewed in semi-structured interviews either face-to-face or via the telephone. The results were presented, discussed and compared with previous literature in two related papers (Chapters 5 and 6).

Chapter 5 reports the qualitative analysis of transcribed interviews with the nurses in regards to their current practice of providing existential/ spiritual care to palliative care patients. The analysis identified facilitators, barriers and strategies to this care provision. Facilitators were identified as development of the nurse- patient relationship, good communication skills and helpful questions. Factors contributing to the development of the nurse-patient relationship

were identified as confidence and experience, walking alongside the patient and patient openness. Good communication skills included active listening, knowing your limitations, allowing silence, showing compassion and being aware of your own and the patient's body language. The nurses also shared their helpful questions to 'create openings' which they used to facilitate the exploration of existential and spiritual concerns. The nurses identified barriers to provision of existential/spiritual care of which by far the most frequent was lack of time, being either too busy or too late in the patient's life. Additional barriers included fear of what you may uncover, lack of privacy, unresolved symptoms, lack of skills in others and differences of religious belief. Strategies to improve provision of existential/spiritual care included making appropriate referrals to other professionals for example pastoral care or social worker where available, maintaining realistic expectations, setting the scene, undertaking counselling courses and clearly documenting assessments about spiritual or existential concerns to assist with continuity of care and team communication.

Chapter 6 reports the results of the twenty nurses' experiences with existential/spiritual interventions in general and their assessment of the feasibility of conducting Outlook, a therapeutic life review intervention in their current practice. The recorded interviews with the nurses were transcribed and subjected to thematic analysis. The results found that the nurses had very little knowledge of or experience with existential/spiritual interventions; of those who did have experience it was vicariously through others such as social workers, volunteers or pastoral care workers having conducted the interventions. The nurses' evaluation of the Outlook intervention was overwhelmingly positive and their responses were categorised into the following six sub-themes: Outlook can provide a framework; exploring forgiveness and regrets is difficult but valuable; benefit for grieving relatives; benefit for the nurse/team; potential difficulties in delivering Outlook; and potential modifications to overcome difficulties in delivering Outlook. The nurses in the interviews were pleased to see the intervention as it validated some of their current practice and gave them a framework in which to explore patients' existential/spiritual domains. As one nurse said, conducting such an intervention would 'feed the spiritual side of me'. Concerns were raised about the amount of time needed to implement the intervention and strategies and modifications to increase feasibility were suggested. The results of the interviews will ideally provide other nurses with facilitators and strategies and encourage the utilisation of Outlook or another validated tool to overcome barriers to existential/spiritual care provision for patients with life-limiting illnesses.

Recommendations for future research into therapeutic life review interventions

Therapeutic life review interventions, though relatively new to the palliative care setting, are showing promise to be adapted into clinical practice by healthcare workers including nurses. Unfortunately these interventions are time, personnel and resource consuming to varying degrees and it is apparent from both the literature (Chapter 2) and this research (Chapters 3 and 4) that lack of time is the most frequently occurring barrier to existential/spiritual care provision. Therefore the interventions chosen for further study must be brief and easily taught. In Chapter 2, the systematic review, therapeutic life review interventions were found to be variable in duration, frequency and complexity. The simplest interventions which showed significant improvements, the Meaning of Life and One Week Short Term life review, were both conducted overseas and it would be worthwhile pursuing these interventions in both a pilot study to check for cultural acceptance and then if successful in a larger randomised trial comparing the most promising intervention against a control group.

Investigation of the Outlook intervention pilot (Chapters 3 and 4) and the review by the nurses (Chapter 5) were positive and culturally acceptable but it was also agreed to be quite time intensive, thereby reducing its feasibility in clinical practice. Several modifications were suggested and these included condensing the three sessions of Outlook into one, asking one question at a time and using a prompt card attached to the nurses' identification badge to remind the nurse of the questions that have been validated as acceptable e.g. 'Are you at peace?' 'What are you most cherished memories?' 'What would you like to accomplish?' Of these modifications suggested, condensing the intervention into one session would seem the most sensible and likely to increase clinical usage. However, care must be taken when adapting an intervention to stay true to the underlying philosophy so collaboration with the intervention's developer would be advisable. Condensing an intervention can be successfully done for example the greatly improved results shown when the four session Life Review intervention was modified to be two session One Week Short-Term Life Review. A modified Outlook intervention could be trialled in a pilot study initially comparing the results to those of this research reported in Chapter 3 and if similar or better, be studied in a larger randomised trial, ideally using practicing nurses rather than those with protected time to investigate the true feasibility.

Recommendations for enhancing existential/spiritual nursing clinical practice through further research

Regardless of the outcome of the studies into therapeutic life review interventions this current research also showed that palliative care nurses are willing to provide holistic care however they lack knowledge around interventions, would benefit from validation of their practice and exposure to evidence-based findings. Addressing the deficits in nursing

knowledge in this area could be by way of a workshop on enhancing existential/spiritual care. This workshop could be conducted face-to-face or via teleconferencing to enable rural and remote nurses to participate. The workshop would include some didactic teaching of the background to existential/spiritual care and results of the research in particular the facilitators, barriers and strategies found in the nurse interviews and reported in Chapter 6.

Key points for the workshop informed by the research conducted in Chapters 5 and 6 would include:

- The importance of the nurse- patient relationship, ways to develop and enhance
- Good communication skills- allowing silence, observing for body language, being empathic
- Knowing your limitations- acknowledging what you can and can't do, being prepared for the conversations, being in the moment
- Understanding yourself better- addressing your spiritual/existential concerns, being aware of your biases and preconceptions
- Being able to share your findings with your colleagues- being respectful, measures and language around existential/spiritual concerns
- Setting the scene- introducing yourself, looking for cues, being comfortable in the situation

A modified Outlook intervention (or an alternative therapeutic life review intervention if one of the briefer interventions is shown to be effective, feasible and acceptable in Australia) could be discussed. The workshop would involve role play of the intervention and the use of facilitators and helpful questions as shared by the nurse participants.

The author is also interested in the consequence of practicing effective existential/spiritual care has on nurses (professionally and personally) and the nurse-patient relationship, which is understood to increase support for both the patient and family whilst allowing the nurse a better understanding of their patient and his/her needs, enhancing job satisfaction and retention. It is envisioned that the nurse workshop participants could form part of the prospective research cohort to assess the effectiveness of an existential/spiritual care teaching program.

Examination of the effect of the education program using validated tools to measure improvements in both nurse and patient outcomes will ideally influence practice and change models of care. For example the nursing model of primary nursing, whereby a patient is assigned a nurse like a case manager who develops a professional nurse-patient relationship, may be more effective in providing holistic nursing care and providing job

satisfaction than the current widely practiced skill mix dependent model. Of course holistic care is not solely the domain of the registered or advanced practice nurse and as many other levels of nurse e.g. personal care assistants and nursing aids have more patient contact time than their registered colleagues, they must be included in any education program as well.

Ongoing shortages of nurses due to an aging workforce, a burgeoning aged population of those with chronic illnesses, and fiscal constraints, require rethinking of resource management. Because nurses are present in almost all health systems and are therefore a universal resource, they are often called upon to provide holistic care ad-hoc in the absence of other more skilled workers. For example, many services have limited or no access to social workers, pastoral care workers or counsellors. Up-skilling current nurses in holistic care, for example in the provision of psychological and spiritual counselling, and incorporating this education into undergraduate training, would allow nurses to have increased skills, autonomy and job satisfaction and is likely to produce better outcomes for patients and families.

A recent study of undergraduate nurses found a high rate (25%) of attrition (Gaynor et al., 2007) possibly due to perceived lack of meaning in their work. The ability to relate closely to their patients, and to feel that they can provide care at a deep and meaningful level, might increase perceived work meaning, and reduce attrition. Additionally the impact of upskilling of nurses to have a greater focus on psychological rather than physical care may be a way of keeping aging nurses in the workforce longer (O'Brien-Pallas & Duffield, 2004), providing skilled nurses with an opportunity to use their experience whilst transitioning to less hands-on care which can be impeded by the practitioner's own health.

In summary, the results of this thesis have answered several questions, what is the evidence for therapeutic life review interventions, is it effective and feasible to conduct a therapeutic life review intervention, what are the concerns of palliative care patients found as a result of the therapeutic life review, how do palliative care nurses perceive therapeutic life reviews and what are their current practices. There is room for further studies into all of these areas and dissemination of the current and future results throughout the nursing community in order to positively influence practice and enhance existential/spiritual concerns for palliative care patients from both a nursing and patient perspective.

REFERENCES

- Allen, R. S., Hilgeman, M. M., Ege, M. A., Shuster, J. L., & Burgio, L. D. (2008). Legacy Activities as Interventions Approaching the End of Life. *Journal of Palliative Medicine, 11*(7), 1029-1038.
- Ando, M., Morita, T., Akechi, T., & Okamoto, T. (2010). Efficacy of short-term life-review interviews on the spiritual well-being of terminally ill cancer patients. *Journal of Pain & Symptom Management, 39*(6), 993-1002.
- Ando, M., Morita, T., Okamoto, T., & Ninosaka, Y. (2008). One-week Short-Term Life Review interview can improve spiritual well-being of terminally ill cancer patients. *Psychooncology, 17*(9), 885-890.
- Ando, M., Tsuda, A., & Morita, T. (2007). Life review interviews on the spiritual well-being of terminally ill cancer patients. *Supportive Care in Cancer, 15*(2), 225-231.
- Breitbart, W., Poppito, S., Rosenfeld, B., Vickers, A. J., Li, Y., Abbey, J., . . . Cassileth, B. R. (2012). Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *Journal of Clinical Oncology, 30*(12), 1304-1309.
- Breitbart, W., Rosenfeld, B., Gibson, C., Pessin, H., Poppito, S., Nelson, C., . . . Olden, M. (2010). Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psychooncology, 19*(1), 21-28.
- Chambless, D. L., & Hollon, S. D. (1998). Defining empirically supported therapies. *Journal of Consulting and Clinical Psychology, 66*(1), 7-18.
- Chochinov, H. M., Hack, T., Hassard, T., Kristjanson, L. J., McClement, S., & Harlos, M. (2005). Dignity Therapy: A Novel Psychotherapeutic Intervention for Patients Near the End of Life. *Journal of Clinical Oncology, 23*(24), 5520-5525.
- Chochinov, H. M., Kristjanson, L. J., Breitbart, W., McClement, S., Hack, T. F., Hassard, T., & Harlos, M. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncology, 12*(8), 753-762.
- Gaynor, L., Gallasch, T., Yorkston, E., Stewart, S., Bogossian, F., Fairweather, C., . . . Turner, C. (2007). The future nursing workforce in Australia: baseline data for a prospective study of the profile, attrition rates and graduate outcomes in a contemporary cohort of undergraduates. *Australian Journal of Advanced Nursing, 25*(2), 11-20.
- Hansen, M. J., Enright, R. D., Baskin, T. W., & Klatt, J. (2009). A Palliative Care Intervention in Forgiveness Therapy for Elderly Terminally Ill Cancer Patients. *Journal of Palliative Care, 25*(1), 51-60.

- Henry, M., Cohen, S. R., Lee, V., Sauthier, P., Provencher, D., Drouin, P., . . . Mayo, N. (2010). The Meaning-Making intervention (MMi) appears to increase meaning in life in advanced ovarian cancer: a randomized controlled pilot study. *Psychooncology, 19*(12), 1340-1347.
- Keall, R. M., Butow, P. N., Steinhauser, K. E., & Clayton, J. M. (2013). Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care
- Lee, V., Cohen, S. R., Edgar, L., Laizner, A. M., & Gagnon, A. J. (2006). Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Social Science & Medicine, 62*(12), 3133-3145.
- Mok, E., Lau, K.-P., Lai, T., & Ching, S. (2012). The Meaning of Life Intervention for Patients With Advanced-Stage Cancer: Development and Pilot Study. *Oncology Nursing Forum, 39*(6), E480-488.
- O'Brien-Pallas, L., & Duffield, C. (2004). Who will be there to nurse? Retention of nurses nearing retirement. *Journal of Nursing Administration, 34*(6), 298-302.
- Reid, K., Flowers, P., & Larkin, M. (2005). Exploring lived experience. *Psychologist, 18*(1), 20-23.
- Steinhauser, K. E., Alexander, S. C., Byock, I. R., George, L. K., Olsen, M. K., & Tulsky, J. A. (2008). Do preparation and life completion discussions improve functioning and quality of life in seriously ill patients? Pilot randomized control trial. *Journal of Palliative Medicine, 11*(9), 1234-1240.

APPENDIX I

Signed statements from the co-authors of the four articles and one manuscript that form part of the body of this thesis, stating each authors' contribution



THE UNIVERSITY OF
SYDNEY

To whom it may concern

Faculty of Medicine

University of Sydney

Re: "How do Australian palliative care nurses address existential and spiritual concerns?

Facilitators, barriers and strategies." Paper accepted by Journal of Clinical Nursing, and also to be submitted as part of Robyn Keall's PhD thesis.

This is a letter to state the various authors' contribution to this paper which will be submitted as part of Robyn Keall's PhD thesis.

Robyn Keall is the principal author on this paper. She conceived and designed the study, conducted the individual patient interviews, analysed the data and wrote the paper.

Professor Phyllis Butow contributed to the idea, study design, assisted with data analysis and edited the paper.

Associate Professor Josephine Clayton contributed to the idea, study design and assisted with editing the paper.

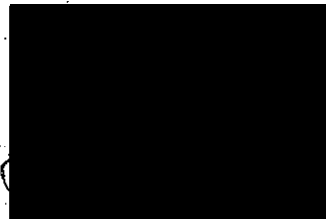
Yours sincerely

Professor Phyllis Butow,

23/5/2014

Associate Professor Josephine Clayton

22/5/2014





THE UNIVERSITY OF
SYDNEY

To whom it may concern

Faculty of Medicine

University of Sydney

Re: "Australian Palliative Care Nurses' Reflections on Existential/Spiritual Interventions." Paper published in Journal of Hospice & Palliative Nursing (2014; 16 (2): 105-112) and also to be submitted as part of Robyn Keall's PhD thesis.

This is a letter to state the various authors' contribution to this paper which will be submitted as part of Robyn Keall's PhD thesis.

Robyn Keall is the principal author on this paper. She conceived and designed the study, conducted the individual patient interviews, analysed the data and wrote the paper.

Professor Phyllis Butow contributed to the idea, study design, assisted with data analysis and edited the paper.

Associate Professor Josephine Clayton contributed to the idea, study design and assisted with editing the paper.

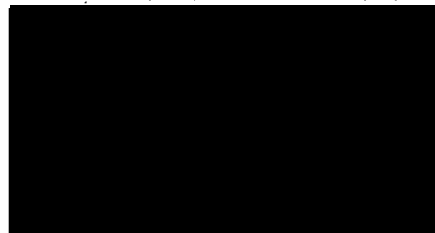
Yours sincerely

Professor Phyllis Butow,

23/5/2014

Associate Professor Josephine Clayton

22/5/2014





THE UNIVERSITY OF
SYDNEY

To whom it may concern

Faculty of Medicine

University of Sydney

Re: "Therapeutic life review in palliative care: a systematic review of quantitative evaluations."

Manuscript to be submitted as part of Robyn Keall's PhD thesis.

This is a letter to state the various authors' contribution to this paper which will be submitted as part of Robyn Keall's PhD thesis.

Robyn Keall is the principal author on this paper. She conceived and designed the study, conducted the systematic review, analysed the data and wrote the paper.

Professor Phyllis Butow contributed to the idea, study design, assisted with data analysis and edited the paper.

Associate Professor Josephine Clayton contributed to the idea, study design and assisted with data analysis and edited the paper.

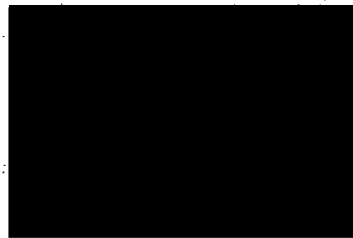
Yours sincerely

Professor Phyllis Butow,

23/5/2014

Associate Professor Josephine Clayton

22/5/2014





THE UNIVERSITY OF
SYDNEY

To whom it may concern

Faculty of Medicine

University of Sydney

Re: "Discussing life story, forgiveness, heritage, and legacy with patients with life-limiting illnesses."

Paper published in International Journal of Palliative Nursing (2011; 17 (9): 454-460) and also to be submitted as part of Robyn Keall's PhD thesis.

This is a letter to state the various authors' contribution to this paper which will be submitted as part of Robyn Keall's PhD thesis.

Robyn Keall is the principal author on this paper. She conceived and designed the study, conducted the individual patient interviews, analysed the data and wrote the paper.

Professor Phyllis Butow contributed to the idea, study design, assisted with data analysis and edited the paper.

Associate Professor Josephine Clayton contributed to the idea, study design and assisted with editing the paper.

Associate Professor Karen Steinhauser developed the Outlook intervention, which was studied, and gave clarification about the intervention use and contributed to editing the paper.

Yours sincerely

Professor Phyllis Butow,

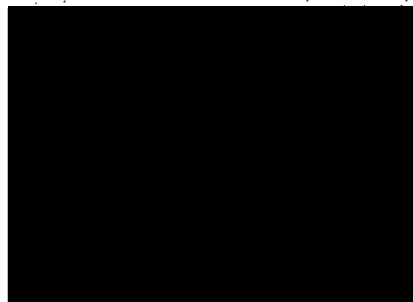
23/5/2014

Associate Professor Josephine Clayton,

22/5/2014

Associate Professor Karen Steinhauser

19/5/2014





THE UNIVERSITY OF
SYDNEY

To whom it may concern

Faculty of Medicine

University of Sydney

Re: "Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care setting: results from a phase 2 trial" Paper published in Cancer Nursing (2013; 36 (3) E39-46) and also to be submitted as part of Robyn Keall's PhD thesis.

This is a letter to state the various authors' contribution to this paper which will be submitted as part of Robyn Keall's PhD thesis.

Robyn Keall is the principal author on this paper. She conceived and designed the study, conducted the individual patient interviews, analysed the data and wrote the paper.

Professor Phyllis Butow contributed to the idea, study design, assisted with data analysis and edited the paper.

Associate Professor Josephine Clayton contributed to the idea, study design and assisted with editing the paper.

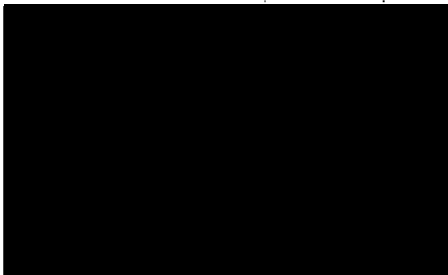
Associate Professor Karen Steinhauser developed the Outlook intervention, which was studied, and gave clarification about the intervention use and contributed to editing the paper.

Yours sincerely

Professor Phyllis Butow, 23/5/2014

Associate Professor Josephine Clayton, 22/5/2014

Associate Professor Karen Steinhauser 19/5/2014



APPENDIX II

Examples of recruitment flyers, participant information sheets and consent forms for the Outlook intervention pilot study



The University of Sydney

WOULD YOU BE INTERESTED TO HEAR MORE ABOUT A LIFE REVIEW STUDY?

Why life review? Studies have shown that life review (reflecting about one’s life and how you want to be remembered) can be helpful to people. People who have participated in this process say they feel clearer in their thinking and more able to plan their life. Some people have shown improvement in their general well-being.

What does it involve? Three individual sessions (each lasting no more than one hour) with an experienced nurse. You will also be asked to complete questionnaires before and after the program. All responses in your questionnaires and individual sessions will be treated confidentially.

Where does it take place? Wherever is most convenient to you - your home, the clinic or hospital.

If you are willing to hear more about this project please complete the lower section and give it to the receptionist or your health provider and Robyn Keall, RN, MS will contact you with further information.



Robyn Keall, RN MS
[Redacted]
Fax: +61 (0)2 9036 5420
Email: rkeall@usyd.edu.au



Name:

Contact phone number:

10th August, 2009

Dear Palliative Care Practitioner,

We are conducting a pilot research study into a life review tool in the Palliative Care population. This tool known as Outlook has been designed and trialed in the US and we would like to check the feasibility and acceptability in the Australian population. The intervention is a set of questions designed to assist patients complete life review and death preparation tasks, and potentially assist in spiritual and existential distress.

We are looking to recruit 10 participants who fit the following criteria;

- Experiencing a life shortening illness
- Life expectancy greater than 3 months
- Over the age of 18
- Fluent English speakers
- Mentally competent
- Willing to participate in 3 weekly one hour sessions

We would appreciate it if you would mention this study to your clients who fit the criteria and if they agree to participate that you complete the following questions.

Should you have queries or concerns about this study please do not hesitate to contact Ms. Keall on 045 8215562,

With many thanks

Ms. Robyn Keall, R.N., M.S.

Dr. Josephine Clayton, M.D., PhD.

Prof. Phyllis Butow

Dr. Karen Steinhauser, PhD.

Ms. Angela Robl, B.A.(psych)

Patient research ID: _____

Data Sheet: Research study into evaluating a life review intervention for palliative care patients*** This information is to be obtained from the Palliative Care practitioner or medical records.**

1. Date of consultation: _____
2. Patient's main diagnosis resulting in referral to palliative care:

3. Patient's extent of malignancy if applicable (tick):
 - Locally advanced
 - Metastatic
 - Other (please specify) _____
4. The Palliative Care practitioner's estimate of the patient's likely survival (best guess in order of number of months.)

5. What is the best way to contact this patient?
 - Telephone number _____
 - Next clinic visit , scheduled for _____
 - Letter/email address _____
6. Is there anything else you would like us to know about this potential participant?

Thank you for participating in this research project. Your time and co – operation is very much appreciated.



PARTICIPANT INFORMATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

Page 1 of 6

Invitation

You are invited to participate in a research study which explores the benefits of a series of three structured interviews with an experienced nurse. The interviews consist of several questions designed to assist people to look back on their lives, address outstanding issues and set future goals. We know through other studies that life review work has been helpful to people in many stages of their lives. Some people have found that through organisation of complex thoughts and feelings they have been more able to be clear about other aspects of their lives.

This model has been developed in USA and found to be helpful in improving levels of anxiety and depression. We would like to measure these and other symptoms before and after the intervention using questionnaires. We would like to try this model of intervention in Australia to see if it is acceptable and helpful in our culture. We would greatly value your feedback about the intervention and if and how it should be adapted for the Australian context. Patients with incurable diseases face many challenges and it is hoped that this intervention will help with some of those difficulties.

The study is being conducted by;

Ms Robyn Keall, R.N. Research Nurse, Centre for Medical Psychology and Evidence Based Decision Making, University of Sydney

Dr Josephine Clayton, Staff Specialist and Head of Department, Palliative Medicine, Royal North Shore Hospital

Professor Phyllis Butow, Professor of Psychology, University of Sydney.

Dr Karen Steinhauser, Associate Research Professor, Duke University.

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney

PARTICIPANT INFORMATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

Page 2 of 6

Before you decide whether or not you wish to participate in this study, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish.

1. 'What is the purpose of this study?'

This study is to trial a life review tool, a series of questions, in an Australian setting to find if it is both acceptable and helpful.

2. 'Why have I been invited to participate in this study?'

You are eligible to participate in this study because you are experiencing a life threatening illness and we value your feedback on this intervention.

3. 'What if I don't want to take part in this study or if I want to withdraw later?'

Participation in this study is voluntary. It is completely up to you whether or not you participate. If you decide not to participate, it will not affect the treatment you receive now or in the future. Whatever your decision, it will not affect your relationship with the staff caring for you.

New information about the treatment being studied may become available during the course of the study. You will be kept informed of any significant new findings that may affect your willingness to continue in the study.

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason.

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney

PARTICIPANT INFORMATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

Page 3 of 6

4. 'What does this study involve?'

If you agree to participate in this study, you will be asked to sign the Participant Consent Form.

This study will be conducted over 6 meetings including this one. The sessions can take place at your convenience, we could meet at the hospital/clinic/ or your home. The second session will take 45-90 minutes of your time and involve completing several brief questionnaires and taking part in an interview with an experienced research nurse. The third and fourth sessions will take around 45-60 minutes and consist of further interviews with the research nurse. There is preferably one week between each of the sessions 2-6. The fifth session will take around 45 minutes and involve repeating the several brief questionnaires and an evaluation form. The final session will be scheduled for 3 weeks after the session 5 and will involve completing the brief questionnaires once more and a patient evaluation form.

We also ask your permission to discuss your health information with your Palliative Care practitioner and review your medical record pertaining to your medical condition.

6. 'How is this study being paid for?'

The study is being sponsored by research funds for the Centre for Medical Psychology and Evidence Based Decision Making. No money is paid directly to individual researchers.

7. 'Are there risks to me in taking part in this study?'

The intervention involves asking questions which may uncover some memories or feelings that you have not wished to think about. Should this occur we will offer referrals to trained mental health practitioners. You will be able to refuse to answer questions and withdraw from the intervention at anytime.

8. 'Will participating in this study affect my plans to start a family?'

No.

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney

PARTICIPANT INFORMATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

Page 4 of 6

9. 'What happens if I adverse effects as a result of the study?'

If you suffer any adverse feelings as a result of this study, you should contact the study nurse as soon as possible, who will assist you in arranging appropriate support and follow up.

10. 'Will I benefit from the study?'

This study aims to improve the well being of people facing a life threatening illnesses. We hope that you will benefit by taking part in this study.

11. 'Will taking part in this study cost me anything, and will I be paid?'

Participation in this study will not cost you anything.

12. 'How will my confidentiality be protected?'

Of the people treating you, only the researchers named above will know whether or not you are participating in this study. Any identifiable information that is collected about you in connection with this study will remain confidential and will be disclosed only with your permission, or except as required by law. Only the researchers named above will have access to your details and results that will be held securely at the Centre for Medical Psychology and Evidence Based Decision Making, University of Sydney.

13. 'What happens with the results?'

If you give us your permission by signing the consent document, we plan to discuss/publish the results in peer reviewed journals and conferences. If after formal evaluation the intervention is found to be beneficial then we hope to make the intervention widely available through local palliative care teams.

In any publication, information will be provided in such a way that you cannot be identified. Results of the study will be provided to you, if you wish.

14. 'What happens to my treatment when the study is finished?'

Your Palliative Care treatment will not be interrupted during the study period, and will continue as required following completion of the study.

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney

PARTICIPANT INFORMATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

Page 5 of 6

15. 'What should I do if I want to discuss this study further before I decide?'

When you have read this information, the research nurse Robyn Keall will discuss it with you and any queries you may have. If you would like to know more at any stage, please do not hesitate to contact her on 0458 215 562.

16. 'Who should I contact if I have concerns about the conduct of this study?'

This study has been approved by the Harbour HREC of Northern Sydney central Coast Health (NSCCH). Any person with concerns or complaints about the conduct of this study should contact the Research Office who is nominated to receive complaints from research participants. You should contact them on 02 9926 8106 and quote [0907-182M].

**Thank you for taking the time to consider this study.
If you wish to take part in it, please sign the attached consent form.
This information sheet is for you to keep.**

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney



CONSENT FORM

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

1. I,.....
of.....
agree to participate as a subject in the study described in the participant information statement attached to this form.
2. I acknowledge that I have read the participant information statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.
3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and I have received satisfactory answers.
4. I understand that I can withdraw from the study at any time without prejudice to my relationship to the Northern Sydney and Central Coast Palliative Care Service.
5. I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.
6. I understand that if I have any questions relating to my participation in this research, I may contact Ms Robyn Keall, R.N. on telephone 0458215562, who will be happy to answer them.
7. I acknowledge receipt of a copy of this Consent Form and the Participant Information Statement.

Complaints may be directed to the NSCCAHS Research Office on 02 9926 8106.

Signature of subject

Please PRINT name

Date

Signature of investigator

Please PRINT name

Date

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney



REVOCATION OF CONSENT

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

I hereby wish to **WITHDRAW** my consent to participate in the study described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the Northern Sydney Central Coast Area Health Palliative Care Service.

Signature

Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to
Ms Robyn Keall,
Research Nurse,
CeMPED
Blackburn Building, D06
UNIVERSITY OF SYDNEY
NSW, 2006 AUSTRALIA

Version 2, 14th August 2009

Centre for Medical Psychology & Evidence-based Decision-making (CeMPED)

Faculty of Medicine, Blackburn Building D06

The University of Sydney, NSW 2006 Australia

Phone: +61 (0)2 9036 5396

Fax: +61 (0)2 9036 5420

www.psych.usyd.edu.au/cemped



The University of Sydney

APPENDIX III

Examples of Outlook intervention questions and prompt card information given to participants as part of the Outlook intervention pilot study

INTERVENTION QUESTIONS

<i>Session I- Life Story</i>	<i>Session II- Forgiveness</i>	<i>Session III- Heritage and Legacy</i>
<p>1. Tell me about your life?</p> <p>2. What are cherished times?</p> <p>3. Of what are you most proud?</p> <p>4. If someone were to make a movie of your life, what would be important to include?</p>	<p>5. If you were to do things again, what might you do differently?</p> <p>6. Are there things or times you regret?</p> <p>7. Is there anyone to whom you would like to offer forgiveness?</p> <p>8. Is there anyone from whom you would like to ask forgiveness?</p> <p>9. Are you at peace?</p>	<p>10. What are your most valuable lessons learned?</p> <p>11. What would you like to share with future generations?</p> <p>12. If you could choose one thing to pass on as your legacy what would that be?</p> <p>13. What things would you like to accomplish?</p>

**WRITTEN INFORMATION TO BE GIVEN TO
THE PARTICIPANTS FOLLOWING
INTERVIEW SESSION I**

Page 1 of 2

Reflecting

Serious illness gives people the opportunity to reflect upon what is most important in their lives. It often feels good to review the path of our life, recalling people, places, and times that have been important to us, recalling things we are most proud of.

These cards offer a few ideas to guide you through that process. It is only a suggested starting point – you are the author of this story. Remember, your interpretation of events is valid whether others agree with it or not. This is your story.

**WRITTEN INFORMATION FOLLOWING
INTERVIEW SESSION I**

Page 2 of 2

The Story of My Life

In our busy lives, we often don't take the time to reflect on the things that are important to us.

In the beginning...

Take a few moments to place yourself and your life within history. When and where were you born? How many siblings did you have? Where were you in that order? What were your parents like? What did they do for a living? Where were they born? How did these things create a unique backdrop for your life story?

People...

Who have been the most important people in your life? Are they family, friends, neighbors, co-workers, role models? Who has influenced you to become the person you are? What have you valued about your relationship with these people? What have you learned from them?

Places...

What places hold special meaning for you? Some of these are places you may have lived -- Where were they? With whom did you share that home? Some are places you have visited or always wanted to visit -- What was special about them? What memories or dreams do you associate with them?

Events...

What are some of the most important events that have occurred in your life? Some events may be shared by a whole generation, such as living through a war. Others are unique to you. When did these things happen and what made them significant? How did they shape your life?

Recalling your story: In recalling memories, some people find it helpful to go through photo albums with family or friends, using pictures to illustrate the stories of their unique heritage. Others may reread a diary or listen to favorite music.

WRITTEN INFORMATION FOLLOWING INTERVIEW SESSION II

Page 1 of 2 Forgiveness

As each of us thinks about how we have lived our lives, there are things with which we feel totally at peace. Other things feel unresolved. Some may be plans or dreams. Others may involve personal relationships.

As we reflect on our lives, it is common to have at least a few regrets. There are always things we wish we had a chance to do over again, this time, "getting it right." Sometimes we've said things we wish we could take back. Nobody goes through life perfectly. Imperfection is an inescapable part of being human.

What is forgiveness?

Many people confuse forgiveness with excusing. Forgiveness does not excuse someone from doing something wrong. It does not lessen their guilt or what they may have done. Instead, forgiveness accepts the past as it was, embraces the present, and faces the future. Forgiveness is a strategy for you to become free of hurt and anger. Hate, fury, vengeance, and blame weigh us down. The ball and chain of old wounds tethers us to our past and limits our ability to move forward with life.

Forgiving ourselves

Sometimes the hardest person to forgive is our self. But, we all are worthy of self-acceptance and of love, right now. Even with our imperfections and faults. All of us have things we wish we hadn't done, even dark secrets that we hide in shame. You might think that other people don't have them, but they do. Yes, you are flawed, you have made mistakes, some serious. Who hasn't? It only proves that you are human. Forgive yourself and show yourself some love.

**WRITTEN INFORMATION FOLLOWING
INTERVIEW SESSION II**

Page 2 of 2

Think about your life as a long, rich novel. Let's assume that as a reader, you were able to see the difficult circumstances that the main character was dealing with and you knew his or her motives were good. You could see that some things had not worked out the way he or she wanted through life. How would you feel towards the main character? Would you feel some degree of mercy? Can you extend yourself the same mercy you would to this character in the story?

WRITTEN INFORMATION FOLLOWING INTERVIEW SESSION III

Heritage and Legacy

No matter how young or old you are, you have something to say that no one else can say. Only you can share what you have already learned, loved and cared about.

Questions to guide reflection

What are some of the values your parents or family had that you have tried to live in your life? What are some of the beliefs or values you have chosen as an adult that are unique and different from your family?

What traditions are important to you? How have you celebrated them? What is the special meaning they give to your life?

What are some of the lessons you have learned? If you could talk to younger people, what advice would you give them? What would you say?

What have been your hopes and fears? How have these changed over time?

How have you gathered strength? Has this changed over time?

What did you consider as the meaning of success, when you were younger? What is success now?

Ways of sharing heritage

There are many ways to share the wisdom you have learned, the values you have worked for and cherished. Some people use videotapes or letters to provide messages of legacy and love. Some messages are meant for special birthdays, graduations, or weddings. Others may gather special items in a "heritage box" that can be shared between generations.

APPENDIX IV

Participant questionnaires for the Outlook intervention pilot study

Date: _____

Identification number: _____

<p>1. What is your gender? Tick one. <input type="checkbox"/> Male <input type="checkbox"/> Female</p>	<p>2. What is your year of birth? 19____</p>
<p>3. With which ethnic group do you most closely identify? Tick one. <input type="checkbox"/> Aboriginal/Torres Strait Islander <input type="checkbox"/> Asian <input type="checkbox"/> Caucasian <input type="checkbox"/> Pacific Islander <input type="checkbox"/> African <input type="checkbox"/> Other, please specify _____</p>	<p>4. Who lives in your household? Tick all that apply. <input type="checkbox"/> Spouse/partner <input type="checkbox"/> Parent <input type="checkbox"/> Child <input type="checkbox"/> Other <input type="checkbox"/> I live alone</p>
<p>5. What was your main occupation during your adult life? _____</p>	<p>6. Which is your main illness requiring palliative care service? _____ If cancer, please indicate what type _____</p>
<p>7. What is your current marital status? Tick one. <input type="checkbox"/> Married/Partnered <input type="checkbox"/> Single <input type="checkbox"/> Divorced/Separated <input type="checkbox"/> Widowed <input type="checkbox"/> Never married</p>	<p>8. What is the highest level of education you have reached? Tick one. <input type="checkbox"/> Less than a school certificate <input type="checkbox"/> Higher school certificate <input type="checkbox"/> Trade certificate <input type="checkbox"/> Diploma <input type="checkbox"/> Graduate/professional degree</p>
<p>9. What is your religion? Tick one. <input type="checkbox"/> Protestant <input type="checkbox"/> Roman Catholic <input type="checkbox"/> Jewish <input type="checkbox"/> Orthodox <input type="checkbox"/> Muslim <input type="checkbox"/> Other, please specify _____ <input type="checkbox"/> I do not consider myself a member of any religion Are you practicing your faith? <input type="checkbox"/> Yes <input type="checkbox"/> No</p>	<p>10. How important is spirituality or faith in you life? Tick one. <input type="checkbox"/> Very important <input type="checkbox"/> Somewhat important <input type="checkbox"/> Not at all important</p>



RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

PARTICIPANT QUESTIONNAIRE (Baseline)

CONFIDENTIALITY:

We would like to ask you to complete the following questionnaire. All the information in this questionnaire will be treated as *strictly confidential* and your identity will never be revealed in any reports. The completed questionnaires will be kept separately from any information that could identify you and will be kept securely under lock and key. There is no need to write your name on this questionnaire.

INSTRUCTIONS:

There are no right or wrong answers, just circle or tick those answers that most apply to you.

When you have completed the questionnaire, please hand it back to the researcher or return it to us in the reply paid envelope provided.

ID: _____

DATE ____ / ____ / ____

Day Month Year

Version 2, Date 23 June 2009



Over the last 7 days, how often did the following occur:

(Circle one number for each question)

		Rarely or none of the time (< 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most or all of the time (5-7 days)
C1	I was bothered by things that don't usually bother me.	1	2	3	4
C2	I had trouble keeping my mind on what I was doing.	1	2	3	4
C3	I felt depressed.	1	2	3	4
C4	I felt that everything I did was an effort.	1	2	3	4
C5	I felt hopeful about the future.	1	2	3	4
C6	I felt fearful.	1	2	3	4
C7	My sleep was restless.	1	2	3	4
C8	I was happy.	1	2	3	4
C9	I felt lonely.	1	2	3	4
C10	I could not get "going".	1	2	3	4

Over the last 7 days, how often did the following occur:

(Circle one number for each question)

		Not at all	A little bit	Moderately	Quite a bit	Extremely
T1	How much have you felt tense?	0	1	2	3	4
T2	How much have you felt on-edge?	0	1	2	3	4
T3	How much have you felt uneasy?	0	1	2	3	4
T4	How much have you felt restless?	0	1	2	3	4
T5	How much have you felt anxious?	0	1	2	3	4

The next set is a list of statements that other people with a serious illness have said may be important. Please tell me how true each statement is for you:

(Circle one number for each question)

		Not at all	A little bit	A moderate amount	Quite a bit	Completely
Q1	Although you cannot control certain aspects of your illness, you have a sense of control about your treatment decisions.	1	2	3	4	5
Q2	You participate as much as you want in the decisions about your care.	1	2	3	4	5
Q3	Beyond your illness, your doctor has a sense of who you are as a person.	1	2	3	4	5
Q4	In general, you know what to expect about the course of your illness.	1	2	3	4	5
Q5	As your illness progresses, you know where to go to get answers to your questions.	1	2	3	4	5
Q6	You worry that your family is not prepared to cope with the future.	1	2	3	4	5
Q7	You have regrets about the way you have lived your life.	1	2	3	4	5
Q8	At times, you worry you will be a burden to your family.	1	2	3	4	5
Q9	You worry about the financial strain caused by your illness.	1	2	3	4	5
Q10	You have been able to say important things to those close to you.	1	2	3	4	5

		Not at all	A little bit	A moderate amount	Quite a bit	Completely
Q11	You make a positive difference in the lives of others.	1	2	3	4	5
Q12	You have been able to help others through time together, gifts, or wisdom.	1	2	3	4	5
Q13	You have been able to share important things with your family.	1	2	3	4	5
Q14	Despite your illness, you have a sense of meaning in your life.	1	2	3	4	5
Q15	You feel at peace.	1	2	3	4	5
Q16	There is someone in your life with who you can share your deepest thoughts.	1	2	3	4	5

The last set is a list of statements that other people with your illness have said are important. Please indicate how true each statement has been for you during the past week:

		Not at all true	A little bit true	Somewhat true	Quite a bit true	Very much true
R1	During the past week, you felt peaceful.	0	1	2	3	4
R2	You had reason for living.	0	1	2	3	4
R3	Your life has been productive.	0	1	2	3	4
R4	During the past week, you had trouble feeling peace of mind.	0	1	2	3	4
R5	You felt a sense of purpose in your life.	0	1	2	3	4
R6	You were able to reach down deep into yourself for comfort.	0	1	2	3	4
R7	During the past week, you felt a sense of harmony within yourself.	0	1	2	3	4
R8	Your life lacked meaning and purpose.	0	1	2	3	4
R9	You found comfort in your faith or spiritual beliefs.	0	1	2	3	4
R10	During the past week, you found strength in your faith or spiritual beliefs.	0	1	2	3	4
R11	Your illness has strengthened your faith or spiritual beliefs.	0	1	2	3	4
R12	You knew that whatever happened with your illness, things would be okay.	0	1	2	3	4

MEMORIAL SYMPTOM ASSESSMENT SCALE

Section 1

Instructions: We have listed 24 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how **OFTEN** you had it, how **SEVERE** it was usually and how much it **DISTRESSED** or **BOTHERED** you by circling the appropriate number. If you **DID NOT HAVE** the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK Did you have any of the following symptoms?	D I D N O T H A V E	IF YES How OFTEN did you have it?				IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness/tingling in hands/feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhoea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

Section 2

INSTRUCTIONS: We have listed 8 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how **SEVERE** it was usually and how much it **DISTRESSED** or **BOTHERED** you by circling the appropriate number. If you **DID NOT HAVE** the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK Did you have any of the following symptoms?	D I D N O T H A V E	IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?				
		Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Mouth sores		1	2	3	4	0	1	2	3	4
Change in the way food tastes		1	2	3	4	0	1	2	3	4
Weight loss		1	2	3	4	0	1	2	3	4
Hair loss		1	2	3	4	0	1	2	3	4
Constipation		1	2	3	4	0	1	2	3	4
Swelling of arms or legs		1	2	3	4	0	1	2	3	4
"I don't look like myself"		1	2	3	4	0	1	2	3	4
Changes in skin		1	2	3	4	0	1	2	3	4
IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.										
Other:						0	1	2	3	4
Other:						0	1	2	3	4
Other:						0	1	2	3	4

PARTICIPANT EVALUATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL
FOR PALLIATIVE CARE PATIENTS

Date: ____/____/____ Patient Identification No : _____

Dear Participants,

Thank you for participating in the Outlook project, we greatly appreciate your time and effort. We ask you now for your honest evaluation of the program that you have participated in. We would greatly appreciate your feedback and suggestions for improvement. *Please circle the most appropriate response.*

	<i>Not at all</i>	<i>Somewhat</i>	<i>Unsure</i>	<i>Mostly</i>	<i>Completely</i>
I found the questions during the sessions with the research nurse easy to understand	1	2	3	4	5
I found the questions during the session with the research nurse upsetting	1	2	3	4	5
I feel the program has helped me to reflect on my life	1	2	3	4	5
I found the interview sessions with the research nurse to be helpful	1	2	3	4	5
It was difficult to find time for the project	1	2	3	4	5
The written materials were distressing to me	1	2	3	4	5
I found the written materials easy to understand	1	2	3	4	5
I found the written materials to be helpful	1	2	3	4	5
Overall I found this program to be helpful	1	2	3	4	5
I would recommend this program	1	2	3	4	5

Page 1 of 3



PARTICIPANT EVALUATION SHEET

RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR PALLIATIVE CARE PATIENTS

1. The thing/s that I liked most about the program was/were:

2. The thing/s that I liked least about the program was/were:

3. What suggestions do you have to improve the program? e.g. include practical activity:

4. How did the conversations make you feel?

5. When is the best time to do this intervention? i.e. in the illness experience:

6. Is there anybody we shouldn't do this intervention with?

7. Which of these questions did you find most useful/thought provoking?

8. Were any of the questions not helpful or concerning? Which ones? Is there anything we could do to reword these to make them more helpful?



PARTICIPANT EVALUATION SHEET

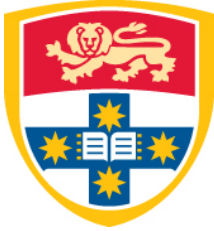
**RESEARCH STUDY OF IMPLEMENTATION AND EVALUATION OF A LIFE REVIEW TOOL FOR
PALLIATIVE CARE PATIENTS**

9. How did you find the number of sessions? Could we have covered the same material in less sessions? What would be the ideal number of sessions?
- _____
- _____
- _____
10. How important was it to have the nurse to talk with?
- _____
- _____
- _____
11. Do you think this intervention could be done on your own? Yes / No *Please comment*
- _____
- _____
- _____
12. Do you think this intervention could be done with your family? Yes / No *Please comment*
- _____
- _____
- _____
13. Do you think this intervention could be done with a volunteer on your own? Yes / No *Please comment:*
- _____
- _____
- _____



APPENDIX V

Examples of recruitment flyers, participant information sheets
and consent forms for nurse interviews



THE UNIVERSITY OF
SYDNEY



Are you an experienced palliative care nurse?

Do you have 45 minutes to spare for a telephone interview?

If so this, read on!

Invitation to participate in a study of Australian palliative care nurses' current practice in assessing, documenting and supporting spiritual and existential concerns of palliative care patients.

As an experienced palliative care nurse you are invited to participate in an interview which explores your current practice when assessing, documenting and supporting spiritual and existential aspects of palliative care patients. It has been highlighted in recent literature that the existential and spiritual domains of palliative patients are not always met. The reasons for this are not known but many potential barriers to addressing this aspect of care exist. We would like to find out how comfortable you feel discussing these issues and how you care for yourself to help you continue providing palliative care. You will also be asked to assess the feasibility of using a tool that has been developed to help address existential and spiritual concerns of patients with advanced life threatening illnesses.

The interview will be conducted by a palliative care nurse researcher and take around 45 minutes to complete. The interviews will be audio-taped and transcribed for analysis. Your responses will be completely confidential and will be de-identified.

We hope that this study will help to identify ways to improve the care of palliative care patients with regards to existential concerns, as well as finding better ways to support palliative care nurses to sustain caring for terminally ill patients.

If you are interested in participating or wish to have more information before deciding, please contact, Robyn Keall on 0458215562

This study is being conducted by

Ms Robyn Keall, R.N., M.S., CNC Palliative Care- Community, Greenwich Hospital, PhD candidate School of Medicine, University of Sydney

Associate Professor Josephine Clayton, Staff Specialist, Palliative Medicine, Greenwich Hospital

Professor Phyllis Butow, Professor of Psychology, University of Sydney, Co-Chair Centre for Medical Psychology and Evidence-based Decision –making (CeMPED)

Research study of Australian palliative care nurses' current practice in assessing, documenting and supporting spiritual and existential concerns of palliative care patients

Version 1 14th November, 2011



The University of Sydney



ABN 15 211 513 464

CHIEF INVESTIGATOR / SUPERVISOR NAME

Professor Phyllis Butow, Associate Professor Josephine Clayton

Room 164

Transient Building

The University of Sydney

NSW 2006 AUSTRALIA

Telephone: +61 2 9351 2859

Facsimile: +61 2

Email: phyllis.butow@sydney.edu.au

Web: <http://www.sydney.edu.au/>

PARTICIPANT CONSENT FORM

I,[PRINT NAME], give consent to my participation in the research project

TITLE: Research study into Australian palliative care nurses' current practice in assessing, documenting and supporting existential and spiritual concerns of palliative care patients.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.
3. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
4. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published however no information about me will be used in any way that is identifiable.
5. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney, CeMPED now or in the future.

Research study of Australian palliative care nurses' current practice in assessing, documenting and supporting spiritual and existential concerns of palliative care patients

6. I understand that I can stop the interview at any time if I do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

7. I consent to

- Audio-recording YES NO

.....
Signature

.....
Please PRINT name

.....
Date

ABN 15 211 513 464

CHIEF INVESTIGATOR / SUPERVISOR NAME

Professor Phyllis Butow, Associate Professor
Josephine Clayton

Room 164
Transient Building
The University of Sydney
NSW 2006 AUSTRALIA
Telephone: +61 2 9351 2859
Facsimile: +61 2
Email: Phyllis.butow@sydney.edu.au
Web: <http://www.sydney.edu.au/>

**Research study of Australian palliative care nurses' current practice in assessing,
documenting and supporting spiritual and existential concerns of palliative care
patients.**

PARTICIPANT INFORMATION STATEMENT

What is the study about?

We know from current literature that health professionals do not adequately address patients' existential and spiritual concerns for many reasons; lack of skills, lack of time, lack of understanding of the issue and the presumed discomfort that such discussions may cause to both patients and professionals. We would like to interview you, as an experienced palliative care nurse, about your current practice in assessing, documenting and supporting the existential and spiritual concerns of the patients for whom you provide care. We would also like your views on the feasibility of an intervention designed to address existential and spiritual concerns of patients with life threatening illnesses. Additionally, as it is important for health professionals to take care of themselves in order that they can continue to provide compassionate care, we would like to explore your personal approach to self-care.

Who is carrying out the study?

The study is being conducted by Robyn Keall, RN, MS and will form the basis for the degree of PhD at The University of Sydney under the supervision of Professor Phyllis Butow and Associate Professor Josephine Clayton.

What does the study involve?

The interview will be conducted by a nurse researcher. The interview will take place over the telephone and will be audio taped and later transcribed. You will be asked a series of questions about your current practice in regards to palliative care patients and their holistic care. You will also be asked some demographic questions. All data will be de-identified.

**Research study of Australian palliative care nurses' current practice in assessing,
documenting and supporting spiritual and existential concerns of palliative care
patients**

How much time will the study take?

The interview will take approximately 30 minutes to complete.

Can I withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with The University of Sydney , School of Medicine or Centre for Medical Psychology and Evidence-based Decision making (CeMPED).

You may stop the interview at any time if you do not wish to continue, the audio recording will be erased and the information provided will not be included in the study.

Will anyone else know the results?

All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants except as required by law.

A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Will the study benefit me?

We cannot and do not guarantee or promise that you will receive any benefits from the study.

Can I tell other people about the study?

Yes, if you know of other colleagues who would be interested in sharing their experiences please direct them to contact Robyn Keall on [REDACTED].

What if I require further information about the study or my involvement in it?

When you have read this information, Robyn Keall will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Robyn Keall, RN, MS, PhD candidate, robyn.keall@sydney.edu.au or [REDACTED].

What if I have a complaint or any concerns?

Any person with concerns or complaints about the conduct of a research study can contact The Manager, Human Ethics Administration, University of Sydney on +61 2 8627 8176 (Telephone); +61 2 8627 8177 (Facsimile) or ro.humanethics@sydney.edu.au (Email).

This information sheet is for you to keep

Research study of Australian palliative care nurses' current practice in assessing, documenting and supporting spiritual and existential concerns of palliative care patients

APPENDIX VI

Participant questionnaires for the palliative care nurse interviews

Demographics

Today's date: ____/____/____

Date of Birth: ____/____/____ Age: _____

Gender : Male Female

What is your nursing position:

- 0 Enrolled nurse
- 1 Registered nurse
- 2 CNS
- 2 CNC
- 4 Other, please specify _____

What is your area of practice?

- 0 Community
- 1 Acute Hospital
- 2 Inpatient palliative Care Unit
- 4 Other, please specify _____

Where do you currently practice?

- 0 Major city (eg Sydney)_
- 1 Large metropolitan area (eg Newcastle)
- 2 Semi rural area (e.g. Dubbo)
- 3 Remote rural area (eg Wilcania)
- 4 Other, please specify _____

Years of experience as a registered or enrolled nurse: _____ years.

**Research study of Australian palliative care nurses' current practice in
assessing, documenting and supporting spiritual and existential concerns of
palliative care patient**

Page 1 of 4

Version 1 14th October, 2011

Do you identify with a particular
religion or spiritual belief? : Yes No

If yes, what is that religion or spiritual belief?

- 0 Christianity
- 1 Judaism
- 2 Muslim
- 3 Buddhism
- 4 Other, please specify _____

If yes, how important is this in your life?

- 1 Extremely important
- 2 Very important
- 3 Important
- 4 Not very important
- 5 Not at all important

Now I would like to ask some questions about your experience and views concerning the place of spiritual and existential care in your clinical practice. There are no right and wrong answers; we are simply interested in people's views. If you don't want to answer any of these questions please just say so.

What does the term spirituality mean to you?

What does the term existential mean to you?

Do you feel that spiritual and existential concerns are important to your patients? If so, in what ways?

What do you think the role of the palliative care nurse is (if any), in the spiritual and existential care of patients?

Do you think the nurse should be involved in assessing spiritual and existential well-being?

If so, how often? If not routinely, what makes you decide it is appropriate or important to raise spirituality or existential issues? In what circumstances? What helps this process? What hinders? How do you document your findings? How do you think they should be documented?

Can you recall a patient who you felt was experiencing spiritual and existential distress?

If so tell me about that patient. What did you do? Was it successful? How did it make you feel? Would you approach the situation differently now?

Do you know or use any treatments or interventions to help with existential and spiritual care?

If so tell me about them. How well do they work? What makes it easier or harder to deliver?

Please review the questions headed Outlook questions. It involves 3 sessions of approximately 45 minutes of nurse and patient time.

Would you consider using this tool?

Which questions do you think would be most useful to be employed
In your practice?

Would it be feasible and acceptable to use in your practice?

Do you think that this would be feasible in a modified form?

If so, what modifications would you suggest?

How do you care for yourself and sustain your practice as a palliative care nurse?

What strategies do you currently use?

**Research study of Australian palliative care nurses' current practice in
assessing, documenting and supporting spiritual and existential concerns of
palliative care patient**

Page 3 of 4

Version 1 14th October, 2011



What strategies would you ideally use?
What are barriers and facilitators to your self-care practice?
Are there any things that you think would be helpful in improving your
ability to practice self-care; personal or organisational?
How would you look after yourself in a time of crisis?

The set questions are completed Is there anything else you would like to add on
these subjects?

**Research study of Australian palliative care nurses' current practice in
assessing, documenting and supporting spiritual and existential concerns of
palliative care patient**

Page 4 of 4

Version 1 14th October, 2011