Joy at the End of Life:

An Interpretive Description

By

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A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Faculty of Nursing

University of Alberta

Abstract

Background: Current demographic trends indicate that the annual number of expected deaths in Canada will double between 2005 and 2036, thus demanding further knowledge development to ensure quality end of life care in the future for an increasing part of the population. End of life care has evolved over time and continues to adapt to societal changes globally. In the western world, the current end of life care context is in flux, and the process of dying is becoming increasingly marginalised and viewed as a predominantly negative experience, both within the broad social and palliative care discourses. Positive concepts, such as joy, are understudied and often sidelined in the increasingly medicalised context of palliative and end of life care. To reclaim a more positive view of dying, and to improve the quality of life for individuals at the end of life, there is a need to forefront positive concepts, such as joy, in the context of end of life care.

Purpose: The purpose of this dissertation was to explore the concept of joy in the context of the end of life and, more specifically, to better understand the experience of joy in adults with advanced cancer in hospice.

Methods: The dissertation consists of four related and sequential papers: (1) a concept analysis of joy and happiness to determine the differences between the two concepts and to provide an initial definition of joy; (2) an integrative literature review of the "good death" in western society to explore how the dying process is represented and enacted in contemporary society and within the contemporary palliative care discourse; (3) a methods paper describing the role of transcripts in an interpretive description study; and (4) a findings paper describing a qualitative interpretive description study to understand the experience of joy from the perspective of adults with advanced cancer in the context of hospice.

Findings and Conclusions: Dying in contemporary western society is portrayed as a predominantly negative process in both social and palliative care discourses. A contemporary "good death" ideally occurs without a dying process, as dying becomes less visible, more undesirable, in social discourse. But dying is undeniably an important part of living and as such, exploring and exposing positive dying experiences may help to reframe attitudes to dying and improve quality of life by improving end of life care. Although some research attention is given to positive concepts in palliative care, more emphasis needs to be given to concepts such as hope and joy, to reframe and reclaim the dying process.

In this qualitative study, seven persons with advanced cancer residing in a hospice in an urban western Canadian city and six nurses were interviewed to explore the experience of joy in this population. Findings indicated that participants not only experienced joy at or near the end of life, but they valued their moments of joy, as these moments of joy made them feel connected, exhilarated, and alive. Participants described the experience of joy as a sudden "moment in time in which everything comes together" and from which comes strength, freedom, and the feeling of being alive. Participants associated joy with an intense feeling of deep connection. The findings of this study suggest that experiencing moments of joy may help patients feel cared for, alive, and connected to themselves and to others. Moments of joy may help those individuals with advanced illness who experience dislocation and alienation associated with liminality; joy may provide the connection that protects from despair and alienation and fosters healing. Based on my findings, I would like to encourage nurses who work in end of life settings or who study end of life issues to focus on providing more opportunities for individuals to experience joy.

Preface

Ethics approval to conduct the study reported in Chapter 5 of this dissertation was received from the University of Alberta Research Ethics Board, Project Name "Joy at the end of life: A constructivist grounded theory study" No. Pro00064093 on 4 May 2016. It was subsequently amended and approved with the title: Joy at the end of life: an interpretive description" on 11 April 2017.

A version of Chapter 2 of this dissertation was accepted for publication on 9 March 2016 and published in the *Journal of Advanced Nursing*, (John Wiley and Sons) volume 72(7) as: Cottrell, L. (2016). Joy and happiness: A simultaneous and evolutionary concept analysis (© John Wiley & Sons; reprinted with permission). I was responsible for the conceptualisation of this concept analysis, as well as the literature review and drafting the manuscript, with support and assistance from Dr. Jude Spiers and Dr. Wendy Duggleby.

A version of Chapter 3 of this dissertation was accepted for publication on 13 October 2015 and published in January 2016 (volume 14) in *Palliative and Supportive Care* (Cambridge University Press) as: Cottrell, L., & Duggleby, W. The "Good Death": An integrative literature review. (© Cambridge University Press 2016; reprinted with permission). I was responsible for the conceptualisation of this review, completing the search and screening, data extraction and analysis, and drafting the manuscript. The second author, W. Duggleby, contributed to and supported the review conceptualisation and design, analysis, and revision of manuscript drafts for important intellectual content.

A version of Chapter 4 of this dissertation will be submitted to *The International Journal of Qualitative Methods* as: Cottrell, L., Duggleby, W., Olson, K., & Nekolaichuk, C. "The role of transcripts in interpretive description". I was responsible for manuscript conceptualisation, drafting the manuscript, and responding to feedback from co-authors. W. Duggleby, K. Olson, and C. Nekolaichuk contributed to and supported manuscript conceptualisation, critically reviewed manuscript drafts, and provided substantive feedback.

Chapter 5 of this dissertation is in preparation for submission to *The Journal of Advanced Nursing* as "Cottrell, L., Duggleby, W., Olson, K., & Nekolaichuk, C. "Being alive": An interpretive description of joy at the end of life". I was responsible for study conceptualisation and design, data collection, conducting analysis, and drafting the manuscript. W. Duggleby, K. Olson, and C. Nekolaichuk supported study conceptualisation and design, data analysis, and provided critical reviews of manuscript drafts with substantive feedback, contributing important intellectual content.

Dedication

Time close to the end of life is perhaps the most valuable of all. I dedicate this dissertation to my study participants, who gave so willingly their time to share with me their stories of joy.

> "Time held me green and dying, though I sang in my chains like the sea"
>
> Dylan Thomas, *Fern Hill,* 1945

Acknowledgements

Research and education are collaborative processes, and a large supportive network has made it possible for me to complete this work.

Thank you to the funders who have provided me with generous support: The University of Alberta QEII and Doctoral Recruitment Scholarships, the Canadian Frailty Network, and the individuals and families who provided the following scholarships: Dr. Herman & Elly de Jongh Award, the Wynn Weist Memorial Award, and the Sandy McKinnon Memorial Scholarship. Your support allowed me to focus on my research and to develop academically.

Thank you to my supervisor, Dr. Wendy Duggleby. You devoted hours of your life to support my scholarly development; you kept me organised (no small task) and encouraged me to focus, while asking me challenging questions to improve this work. Thank you for being so kind, consistent, and patient throughout this process.

Thank you to my committee members Dr. Karin Olson and Dr. Cheryl Nekolaichuk. Karin: thank you for your enthusiasm and the energy you infused into this process. Thank you for asking me difficult questions, encouraging me to think harder, and for sharing your knowledge of research with me. Cheryl: Thank you for your thoughtful feedback, your kindness, and for bringing a unique perspective and scrupulous attention to detail to this work. Thank you for encouraging me to think from different angles and to keep questioning.

Thank you to Heather McKay Maddox, who provided unfailing support and instrumental assistance with recruitment.

Thank you to Lisa Garland Baird, who frequently fielded my frantic questions, knew all the procedural things, and supported me when life was hard both academically and personally.

Thank you to my niece Maureen Metz, who gave up her home to make it possible for me to live in Edmonton for my residency term, and made me feel welcome and warm during the cold winter.

Thank you to my partner Arthur Neele, who endured five years of listening to me discuss papers and deadlines and qualitative research; who spent hours proofreading, sharing ideas, and making dinners, all the while calmly supporting and encouraging me. I could not have done this without you.

And thank you to my daughter Stella Giannakos, who essentially had no mother for five years, but who always supported my studies, and whose enthusiasm for and fascination with my topic was a constant source of inspiration. You have always been both my inspiration and my joy.

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Chapter 1: Introducing the Problem

The population in Canada and worldwide is aging; by 2032, the proportion of Canadians aged 65 and older will grow from approximately 1 in 8 (between 2003-2007) to 1 in 4 (Canadian Cancer Society, 2015). By 2061, there will be between 11.9 million and 15 million persons aged 65 and over. In older adults, the incidence of cancer is higher than all other age groups, accounting for 89% of new diagnoses (CCS, 2015); for both males and females, the median age at diagnosis is between 65 and 69 years of age (CCS, 2015). Furthermore, the incidence of and mortality from cancers are expected to increase. According to the Canadian Cancer Society, by 2032, the number of new cancer cases is expected to more than double in those aged 65 and over. These demographic trends mean that the annual number of expected deaths in Canada will double between 2005 and 2036 (Fowler & Hammer, 2013), thus demanding further knowledge development to ensure quality end of life care in the future.

End of life care has evolved over time and continues to adapt to societal changes. In the western world, the current end of life care context is in flux, and the process of dying is being increasingly marginalised with death continuing to be viewed as a predominantly negative experience (Cottrell & Duggleby, 2016). In a literature review on exploring contemporary western attitudes to death and dying, specifically the "good death", (Cottrell & Duggleby, 2016) we found that the process of dying in western society is negatively portrayed and often ignored, to the extent that dying is becoming increasingly absent from social discourse. Forefronting positive concepts such as joy in the context of the end of life care may help reclaim a more positive view of death (Cottrell & Duggleby 2016). Though there are various different kinds of joy (Cottrell, 2016; Meadows, 1975; Potkay, 2007), I defined it as a sudden and intense positive emotion associated with freedom, vitality, and a deep connection to self, others, and God and/or nature or the universe (Cottrell, 2016).

In this introductory chapter, I will explore the small body of literature on joy in the palliative care context. This will be followed by definitions of key terms for my research. I will also describe my personal reasons for conducting this research, because I think it is important for readers to know my motivations for asking this particular research question. I will briefly discuss the disciplinary scaffold underpinning this work, and will explain my rationale for choosing to change my research method during my study. I conclude this chapter with a short description of each of the four papers included in this dissertation, including their purpose, main points, and linkage to the other papers.

Literature Review: Joy

I conducted a scoping review of the palliative care literature on joy using the search terms "(joy" and "palliative or terminal or end of life or dying") in the following databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medline, Academic Search Complete, and ProQuest Dissertation & Theses Database. I included empirical and non-empirical literature in which joy was an explicit focus or a study finding in patient, family, health care practitioner, or volunteer populations. Studies and non-empirical papers were excluded if they did not focus on joy or did not pertain to palliative or end of life care. The search was not restricted to time, as I anticipated a small number of studies, but was restricted to peer-reviewed academic literature published in English. The search retrieved 240 articles: after deleting duplicates and articles that did not meet the inclusion criteria (for various reasons; see Figure 1.1), the review included 14 articles and one abstract representing 10 empirical and five non-empirical articles.

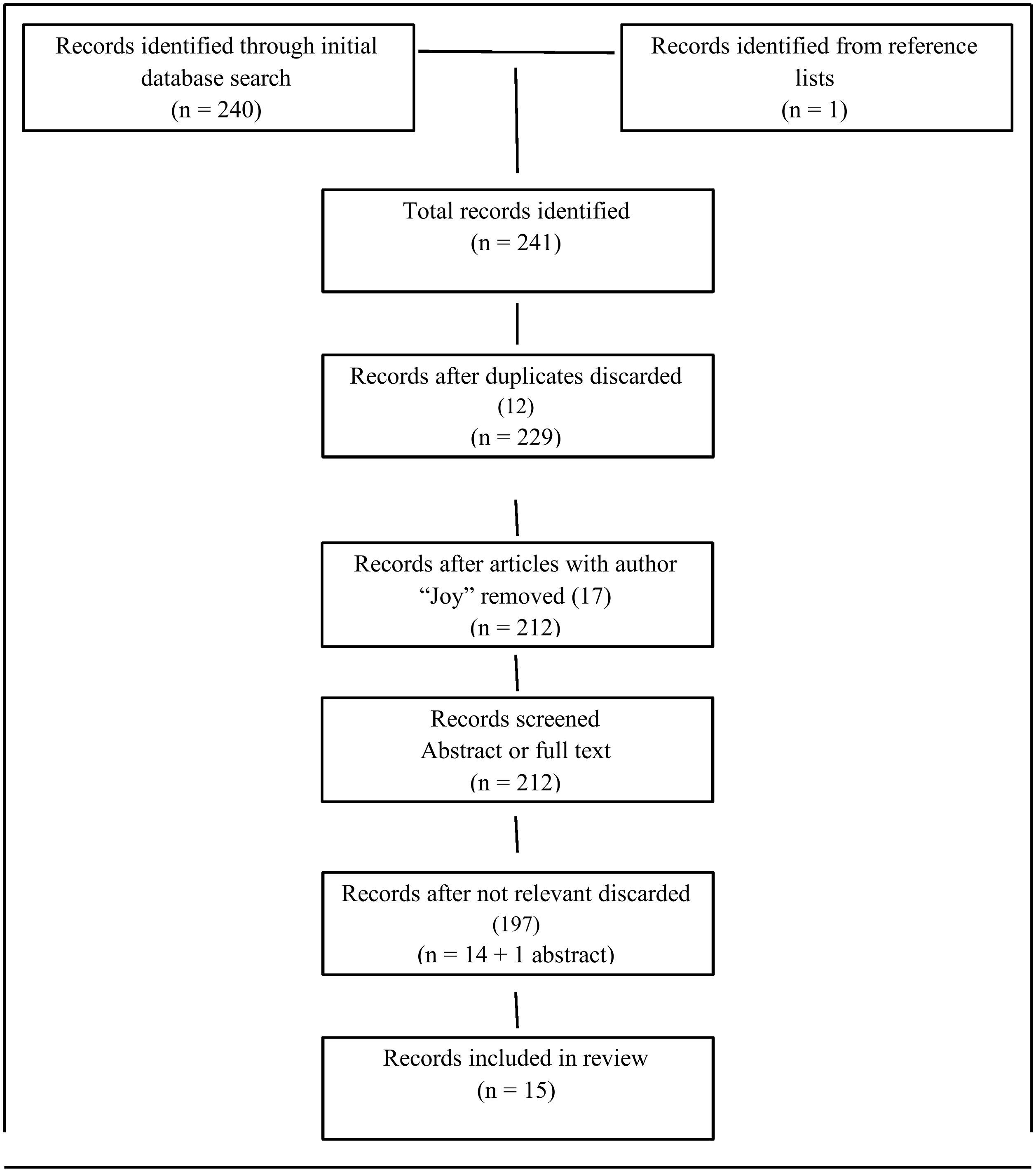

Figure 1.1: Literature search joy PRISMA diagram

The concept of joy surfaced in ten studies (refer to Table 1.1), though notably none defined the concept (Afeef & Alkhoulli, 2010; Banos et al., 2013, Horsfall, Noonan, and Leonard, 2012; Lewis, 2014; Lin, 2003; Linge, 2011; Magill, 2009; Muckaden & Pandya, 2016; Olsson, Ostlund, Strang, and Friedrichsen, 2011; Soares, da Silva, & Santos, 2016). Joy was, however, an explicit focus of just three studies (Banos, 2013; Linge, 2011; Magill, 2009). Banos et al. (2013) studied 19 hospitalized patients with advanced cancer, exploring their experiences after completing a virtual reality program designed to create or simulate joy. Findings from this study indicated that joy increased positive emotions and led to further benefits, such as "distraction, entertainment, and relaxation" (p. 263) while decreasing negative emotions. Although the authors did not provide a definition for joy, they postulated that joy can improve patients' quality of life during dying.

Magill (2009) used naturalistic inquiry to study joy in seven caregivers of advanced cancer patients during music therapy sessions prior to death. Magill (2009) discovered the existence of two types of joy in this population: autonomous (when the caregiver felt joy directly) or empathic joy (when the caregiver felt joy as a result of witnessing the patient's joy). Though Magill (2009) did not define joy, it was viewed as a "sustaining" theme (p. 99) and was associated with "general happiness and pleasure" (p. 100). Magill (2009) discovered that joy brought caregivers self-renewal and meaning through transcendence; the patients themselves had the opportunity to experience "moments of joy . . . rather than sorrow and lamentation" (p. 106) at the end of life. Although there were only seven participants, who were caregivers for community-dwelling hospice patients in the US, the findings contribute to an understanding of joy. As Magill (2009) noted, joy may "allow for relationship completion, lead to healing, and inspire improved appreciation for the value of one another's lives" (p. 106) and may provide "for healthy outcomes of grief and bereavement" (p. 106).

Linge (2011) studied how clowns can encourage joy in children hospitalized with advanced cancer through a study of 20 caregivers (physicians, nurses, and a play therapist) on three wards in three teaching hospitals in Sweden. Linge (2011) did not define joy, but the findings suggested that participants associated joy with "possibilities and a feeling of freedom" (p. 7). Joy was associated with "a place of refuge" (p. 4); through joy "something different happened" (p. 4) and children "got a moment of relaxation and liberation" (p. 4) from the realities of illness and hospitalization. Linge (2011) suggested that joy is "needed to form and maintain relationships" (p. 6) and is "infectious in social situations" (p. 6). Significantly, Linge's (2011) study found that although joy is encapsulated in moments of freedom--"the rush of joy"(p. 4)--its effects were lingering and associated with increased vitality. This freedom may provide refuge and "a safe area for recovery"(p. 7) or healing. Although this study focuses on a paediatric population and the joy inspired by hospital clowns, its findings may be salient to other populations and settings.

These three studies are important because they explore the concept of joy in populations at the end of life, albeit there were differences related to age, setting, and methods. Despite these differences, all three studies reported positive findings pertaining to joy, yet there remains a paucity of experimental literature that explores joy explicitly in palliative care.

In seven palliative care studies, joy was not the explicit focus of the study, but emerged as a study finding. For example, Soares, da Silva, and Santos (2016) discovered that hospitalised children with cancer found joy through playing, and Olsson, Ostlund, Strang, Grassman and Friedrichsen (2011) found that palliative home care patients “held onto moments of joy” (p. 52).

Lin's (2003) doctoral dissertation on narratives of Chinese immigrants with metastatic cancer reported that "participants found meaning when they had joy" (p. 141) and Afeef and Allkhoulli (2010) reported that palliative care patients found joy in their relationship with family members or with God, and through giving by providing care for others.

Caregivers in Horsfall, Noonan, and Leonard's (2012) study similarly reported finding joy when caring for relatives at the end of life, as did caregivers of persons living with dementia at the end of life in Lewis' (2014) doctoral dissertation. Lewis (2014) did not provide a definition for joy, but articulated three themes that described the caregivers' joy: "living in the moment", "entering into his world", and "falling in love".

Joy emerged as a finding in all of these studies, yet none of these authors defined joy and few discussed the significance of joy to their participants. Often, joy was either not discussed or was subsumed by the concepts of meaning or spirituality.

In the non-empirical literature, joy was not defined, but was characterised as unexpected or paradoxical in the context of palliative care (Gauger, 2014; Lannie, 1978; Twycross, 1997). In all instances, joy was viewed as a positive benefit for health care professionals (Kirkland, 2014; Lannie, 1978; Witt-Sherman, 2015) or as the underlying purpose of palliative care practice (Gauger, 2014; Lannie, 1978;Twycross, 1997; Witt-Sherman, 2015).

Table 1.1 Literature review table: Joy in palliative care

Empirical literature: joy main focus			
1. Author: Banos, Espinoza, Garcia-Palacios, Cervera, Ewquerdo,	Discipline: psychology Institution: Universitat de Valencia	Type: Not explicitly discussed, but mixed QL/QT,	Purpose: To test the feasibility of a psychological intervention that uses virtual reality techniques and is focused on

Barrajon, & Botella Journal:*Support Care Cancer* Title: A positive psychological intervention using virtual reality for patients with advanced cancer in a hospital setting: a pilot study to assess feasibility Year: 2013 Country: Spain	Funding: Generalitat Valenciana PROMETEO (2008/157), Ministerio de Ciencia y Tecnologia (PSI2010-09568-E).	using (various tools/scales) Participants: N=19	the induction of positive emotional states in oncology in patients with advanced stages of disease in a hospital setting. Intervention: The induction of joy and relaxation in 4 sessions during 1 week (sessions 1 and 3 on joy; 2 and 4 on relaxation). Two virtual environments were created: "emotional parks" and "walk through nature" (used for both joy and relaxation). Emotional parks was an urban park through which participants can virtually walk. Walk through nature environment was a walk in a forest, used for both joy and relaxation (with breathing and mindfulness exercises) Main Findings: (relevant to joy) *main benefits were distraction, entertainment, and relaxation. *joy characterised as a "positive mood" and seen as

			important for well-being, self-efficacy, and coping. *joy not defined
2. Author: Linge, L. Journal: *International Journal of Qualitative Studies* of *Health & Well-being* Title: Joy without demands: Hospital clowns in the world of ailing children Year: 2011 Country: Sweden	Discipline: Social and Health Sciences Institution: Halmstad University Funding: Swedish Childhood Cancer Foundation	Type Qualitative (IPA) (n=20) (17F; 3M) HC providers	Purpose: To achieve a deeper psychological understanding of hospital clowns' work in the care of ailing children, seen from a caregiver perspective. Main Findings: (relevant to joy) *clowns brought a "rush of joy" (p. 4) and a "place of refuge" (p.4) *joy was connected to a feeling of vitality and a chance to transcend boundaries: freedom *joy put children into a non-demanding state; in the moment, away from pressures of illness *joy not defined
3. Author: Magill, L. Journal: *Palliative & Supportive Care* Title: The spiritual meaning of pre-loss music therapy to bereaved	Discipline: Music therapy Institution: University of Windsor Funding: none declared	Type: Empirical Naturalistic inquiry N=7 (6F;1M)	Purpose: To discover and describe the spiritual meaning of music therapy experienced before the death of a loved one. Main Findings: (relevant to joy)

caregivers of advanced cancer patients Year: 2009 Country: Canada (study site in USA)			*Joy was a sustaining theme, both autonomous joy (affected caregiver directly) and empathic joy (caregivers' joy based on remembering seeing patient happy). *Reflective themes: connectedness with self, with others, and with "the beyond" (reflecting on present), remembrance (reflecting on past), and hope (reflecting on future). *Meaning through transcendence was found to be the overarching theme *Music therapy can assist caregivers in times of bereavement as they retain memories of joy and empowerment rather than memories of pain and distress. *joy not defined
Empirical literature: joy not main focus			
4. Author: Afeef, J., & Alkhoulli, L. Journal: *Asian Pacific Journal of Cancer Prevention*	Discipline: medicine/oncology Institution: King Hussein Cancer Centre	Type: Narrative case study of patients with advanced	Purpose: to understand patients' suffering Main Findings: (relevant to joy) *Case study I: (24M)

Title: Surprised by Joy: a journey through suffering Year: 2010 Country: Jordan	Funding: None declared	cancer receiving palliative care N=3	suffering/isolation: major relief of suffering through surrender and faith in will of God and spending joyful moments with daughters *Case study II (38F) Suffering due to pain, cachexia, and skin discolouration. Caregiver for handicapped husband, with 3 children. Many financial and logistical problems; felt helpless and powerless as she watched her health slip away. Relief of suffering through surrender and commitment to God. Taking care of her handicapped husband gave her the joyful meaning of giving in life. *Case study III: (54F) Suffering due to pain, dyspnea, and seizures; also stress due to financial troubles. Was lonely and sad and hopeless. Found joy in spirituality and prayers. *joy not defined

5. Author: Horsfall, D., Noonan, K., & Leonard, R. Journal: *Health Sociology Review* Title: Bringing our dying home: How caring for someone at end of life builds social capital and develops compassionate communities Year: 2012 Country: Australia	Discipline: Social Sciences & Psychology Institution: University of Western Sydney Funding: University of Sydney (UWS) and HOME Hospice and Cancer Council NSW (industry partners)	Type: QL unspecified, included photovoice and network mapping, individual and group interviews Participants: N=94 (primary carers)	Purpose: Part of a larger study focused on informal caregivers of people who die at home; this study explored the role of informal care networks in EOL care at home and how such networks build social capital and increase the community's capacity for compassion Main Findings: (relevant to joy) *caregiving work was deeply profound; caregivers reported "joy and grey hallows" *caregivers felt joy, privilege, and honour (and love) *joy described as "an alternative, or resistance, narrative to those usually heard in research about caring for a dying person" (p. 378) *joy not defined
6. Author: Lewis, L.F. Journal: Doctoral dissertation	Discipline: Nursing Institution: University of Connecticut	Type: Classic Glaserian Grounded Theory	Purpose: to discover a substantive theory that identifies the main problem that caregivers for loved

Title: *Caregiving for a loved one with dementia at the end of life: an emergent theory of the basic social psychological process of rediscovering* Year: 2014 Country: USA	Funding: None declared	N=101 caregivers describing 104 persons with dementia at EOL. Data collection methods included face to face interviews, online interviews, published books, blogs, and participant observation.	ones with dementia face at the end of life and the basic social process by which they resolve this problem. Main Findings: (relevant to joy) *Caregivers were able to rediscover their loved ones and to find true joy in their roles. Joy was associated with living in the moment, entering into his world, and falling in love. Caregivers shifted their focus from providing care to providing joy, and, in doing so, found joy. *joy not defined
7. Author: Lin, H.R. Journal: Doctoral Dissertation Title: *One thousand words of luck: Narratives and analysis of US resident Chinese immigrants with metastatic cancer* Year: 2003 Country: USA	Discipline: Nursing Institution: University of Massachusetts Amherst Funding: None declared	Type: Qualitative (topical life history) N=12 (5F; 7M)	Purpose: Main Findings (relevant to joy) *Joy was a component of a good death (ability to feel joy), was related to improved quality of life, and was discussed as a component of finding meaning in life *joy was associated with having a good and valuable life, having good

			connections with family and friends, religious practice, appreciating and enjoying the present moment, and keeping everyday life normal *joy brought meaning to life *joy not defined
8. Author: Muckaden, M.A., & Pandya, S.S. Journal: *Indian Journal of Palliative Care* Title: Motivation of volunteers to work in palliative care setting: a qualitative study Year: 2016 Country: India	Discipline: ?medicine Institution: Tata Memorial Hospital, Mumbai Funding: None declared	Type Qualitative (no specific method identified; possibly thematic analysis) N=10 participants (palliative care volunteers)	Purpose: To identify the motivation to volunteer in the palliative care unit; to identify the rewards and the challenges of being a volunteer in palliative care; to understand the impact of volunteering on social relationships and self. Main Findings: (relevant to joy) *"the joy of giving" was an important motivator for volunteers *joy not defined
9. Author: Olsson, L., Ostlund, G., Strang, P., Grassman, E.J., & Friedrichsen, M. Journal: *Palliative & Supportive Care*	Discipline: Social & Welfare Studies, Faculty of Health Sciences Institution: Linkoping University	Type: QL (Strauss & Corbin GT) Participants: N=11 (5F; 6M; median age 58)	Purpose: To explore how cancer patients admitted to palliative home care experienced the significance of hope and used hope during 6 weeks throughout the last phase of their life,

Title: The glimmering embers: Experiences of hope among cancer patients in palliative home care Year: 2011 Country: Sweden	Funding: None declared		and to assess their symptoms and hope states. Main Findings (relevant to joy): *joy associated with hope and the desire to continue to seize the day and hold onto moments of joy *Patients with just "fragments of hope" could still cling to small moments of joy
10. Author: Soares, A.V., da Silva, L.F., Mattos do Santos, P. & Depianti, J.R.B. Journal: *Journal of Nursing, UFPE OnLine* Title: The importance of playing for hospitalized children with cancer in palliative care [abstract] Year: 2016 Country: Brazil	Discipline: Nursing Institution: Nursing School Aurora de Afonso Costa/EEAAC/UFF Funding: None declared	Type: QL thematic analysis N=11 Healthcare professionals	Purpose: to identify the importance of playing in the palliative care of hospitalized children with cancer in the perception of the nursing team Main Findings: (relevant to joy) *playing brings children joy, which is important as it helps the child to become more cheerful, promotes well-being, and is more humanized care *joy not defined

Non-empirical literature			
11. Author: Gauger, R.W. Journal: *Journal of Pastoral Care & Counseling* Title: In pain and in joy Year: 2014 Country: USA	Discipline: Pastoral care Institution: Baptist South Hospital Funding: None declared	Type: Non-empirical/Narrative	Purpose: How joy can manifest at EOL Main Findings: (relevant to joy) *similarities between childbirth and death (birthing into the world that follows) *in both situations there is great pain, but there can also be great joy. *Joy may not be apparent in the context of EOL, but often comes unexpectedly. *joy not defined
12. Author: Kirkland, K.B. Journal: *JAMA* Title: Finding joy in practice: cocreation in palliative care Year: 2017 Country: USA	Discipline: medicine Institution: Geisel School of Medicine at Dartmouth, Dartmouth-Hitchcock Medical Centre Funding: None declared	Type: Non-empirical/opinion	Purpose: To describe specialist palliative care practice (a day/events) and its importance not only to patients, but to the medical professionals Main Findings: (relevant to joy) *the world of palliative care … is not a place of overwhelming sadness. Instead, we find (or perhaps we cocreate) meaning, and even joy in our work.

			This is allowed by: a) honouring patients' preferences and working together toward shared goals; b) the work is grounded in narrative practice: have the privilege of knowing people and seeing through various lenses (literature, art, music, and spirituality); c) the work is deeply collaborative *joy not defined
13. Author: Lannie, V.J. Journal: Supervisor Nurse Title: The joy of caring for the dying Year: 1978 Country: ?USA	Discipline: Nursing Institution: Not specified Funding: None declared	Type: Non-empirical	Purpose: To discuss the presence of joy in caring for the dying Main Findings: (relevant to joy) *Dying is framed as a rather negative experience; it may be paradoxical to associate death with joy (p. 66). *Joy emerges in the relationship between nurse and patient through shared grief *There is joy in dying with dignity, but sorrow is necessary *As we mourn with the patient the impending loss

			of life, we are made aware of the treasures which comprise life itself *It is joy resulting from personal transformation and acceptance which gives one a profound and appropriate sense of the relative insignificance of one's personal existence; joy is experienced when death is viewed as a process of fulfillment, or regarded as the final achievement, rather than extinction
14. Author: Twycross, R. Journal: *The Lancet* Title: The joy of death Year: 1997 Country: UK	Discipline: medicine Institution: Churchill Hospital, Oxford Funding: None declared	Type: Non-empirical/editorial	Purpose: Discuss future directions for palliative care in UK Main Findings: (relevant to joy) *visiting a palliative care unit leads to the strange discovery of life and joy in the midst of death and distress. It is perhaps in this paradox that the secret of palliative care resides. Truthfulness in palliative care is important, as is creative activity to help

			people search for meaning and manage suffering.
15. Author: Witt-Sherman, D. Journal: *Journal of Palliative Medicine* Title: Palliative Care: A specialty focused on the relief of suffering of individuals, families, communities, and populations Year: 2015 Country: USA	Discipline: Nursing Institution: Nicole Wertheim College of Nursing & Health Sciences Funding: None declared	Type: Non-empirical/editorial	Purpose: To discuss purposes of specialist palliative care in various contexts Main Findings: (relevant to joy) Palliative care is evolving and, despite progress, we are not yet able to adequately address the needs of individual patients and their families and communities, never mind entire populations of patients. *Palliative care has focused on the relief of suffering, which is a part of the human condition, and refers to a lack of integrity of persons. *In contrast to suffering, there is joy: the small joys of everyday life like sunshine and smiles when trauma and drama is replaced with the normal and ordinary which so often is taken for granted".

			*The goal of palliative care is to alleviate all forms of suffering and, as such, “we must replace suffering with joy” (p.477)

Joy has surfaced as a finding in other settings, such as midwifery, where joy may be expected when welcoming a new life (Crowther, 2014) and in disability studies (Sunderland, Catalano, & Kendall, 2009). Even in the context of childbirth, however, explicit mention of joy is rare; instead, “joy … was often ignored, hidden, or covered over” (Crowther, 2014, p. e157). Furthermore, Sunderland, Catalano, and Kendall (2009) described joy as “a missing discourse” (p. 703) in the context of disability.

In nursing, theoretically, there are no reported theories or conceptual frameworks that focus specifically on joy. However, Parse (1997) explored the link between joy and suffering through what she called the paradoxical rhythm of "joy-sorrow". Parse defined joy-sorrow as an oscillating pattern through which individuals simultaneously experience exaltation and despair, and although she does not define joy, she likened it to an aesthetic or religious experience, associated with transcendence, freedom, and possibility (Parse, 1997). Parse's concept of joy-sorrow is unique in that it is a unified experience in which neither joy nor sorrow exist independently, but are inextricably connected, shifting rhythmically in a constant flux (Parse, 1997).

Parse's (1997) work is significant as it explores the concept of joy in nursing, though is focused on the simultaneous coexistence of joy and sorrow, rather than joy in isolation. It generated two further discussion articles on joy-sorrow (Bunkers, 2006; Pilkington, 2006), as well as two studies (Cinta Estrada Ferrando et al., 2012; Baumann & Braddick, 1999). Joy-sorrow may describe findings discussed by Horsfall, Noonan, & Leonard in their 2012 study of caregivers of dying relatives; although the authors did not discuss Parse's (1997) concept of joy-sorrow, study participants stated that "there was joy and grey hollows" (p. 378) in providing care for the dying. Whereas joy-sorrow may share similarities with joy, its dependence on suffering makes it conceptually distinct from joy alone.

In both the empirical and non-empirical literature on joy, joy was viewed as a positive concept that had healing and transformative potential. Yet joy was often ignored or sublimated to concepts such as meaning or spirituality. Few studies examined joy explicitly and from the perspective of individuals with life-limiting illness. This underscores the need to explore joy from the perspective of people who are at or near the end of life

Key Terms

End of Life Care: As suggested by Izumi and Nagae (2012), several definitions of end of life (EOL) care exist, yet are problematic as many are based from a medical perspective (presence of terminal illness or estimate of time remaining to live). The EOL is a discrete time period in which the person is aware of his/her impending death; end of life care can be defined as follows: “to assist persons who are facing imminent or distant death to have the best quality of life possible until the end of their life, regardless of their medical diagnosis, health conditions, or ages” (Izumi & Nagae, 2012).

Hospice: Hospice is both a setting and a philosophy. As a setting, an in-patient hospice is a home-like institution where individuals with an estimated life span of 3-6 months are admitted for end of life care (Fraser Health, 2007). As a philosophy, hospice is predicated on the recognition of dying as an important and normal part of living, and privileges maintaining or enhancing quality of life, while neither hastening or postponing death (Conant & Lowney, 1996).

The Good Death: Though subtle variations exist, the western idealised "good death" is a peaceful and dignified death, free from pain and other distressing physical symptoms. Death occurs in old age and follows a predictable course. It occurs at home, with the dying individual surrounded by family members. The dying individual is aware of and accepts their impending death, has made appropriate legal and financial preparations, and, ideally, has planned their dying experience through an advance directive (Cottrell & Duggleby, 2016; Granda-Cameron & Houldin, 2012; Kehl, 2006).

Joy: Joy is a spontaneous, sudden and transient concept associated with intense feelings of connection, awareness, and freedom (Cottrell, 2016).

Researcher Motivation and Positioning

My interest in joy stems from my experience as a palliative home care and hospice nurse. During this time, I worked with many patients (and their families) who were facing death. Expecting, often, to enter a home or a hospice room to find sorrow, pain, and existential suffering, I was surprised, often, by what I encountered: not sorrow, but joy; not pain, loneliness or existential suffering, but laughter, warmth, and a strong spirit of togetherness.

As a nurse, I have seen pain, fear, and suffering in patients at end of life. But I have also seen joy. My aim is to address its absence in the palliative care literature by exploring the concept of joy from the perspective of individuals with advanced cancer in hospice. The question underlying this work is "how can we better understand the experience of joy in individuals with advanced cancer in the context of hospice?"

Research Method

I discuss my research method in more detail in Chapter 4, but will explain in this introduction why I changed my method during the course of this study. I initially proposed my study using Charmaz' (2014) constructivist grounded theory, but changed my research method to Thorne's (2016) interpretive description (ID) for several reasons. First, recruitment was more challenging than originally anticipated, and after failing to secure additional recruitment sites, I realised that my sample size would likely be insufficient from which to develop a robust theory, which is an aim of a grounded theory study. As well, as the participants were at the end of life the feasibility of conducting at least two interviews per person was a challenge. ID provided a means to generate meaningful clinical perceptions from a small, but deliberate, sample. As Thorne, Reimer Kirkham, and O'Flynn-Magee (2004) explain, an interpretive description study is often a:

> …smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing the themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding. (p. 3)

Second, as the extant literature on joy is limited, this study was exploratory, and Thorne (2016) supports the use of ID in exploratory work, as its multifaceted gaze at clinically-derived problems may help to identify new information or illuminate new insights. Finally, and perhaps most importantly, as my research question arose from curiosities piqued during clinical practice, situating my work within nursing provided the most appropriate way to answer my research question. Thorne's ID method was designed from within nursing to solve problems relevant to clinical practice. It supports knowledge generation using the disciplinary scaffold of nursing, solving clinical problems and revealing new insights derived from multiple sources, including "subjective, experiential, tacit, and patterned aspects of human health experience" (Thorne, 2016, p. 41), which are always weighed against the imperative of their usefulness to clinical practice

(Thorne, 2016; Thorne, Stevens, & Truant, 2016). Thus ID was developed to guide clinical practice decisions (Thorne, 2016). By generating new insights about joy using ID, my hope is that the results of this study will be directly relevant to practising nurses.

Dissertation Overview

This dissertation includes four interrelated papers. Briefly, the first paper (Chapter 2) is a simultaneous concept analysis of joy and happiness, in which I aimed to determine the differences between the two concepts, and to provide a beginning definition of the concept of joy. In the second paper (Chapter 3), I examined the concept of a "good death" in the context of contemporary attitudes to death and dying, to deepen my understanding of the context of hospice, from which the "good death" philosophy originates, and to situate this work within the contemporary discourse of dying. The third paper (Chapter 4) is a methodological paper, in which I described the role of transcripts in an interpretive description study. Learning to create and analyse transcripts is an important step in the research process, as transcripts facilitate the working and reworking of data, and may have different purposes depending on the research question, method, and overall purpose. The fourth paper (Chapter 5) reports on a qualitative interpretive description study to discover how patients with cancer in the context of hospice describe joy. Joy was co-constructed as consisting of three interrelated themes: "being aware", "being with", and "being alive".

Paper 1: Joy and happiness: A simultaneous and evolutionary concept analysis

<u>Objective</u>: To clarify and analyse the concepts of joy and happiness through adapting and blending a simultaneous concept analysis (SCA) process with Rodgers' (2000) evolutionary method. My aim was not to provide a finished or absolute definition of the concepts of joy and

happiness, but to promote clarity for continued conceptual exploration in nursing practice areas (Rodgers, 2000).

Description: Using the search terms "joy or happiness" I searched seven databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, Academic Search Complete, ATLA Religious Database with ATLASerials, Humanities International Complete, Psych EXTRA, SocINDEX with Full Text, and Philosopher's Index. Inclusion criteria were peer-reviewed academic articles written in English that discussed joy or happiness directly, including those that provided oblique definitions, antecedents, or attributes of either concept. Editorials, articles, and reports of qualitative or quantitative studies were included, in keeping with the integrative nature of an initial scoping search (Haase et al., 2000). Exclusion criteria were book reviews, letters to the editor, and articles that did not discuss joy or happiness directly, as well as those that tested tools to measure either concept.

The final analysis is based on 61 articles and one book, published between 1978 and 2014. The following disciplines are represented in this concept analysis: nursing (9 articles); psychology (24); English literature (4 articles and 1 book); medicine (3); education (1), theology or religious studies (8 articles total: Christianity [5]; Judaism [2]; Buddhism [1]; marketing or economics [5], philosophy [3]; sociology [3]; and history [1]).

Data were analysed using a combination of Rodgers' (2000) method and Kikuchi's (1997) philosophical analysis. Attributes, antecedents, and outcomes of joy and happiness were extracted from salient articles and compared between and across disciplines before creating a validity matrix to compare joy and happiness.

Results from this concept analysis report that although joy and happiness are both positive concepts with similar personality characteristics, they have significant differences.

Differences between the two concepts appear in terms of time, duration, intensity, ethical orientation, intention, and action. Overall characteristics of joy are awareness, insight, union, connection, and freedom, whereas characteristics of happiness are virtue, self-control, and satisfaction. This analysis identified areas for further inquiry, including fieldwork to explore joy across nursing contexts, across the lifespan, and amongst diverse cultures; explorations of joy in related theories, such as gerotranscendence and other ageing theories; and studies that explore the links between joy and health.

Linkage: Paper 1 demonstrates the differences between joy and (long term) happiness and helps to clarify the concepts. Concept analysis is an essential first step in this research, as it provides the bedrock on which to proceed and explore the concept of joy from the perspective of adults with advanced cancer in hospice.

Paper 2: The “good death”: an integrative literature review

Objectives: The purpose of this paper was to describe the underlying discourse in the literature on the “good death” in western societies. In this paper, I aimed to explore the forces that shape western attitudes and beliefs around death and dying, and, in particular, examine how the “good death” discourse frames the dying experience in contemporary society.

Description: Through the examined literature, I constructed four main themes that characterise the “good death” in western society: (1) the “good death” as control; (2) the wrong “good death”; (3) the threatened “good death”; and (4) the denial of dying. Significantly, I found that the “good death” frames dying as an increasingly negative or even unnecessary process, thus marginalising the positive aspects of dying and rendering dying absent, invisible in social discourse.

Linkage: In paper 2, I begin to shape the context of hospice by exploring its underlying philosophy, and also comment on the current discourse of dying in western culture. This knowledge helps to both shape and understand the context from within which palliative and end of life care develops. As the “good death” discourse marginalises not only the positive aspects of dying, but dying itself, this review fueled my quest to better understand the experience of joy from the perspective of individuals with life-limiting illness in the context of hospice.

Paper 3: The role of transcripts in interpretive description

Objectives: The purpose of this paper was to explain the fundamentals of knowledge development in ID and explore the interplay between data and data analysis by examining the role of transcripts in an ID study.

Description: In this paper, I described how transcripts in an interpretive description study are interpretive, naturalistic documents that clearly express verbal as well as contextual data, thus facilitating analysis and promoting rigour.

linkage: By exploring how transcripts are viewed and used within an interpretive description study, this paper helped me to understand their importance in and to qualitative research. I learned the importance of transcribing all aspects of the interview, viewing the transcript as a whole and how transcripts contribute to the analysis process in interpretive description. I used data from my study to provide clarity to my conclusions about using transcripts in ID.

Paper 4: “Being alive”: an interpretive description of joy at the end of life

Objectives: The purpose of this paper was to report a qualitative interpretive description study focused on better understanding the concept of joy at the end of life from the perspective of adults with advanced cancer in hospice.

Description: In this paper I report the findings from a qualitative interpretive description study of joy in adults with advanced cancer in hospice.

Linkage: Paper 1 provided an evolutionary definition of the concept of joy from the literature, and paper 2 provided a description of the sociocultural context in which joy may develop in hospice. Paper 3 focused on use of data (in this case transcripts) in ID. Paper 4 further explores the concept of joy from the perspective of adults with advanced cancer in hospice with the aim to translate the derived knowledge into clinical nursing practice.

Summary of the Dissertation

To respond to a silent discourse of joy in palliative care, in this dissertation I forefront the experiences of joy from the perspective of adults with life-limiting illness in hospice to offer an alternative view of living with life-limiting illness. This alternative view can then help to shape new understandings so that practising nurses can see a wider range of possibilities for hospice care and provide better care for patients at or near the end of life.

The four distinct but related papers that comprise this dissertation focus on joy in the context of its development in contemporary western society. In Chapter 6, I will describe general conclusions that are supported by the findings of my dissertation as a whole and implications of my findings for future research, policy, and nursing practice.

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Chapter 2 – Paper 1: Joy and Happiness: A Simultaneous and Evolutionary Concept Analysis

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A version of this chapter was published as:

Cottrell, L. (2016). Joy and happiness: A simultaneous and evolutionary concept analysis. *Journal of Advanced Nursing, 72*(7), 1506-1517.

Chapter 2: Paper 1: Joy and happiness: A simultaneous and evolutionary concept analysis

Happiness and joy are deeply desired, yet elusive, concepts. Happiness may be considered "the ultimate aim of human beings" (Abdel-Khalek, 2005, p. 949) and is ardently pursued, yet poorly understood. Joy, though often used as a synonym for happiness, is less evident in popular discourse, but equally misunderstood. Both happiness and joy are universal human experiences, relevant cross-culturally and internationally. Yet neither happiness nor joy is evident in the nursing literature, which is striking as they represent a significant portion of human experience. As nursing involves caring for individuals as they experience all facets of the human condition (Meleis, 2012), an exploration of positive concepts, such as joy and happiness, is needed to determine their use in the discipline of nursing.

In the extant nursing literature, the concepts of joy and happiness have received little research attention, and neither concept has been defined or analyzed. Bekhet *et al.*'s (2008) work provides a partial concept analysis of happiness, though it is not identified as a concept analysis. Parse (1996) examined a related concept, the paradoxical rhythm of "joy-sorrow", through her humanbecoming theory. Parse (1996) defined joy-sorrow as an oscillating pattern through which individuals simultaneously experience exaltation and despair, though Parse did not define joy as a concept separate from sorrow. Parse's work generated two further discussion articles on joy-sorrow (see Bunkers 2006 and Pilkington 2006), as well as three case study articles (see Baumann & Braddick 1999; Cintra Estrada Ferrando *et al.* 2012; & Pilkington & Lee, 1999). None of these authors provide a conceptual definition of joy.

Joy has been explored, though not defined, in three other studies in nursing: Magill (2009) studied joy in caregivers of advanced cancer patients during music therapy sessions prior to death; Banos *et al.* (2013) explored the induction of joy through virtual reality in patients with advanced cancer; and Linge (2011) studied joy in hospitalized children with advanced cancer.

Recently, Koffman *et al.* (2013) studied the meanings of happiness and its links to quality of life in individuals living with advanced cancer. Although the authors did not define happiness, they reported that "happiness is an important yet complex multidimensional human experience, which at times is culturally shaped" (p. 1102).

Outside of nursing, the concept of long-term happiness has received considerable research attention, particularly in psychology, though joy has received less research attention. Three main concepts are relevant to the concepts of joy and happiness: Maslow's (1964) peak experiences, Csikszentmihalyi's (1990) concept of flow, and the concept of post-traumatic growth (PTG). Maslow's (1964) concept of the peak experience parallels joy (Close, 1981). Peak experiences are brief, profound and involuntary moments of intense, illuminating, and transcending happiness, through which individuals "have a clear perception . . . that the universe is all of a piece and that one has his place in it" (Maslow,1964, p. 59). Csikszentmihalyi's (1990) concept of flow, the "optimal experience" (p. 3) during which individuals experience exhilaration, enjoyment, and engagement with life is perhaps the culmination of happiness. Like happiness, flow is actively pursued and predicated on participation, self-control, and choice (Csikszentmihalyi, 1990). PTG involves the positive changes that occur following a traumatic event (Mystakidou *et al.,* 2007) and may be related to both happiness and joy. Unlike joy and happiness, however, PTG requires a traumatic event to inspire a cascade of changes including altered priorities, a greater appreciation of life and its possibilities, a greater sense of personal strength, improved relationships with others, and enhanced spirituality (Tang *et al.,* 2015). The positive psychology movement continues to study and refine the concepts of flow, peak experiences, and post-traumatic growth, exploring their links to health and well-being.

Background

The trend in psychology to explore the positive aspects of life, health, and illness (Cooper, 2007; Csikszentmihalyi, 2009; Paquette, 2006) has important implications for nursing knowledge development. Nursing and other health disciplines have been criticized for their focus on problems, deficits, and other negative aspects of the health-illness experience (Cooper, 2007; Csikszentmihalyi & Hunter, 2003; Paguette, 2006; Sunderland *et al.*, 2008). This focus on negative concepts in nursing presents an unbalanced view; it privileges negative concepts, focusing on deficits, while marginalizing positive concepts like joy and happiness. This negative focus shapes the nursing discourse, which insidiously shapes our perception of the nursing world, and creates a certain way to conceptualize nursing, while excluding other possibilities (Cheek, 2004). This discourse thus limits not only the repertoire of the practising nurse, but also the experiential possibilities of individuals who come into contact with nurses. Promoting the exploration of positive concepts, then, may provide possibilities to reframe and rebalance the nursing discourse in a more positive way and shape a view of the nursing world in which focusing on strengths rather than deficits becomes possible.

As neither joy nor happiness is evident in the nursing literature, scientifically, they are immature concepts (Morse *et al.*, 1996). Yet both are well-established colloquial concepts, therefore their evolution into disciplinary or scientific use must begin with an exploration of their colloquial use. Concept analysis is the process through which colloquial concepts can be explored and evaluated for their potential contribution to knowledge development in nursing. This concept analysis is a combination of Rodgers' (2000) evolutionary model and Haase *et al.*'s

(2000) simultaneous concept analysis (SCA) method. From Rodgers (2000), the author examines the concepts of joy and happiness by identifying their attributes, antecedents, related terms, and outcomes. From Haase *et al.*'s (2000) simultaneous concept analysis method, the author identifies differences and similarities between the two concepts, creates process models for each individual concept, and a validity matrix to compare and contrast the two concepts. Exploring joy and happiness together helps to underscore their similarities and differences, and may help to determine which concept may be most useful or beneficial in various nursing contexts.

The concept analysis process is not linear, as it is described here, but iterative and simultaneous. Throughout the process, the author revisited previous decisions and understandings, modifying and making alterations along the way. This non-linear process is supported by Rodgers and Knafl (2000) and Haase *et al.* (2000).

The aim of this paper is to clarify and analyse the concepts of joy and happiness through adapting and blending Haase *et al.*'s (2000) SCA process with Rodgers' (2000) evolutionary method. The aim is not to provide a finished or absolute definition of the concepts of joy and happiness, but to promote clarity for further exploration, description, and inquiry of the concepts as they continue to evolve in nursing (Rodgers, 2000).

Data Sources

Using the search terms "(joy or happiness)" the following databases were searched: Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, Academic Search Complete, ATLA Religious Database with ATLASerials; Humanities International Complete; Psych EXTRA; SocINDEX with Full Text; and Philosopher's Index. Exclusion criteria were book reviews, letters to the editor, and articles that did not discuss joy or happiness directly, as well as those that tested tools (such as the Oxford Happiness Inventory). Inclusion criteria were peer-reviewed academic articles written in English that discussed joy or happiness directly, including those that provided oblique definitions, antecedents, or attributes of either concept. Editorials, articles, and reports of qualitative or quantitative studies were included, in keeping with the integrative nature of an initial scoping search (Haase *et al.,* 2000). The search was not limited by time, hoping to get a sense of the evolution of both concepts over a broad time span.

The initial search retrieved a total of 4819 articles. After scanning titles and abstracts, deleting duplicates and articles not available electronically, 1163 articles were saved. These articles were re-examined either scanning or reading the full text, and a further 1092 articles were discarded. The final sample consists of 61 articles and one book, published between 1978 and 2014.

Disciplines included in this SCA are: nursing, including psychiatric nursing (9 articles); psychology (24); English literature (4 articles and 1 book;); medicine (3: neurology, psychiatry, and gerontology); education (1); theology or religious studies [8 articles total: Christianity (5); Judaism (2); Buddhism (1)]; marketing or economics (5); philosophy (3); sociology (3); and history (1).

Data Analysis and Rigour

The data analysis process involved a combination of Rodgers' (2000) method and Kikuchi's (1997) philosophical analysis. As Rodgers' (2000) method stipulates, the aim in data analysis is not to complete a finished definition, but to provide a beginning point for continued conceptual exploration in the discipline of nursing. Attributes, antecedents, and outcomes of joy and happiness were extracted from salient full text articles, and compared between and across disciplines before creating a validity matrix to compare joy and happiness.

Kikuchi's (1997) philosophical analysis involves "armchair thinking" (p. 100), which consists of reflecting on and analyzing concepts in light of common knowledge. This method of analysis is philosophical rather than scientific (Kikuchi, 1997) and is best suited to colloquial concepts: joy and happiness are not directly observable, scientific concepts, therefore to analyze them through traditional scientific methods would be inappropriate. Philosophical analysis does not, however, mean that the process is not rigorous; it simply approaches knowledge acquisition from a different perspective than scientific observation (Kikuchi, 1997). Rigour in philosophical inquiry is ascertained logically against a background of common human experience (Kikuchi, 1997) and is, like nursing itself, partly an art (Carper, 1978; Sandelowski, 1993). Rather than focusing on narrow criteria to ascertain rigor, this method provides a broader approach to rigour based on creativity and intellectual understanding (Sandelowski, 1993; Schwandt, 1996) and is congruent with the ontological underpinnings of this concept analysis.

Results

Joy

Clarifying the attributes of joy. The most significant attributes, or characteristics, of joy concern its temporal nature, intention, awareness, personal orientation, and physical characteristics (Table 2.1).

Temporality. Joy is sudden, brief, and transient (Close, 1981; Potkay, 2007). Its occurrence is not confined to a particular age group, though it is mentioned in relation to childhood (Akhtar, 2010; Daniels, 2010). Although children may express joy more regularly and exuberantly than adults, individuals of all ages can experience joy (Akhtar, 2010; Daniels, 2010).

Intention. Joy is spontaneous and involuntary. Joy is neither sought nor pursued (Close, 1981, Dennis, 2010; Howard, 2004,); it simply arrives, unsummoned, like an epiphany. Joy is also expressed as a gift (Dennis, 2010; Potkay, 2006,), and, in religious studies literature, a gift from God (Gordon, 2001; Griffin, 1986; Howard, 2004; Potkay, 2007).

Awareness. Awareness is a key attribute of joy; joy is a sense of sudden insight, inspiration, and a returning to oneself after a brief departure (Colebrook, 2007/08; Dennis, 2010; Gordon, 2001; Parse, 1997; Wilson & Spencer 1990). This awareness is frequently associated with a sense of vitality (Colebrook, 2007/08; Lee & Lang, 2009; Linge, 2011; McEntee *et al.*, 2013) or an expansive transformation of self (Barbalet, 2005; McEntee *et al.*, 2013).

Connection. Connection is an important aspect of joy, in particular a connection not to the individual, but to reunion and to the collective. Joy involves a momentary loss of self (Bonic 2010; Colebrook, 2007/08; Dennis, 2010; Potkay, 2007) that gives way to a larger power, be it spiritual, natural, or simply a moment of deep illumination and significance. This loss is marked by the flooding return of a newly transformed self, hence joy's association with rebirth and reunion (Adair, 2013; Barbalet, 2005; Close, 1981; Colebrook, 2007/08; Dennis, 2010; Parse, 1997; Potkay, 2007). This reunion of the self makes possible the reunion with others (Akhtar, 2010; Colebrook 2007/08; Dennis, 2010; McEntee *et al.*, 2013; Parse, 1997), thus joy implies connection. Joy is outwardly focused and concerned with the collective notion of "we" or "us" rather than "I" (, Colebrook, 2007/08; McEntee *et al.*, 2013; Potkay, 2007).

Physical attributes. Joy has physical attributes and can be observed physically by "the smile of the eyes" (Sirvyde, 2009, p. 120), which involves the involuntary contraction of the orbicularis oculi muscle (Sirvyde, 2009). It is associated with physical movements such as dancing, clapping, or laughing (Lee & Lang, 2009; Potkay, 2007) and with tears (Barbalet, 2005;

Lee & Lang, 2009; Potkay, 2007; Sirvyde, 2009). Interestingly, joy is rarely associated with smiling, though it may be linked to an increased release of endorphins (Tse *et al.*, 2010).

Overall, the key attributes of joy describe a positive concept that consists of an intense, sudden and transient loss of self, followed by a deep connection to nature, God, and/or others, which is involuntary, provides insight, and has associated physical characteristics.

Clarifying the antecedents of joy. Antecedents are those things that precede an instance of a concept (Cowles & Rodgers, 2000) and make its existence possible. Antecedents to joy are problematic because joy is capricious; its antecedents, too, can be unpredictable, though the general consensus in the literature included personality traits and links to childhood or memory.

Personality characteristics, such as optimism and extraversion (Csikszentmihalyi & Hunter, 2003), were seen as antecedents of joy. Spirituality (McEntee *et al.*, 2013), a relationship with nature (Griffin, 1986; Potkay 2007; Tolor, 1978) and, in religious literature, a close relationship with God (Charry, 2004; Gordon, 2001; Griffin, 1986; Howard, 2004; Makant 2010) were also presented as antecedents to joy.

The notion of childhood as an antecedent to joy involves innocence (Daniels, 2011; Potkay, 2007,) and openness to the possibility of joy that childhood may bring (Akhtar, 2010; Close, 1981; Csikszentmihalyi & Hunter, 2003; Griffin 1986). In adults, this notion of childhood as an antecedent is described as the reawakening of the inner child (Daniels, 2011).

Memory is another antecedent to joy, though consensus in the literature was not absolute; for some authors, joy did not include a link to memory or nostalgia. Perhaps the antecedent of memory applies only to a certain type of nostalgic joy, which is a prominent feature in English Romantic poetry (Potkay, 2007). Research shows, however, that emotions are physiologically linked to memory (Allmark, 2011; Shanbhogue & Shanbhogue, 2008), which may help to explain the nostalgic longing of joy when associated with memory (Howard, 2004; Zywczok, 2011). Joy's association with nostalgia recalls its proximity to its structural opposite, sorrow, which Parse (1997) explores through the concept of joy-sorrow.

Outcomes of joy. Freedom (Adair, 2013; Colebrook, 2007/08; Dennis, 2010; Lee & Lang, 2009; Linge, 2011) and connection with others (Close, 1981; Linge, 2011; McEntee *et al.* 2013; Potkay, 2007; Rivera *et al.,* 1989), with nature (Griffin, 1986; Potkay, 2007; Tolor, 1978), and with the universe (Griffin, 1986) are significant outcomes of joy. In (Christian) religion, joy is associated with a deep yet brief connection with God (Charry, 2004; Gordon, 2001; Griffin, 1986; Howard, 2004; Makant, 2010). Joy may create the possibility for hope (Close, 1981), sympathy (Dennis, 2010) and, by extension, empathy. In addition, episodes of joy may be beneficial and provide potential for the development of happiness and resilience (Close, 1981; Howard, 2004). The links between joy and health have not been fully empirically explored, though recent authors have reported that joy created a "feeling of freedom" (Linge, 2011, p. 7) as well as self-renewal and meaning through transcendence (Magill, 2009) in studies of patients with advanced cancer. The relationship between joy and health requires further inquiry.

Happiness

Analysis of the literature led to the discovery of two types of happiness: short term and long term. This notion of two types of happiness is not new; Aristotle postulated that happiness was comprised of two elements: *hedonia*, or pleasure, and *eudaimonia*, or a sense of meaning (Wolf *et al*., 2005) or overall well being (Svensson, 2011). Long-term happiness, which is closer to Aristotle's *eudamonia*, was explored more frequently in the literature and is the focus of this concept analysis and the comparison with joy. Following a brief explanation of short-term happiness, the remaining discussion regarding happiness will refer to long-term happiness, unless otherwise indicated.

Short-term happiness is closest to Aristotle's *hedonia*. The etymology of "happiness" may add credence to this position, as the root of happiness is "happ", or "chance" (Allmark, 2011). Chance applies only to short-term happiness; long-term happiness is viewed as a choice rather than simply a reaction to circumstances. In terms of attributes, short-term happiness involves good fortune and is expressed through delight and pleasure (Potkay, 2011; Sloan, 2011). In duration, short-term happiness is related to joy: both are brief, though joy is more intense than short-term happiness. Antecedents for short-term happiness are not specified, but may be broad and diverse.

Short-term and long-term happiness have a complex relationship and are undoubtedly interdependent; Veenhoven (2003), for example, wrote that short-term happiness may negatively affect eudaimonia, as hedonism erodes social bonds and may lead to laziness or addictive behaviors. At the same time, Veenhoven (2003) notes that hedonism may contribute to long-term happiness by preserving health through stress reduction. These differences between short and long-term happiness underscore the need for conceptual clarity and clear terminology within and between disciplines.

Clarifying the attributes of (long-term) happiness. Attributes of happiness are its temporal nature, intention, relationship to virtue, personal contentment, satisfaction and its associated physical characteristics (Table 2.2).

Temporality. Happiness is long lasting. It is characteristically stable, featuring attributes such as constancy and steadiness (Colebrook, 2007/08; Bekhet *et al.*, 2008; Lu, 1999; Martinez & Scott, 2014).

Intention. Happiness is deliberately induced; that is, one *chooses* happiness (Abdel-Khalek, 2005; Barker & Martin, 2011; Bekhet *et al.,* 2008, Delle Fave *et al.,* 2011; Fishman & McCarthy, 2013; Gouthro, 2010, Potkay, 2006). As happiness is a choice, it is connected to (self) control (Csikszentmihalyi & Hunter, 2003; Potkay, 2006). Happiness has also been linked to overall satisfaction or well-being and a life filled with meaning (Bailey & Fernando, 2012; Colebrook 2007/08, Demir *et al*., 2013; Feldman, 2008; McEntee *et al*., 2013; Martinez & Scott, 2014; Veenhoven, 2003).

Personal orientation. Happiness is focused on the individual and on finding one's true self (Baumeister *et al*., 2013; Colebrook, 2007/08; Dierendonck & Mohan, 2006). The choices an individual makes with respect to enduring happiness are geared toward personal gratification (Colebrook, 2007/08; Dennis, 2010); as such, happiness "goes with being a taker more than a giver" (Baumeister *et al,*. 2013 p. 514).

Virtue. Personal choice and control link happiness to virtue (Ahmed, 2010; Barker & Martin, 2011; Charry, 2004; Dierendonck & Mohan, 2006; Feldman, 2008; Gordon, 2001;,; Makant, 2010; Potkay, 2011; Scoffham & Barnes, 2011; Waterman, 2008) another important attribute of happiness. In fact, much of the literature supports the notion that true happiness is inseparable from ethics (Potkay, 2011) or from God (Charry, 2004; Makant, 2010). The ethical component of long-term happiness lends an evaluative aspect to the concept; linked to virtue, happiness is thus judged as good (Feldman, 2008).

The connection between happiness and ethics originated with Epicurus and the Stoics, who believed that virtue is sufficient for happiness, even in the face of apparent misfortune (Allmark, 2011; Potkay, 2011), though the relationship between adverse experiences and long-term happiness is complex. Much of the literature supports the notion that happiness, like *eudaimonia*, can flourish despite adverse experiences, based on the attitude of the individual and the choices they make (Allmark, 2011; Colebrook, 2007/08; Csikszentmihalyi & Hunter, 2003; Dennis, 2010; Scoffham & Barnes, 2011). As such, happiness can exist amidst poverty, disease, hunger, depravation and oppression (Klepfisz, 1986; Potkay, 2011). Bekhet *et al.* (2008), however, discussed the influence of pain or negative feelings (particularly depression and anxiety) on happiness, and postulated that an indirect relationship exists between these variables and happiness. They did not, however, clearly distinguish between short and long-term happiness, and the main thrust in the literature is that long-term happiness is unaffected by adversity. Acute pain and other adverse experiences may affect short-term happiness.

Materialism. Although it is not mentioned in Table 2, materialism has a complex and evolving relationship with happiness. Attaining goods is promoted as a way to achieve happiness in American popular culture (Aaker *et al.,* 2011; Potkay, 2011), but the antisocial aspects implicit in materialism may harm individuals (Bhattacharjee & Mogilner, 2014). In fact, overconsumption is seen as "a symptom of unhappiness" (Pace, 2013, p. 29) and may affect the future of long-term happiness as it erodes the relationship between happiness and virtue (Aaker *et al.,* 2011; Bergsma & Ardelt, 2012; Potkay, 2011).

Physical attributes. The physical attributes of happiness include both voluntary and involuntary muscles. Happiness is frequently expressed outwardly by smiling; movement of the lips is voluntarily controlled by the zygomaticus major muscle (Sirvyde, 2009). This voluntary contraction underscores the relationship between happiness and volition, and also speaks to the notion that individuals can feign artificial happiness. True or genuine happiness is also expressed by the eyes, through the involuntary contraction of the orbicularis oculi muscle

(Sirvyde, 2009). Short-term happiness is associated with the release of endorphins, though long-term happiness is not (Tse *et al.*, 2010).

In summary, the attributes of happiness describe a stable, long-term mental state, which is characterized by satisfaction with oneself and ones' life. It is actively pursued and requires virtue and self-control. Some scholars have suggested the term "flourishing" to denote long-term happiness (Allmark, 2011; Barker & Martin, 2011; McEntee *et al.,* 2013; Murphy 2004; Potkay 2011; Scoffham & Barnes, 2011), which may be a more direct translation of *eudaimonia* (Allmark, 2011).

Clarifying the antecedents of happiness. Personality characteristics, such as optimism, extraversion, and self-esteem are linked to happiness (Bailey & Fernando, 2012; Csikszentmihalyi & Hunter, 2003; Lu, 1999). Future time perspective is linked to happiness as it refers to the way in which an individual sees their life-path and plans to make choices for a happy, virtuous life (Csikszentmihalyi & Hunter, 2003).

Maternal authoritativeness in the form of boundary setting was also mentioned in the literature, as having firm boundaries can help to build self-esteem and the confidence required to make wise choices (Aksan & Kochanska, 2004). Positive social relationships may be linked to the development of happiness (Barker & Martin, 2011; Bailey & Fernando, 2012; Delle Fave *et al.,* 2011) as they promote hedonic networks in the brain (Kringelbach & Berridge, 2010).

A subjective view of good health may be an antecedent to happiness (Bekhet *et al.,* 2008; Csikszentmihalyi & Hunter, 2003), though this finding was inconclusive. Several authors, for example, discussed the possibility of happiness despite ill health and other adverse events, as discussed above (Allmark, 2011; Colebrook, 2007/08; Csikszentmihalyi & Hunter, 2003; Dennis, 2010).

In a 2011 study, Barker and Martin (2011) found that wealth, education, climate, race, and gender did not have a significant effect on the development of long-term happiness. Findings were mixed in terms of the effect of culture on happiness: two studies found happiness to be similar cross-culturally (Barker & Martin, 2011; Lu, 1999), whereas others discussed how cultural shifts over time may affect how happiness is understood in various contexts and at different times (Aaker *et al.,* 2011; Duncan, 2007; Stearns, 2012).

Outcomes of happiness. Several authors explore the links between happiness and health (Kubzansky *et al.,* 2001; Veenhoven, 2008) as well as improved quality of life (Csikszentmihalyi & Hunter, 2003; Koffman *et al*., 2013). Happiness is linked to a reduction in the incidence and severity of stress, cardiovascular and pulmonary disease, diabetes, hypertension, and the common cold (Kubzansky *et al.,* 2001; Veenhoven, 2008). Happiness is also viewed as protection from depression and angst (Bekhet *et al.,* 2008) yet, as Potkay (2011) suggests, the elusiveness of happiness may be a source of anxiety.

Comparison of Joy and Happiness

Discussion Of Validity Matrix

As shown in the validity matrix, joy and long-term happiness, while both positive concepts with similar personality characteristics, have significant differences. (Refer to Table 2.3).

Temporality. In terms of time, joy occurs across the lifespan, though may be expressed more readily in childhood (Akhtar, 2010; Dennis, 2010). Happiness tends to increase with age and may decrease during adolescence (Bhattacharjee & Mogilner, 2014; Csikszentmihalyi & Hunter, 2003). Duration is another important difference: joy is short, sudden, and transient

(Close, 1981; Potkay, 2007) whereas happiness is long-lasting and stable (Bekhet *et al.* 2008; Colebrook, 2007/08; Lu, 1999; Martinez & Scott, 2014).

Intention and personal orientation. In terms of intention, one does not seek joy; it comes as a sudden gift, but happiness is actively pursued. Happiness is a process, whereas joy is a sudden event. Moments of joy can be contained in happiness (Potkay, 2007), but happiness is not necessarily a component of joy.

Personal orientation is also significant, as joy marks a departure of the self toward reunion with others or a deep connection to God, nature, or the universe. Happiness, on the other hand, is focused on the self and on living in a way that leads to personal gains or satisfaction (Ahmed, 2010; Barker & Martin, 2011; Charry, 2004; Colebrook, 2007/08; Dierendonck & Mohan, 2006; Feldman, 2008; Gordon, 2001; Makant, 2010; Potkay, 2011; Scoffham & Barnes, 2011; Waterman, 2008).

Happiness is a chosen, virtuous life, whereas joy is a spontaneous moment of freedom from structure and order (Close, 1981; Colebrook, 2007/08; Potkay, 2007). Yet meaning and spirituality may be found in moments of joy, by revealing deep interpersonal or universal connections (Close, 1981). Joy is about freedom and a loss of control; happiness is about constancy, steadiness, and being in control (Griffin, 1986). Happiness is tied to ethics, virtue, and, consequently, to judgment, whereas joy is not value-laden (Feldman, 2008; Potkay, 2007), although joy in the sense of a connection with God may be seen as virtuous. This evaluative component may be culturally dependent; more research is needed to understand the relationship between happiness, joy, and judgment in various cultural contexts.

Physical manifestations. Happiness and joy have both similar and different physical manifestations: happiness is manifested by both voluntary and involuntary muscle contraction, whereas the muscles associated with joy are involuntary (Sirveyde, 2009). Happiness is expressed by smiling (Sirveyde, 2009); joy, by weeping (Barbalet, 2005). Whereas joy may be associated with endorphin release, long-term happiness is not (Tse *et al.,* 2010).

Relationship to health. Joy may be related to building resilience and hope (Close, 1981; Zywczok, 2011), though its relationship to health has not been fully empirically explored. Happiness has received more research attention, particularly in relation to quality of life (Csikszentmihalyi & Hunter, 2003; Koffman *et al*., 2013), and direct links between happiness and health have been reported (Kubzansky *et al.,* 2008).

Connection with others, nature, or God may be the most significant attribute of joy, along with awareness or insight and freedom. For happiness, the key attributes are flourishing, virtue, and satisfaction. Rather than being virtual synonyms, this analysis proposes that joy and happiness are, in fact, vastly different.

Discussion

These conceptual clarifications are descriptive theories and provide the foundation for further exploration in nursing research (Meleis, 2012). As concepts are dynamic (Rodgers, 2000) and derive meaning from the contexts or theories in which they are used (Paley, 1996), both joy and happiness will require continual clarification, depending on their use. The absence of joy and happiness in the nursing literature has direct implications for nursing research, education, and practice. The absence of joy and happiness in the nursing discourse speaks to values and to what is seen as valuable: if joy and happiness are silent in the nursing discourse they do not exist in the nursing lexicon, thus the nursing repertoire is strictly curtailed. Nursing attitudes, actions, and practices are constrained by this discourse, and practicing nurses are limited in their ability to bring joy or happiness to individuals. To be useful in nursing, the concepts of joy and happiness must be made explicit, valued. They must be discussed, explored, studied. Opportunities for further inquiry include, but are not limited to: fieldwork, such as qualitative studies to explore joy and happiness in patients in a variety of nursing contexts and across the lifespan, examinations of joy and happiness in related theories, such as self- or gero-transcendence or other aging theories, explorations of happiness and joy among diverse cultures, and studies to explore further the links between joy, happiness, and health. Studies that explore the importance of joy and happiness from patient and/or family perspectives are urgently needed. Joy and happiness have applicability across the lifespan, and nursing interventions aimed at encouraging the development of joy and happiness may improve mental, spiritual, and physical health. Although their direct application to nursing practice requires further exploration, happiness and joy may be beneficial for nursing practice in a variety of contexts, and may become increasingly salient as the population ages. Joy and happiness may be most beneficial to the palliative and end of life care context, as well as in the treatment of Alzheimer's and other dementias, in which moments of joy may improve the quality of life for patients and their families.

Limitations

This SCA was hampered by several limitations. As Haase *et al.* (2000) suggest, a lack of group process and expertise may have compromised the findings. A librarian may have completed a more purposeful search, possibly resulting in more rigorous, credible results (Rodgers, 2000). As a student, the author was unable to acquire the direct services of a librarian, though did consult with a health services librarian prior to commencing the initial search.

Conclusion

This analysis establishes a foundation for continued conceptual clarity and further research into happiness and joy. Joy and happiness are significant to all human experience and may have important consequences for health across the lifespan. Exploring and building nursing knowledge to enhance positive aspects of human life is a critical issue for nursing research. It may help to balance the current discourse, which is focused on mitigating negative concepts rather than on promoting positive ones. I encourage nurse scholars in all areas of practice and theory development to explore further the place of these positive concepts in the nursing discipline, the importance of happiness and joy to nursing practice and, ultimately, to the patients for whom we care. Only by examining and incorporating positive concepts into nursing science can we work to create a nursing discourse in which joy and happiness are possible.

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Table 2.1: Process Model Joy

Antecedents	Related Concepts	Attributes	Outcomes
Childhood: • Innocence • Memory Personality Traits Spirituality	Happiness Hope Love Spirituality Delight Tenderness Gratitude Aesthetic experience Pleasure Satisfaction Peak experience Post-traumatic growth	Temporality: • Sudden • Transient Awareness: • Insight • Intense Connection: • We/Us • Union/Reunion Intention: • Involuntary Physical Characteristics: • Involuntary	Freedom Courage Openness Resilience Connection Meaning Activity Creativity Transcendence May build hope and resilience

Table 2.2: Process Model Happiness

Antecedents	Related Concepts	Attributes	Outcomes
Personality traits Firm boundaries Social relationships Health Future time perspective	Joy Well-being Contentment Pleasure Quality of life Satisfaction Success Cheerfulness Humor Flow Post-traumatic growth	Temporality: • Lasting • Stable Intention: • Choice • Voluntary • Virtue Connection: • Self • Me/I Physical Characteristics: • Voluntary and involuntary	Improved health perception Link to improved health Decreased stress Meaning Satisfaction

Table 2.3: Validity Matrix Joy and Happiness

Factor	Joy	Happiness
Personality Characteristics	Extraversion Optimism Curiosity	Extraversion Optimism Self-esteem
Time	Occurs at any age	Increases with age Decreases during adolescence
Duration	Short, sudden, transient	Long, stable
Intensity	High	Low
Intention	None	Pursued
Ethical Orientation	None	Virtuous
Evaluation	None	Implied judgment
Health	Health-determining factors may be outcome	Antecedent and outcome
Personal Orientation	Us/We	I/Me
Action	Spontaneous event	Process
Characteristics	Awareness/Insight Union/Reunion/Connection Freedom	Virtue/Self-control Satisfaction Flourishing

Chapter 3 – Paper 2: The "Good Death": An Integrative Literature Review

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A version of this chapter was published as:

Cottrell, L., & Duggleby, W. (2016). The "good death": An integrative literature review. *Palliative & Supportive Care, 14,* 686-712.

Introduction

Perceptions and social norms about death and dying change over time according to cultural values, beliefs, and attitudes (Aries, 1981; Kellehear, 2007). Though death itself may be a predominantly physical or biological event, both death and the process of dying are imbued with social, cultural, and political meanings. These meanings have shifted temporally in western societies; at various times we have feared, abhorred, denied, accepted, embraced, and, ultimately, managed death and dying (Aries, 1981; Kellehear, 2007; Zimmermann & Rodin, 2004; Zimmermann, 2007).

The notion of the “good death” is not new, but it has evolved over time. According to Kellehear (2007), dying in the Stone Age occurred after death, when family members prepared the body for its journey, providing tools or other important cultural artefacts (Kellehear, 2007). Dying was a natural part of life, a public activity embedded within the community. The development of agriculture, settlements, and, with them, infectious diseases and an awareness of impending death changed the process of dying. The dying process gradually came to precede physical death (Kellehear, 2007), as people had time to make some preparations for death, usually according to religious conventions. Dying was a public-private affair: it occurred in private homes, but the dying and their families were tended to by community members (Kellehear, 2007).

Gradually, however, death became increasingly private, increasingly managed (Kellehear, 2007; Madan, 1992). The “good death” came to be seen as the "well-managed death" (Kellehear, 2007, p. 147). Advances in medical science and technology, as well as improved hygiene and infection control (Kellehear, 2007) prolonged the dying process, allowing more time to prepare for death. Urbanization and, with it, secularization and the rising social value of autonomy changed the “good death”: death became hidden and increasingly professionalized, requiring the services of priests, doctors, and lawyers (Kellehear, 2007). Contemporary dying is characterized by professional intervention, particularly medical and technological. Modern deaths occur in institutions, many under the supervision of specialized palliative care teams.

The contemporary “good death”, what Seale (1998) termed "the 'revivalist' good death", arose as a backlash against this medicalized death and was spurred by the hospice movement (Gott, 2008; Seale, 1998; Walters, 2004). Though subtle variation exists, the western revivalist good death ideal is expressed throughout the literature as a peaceful and dignified death, free from pain and other distressing physical symptoms. Death is timely; it occurs in old age and follows a predictable course. It occurs at home, with the dying individual surrounded by family. The dying individual is aware of and accepts their impending death, has made appropriate legal and financial preparations, and, ideally, has planned their dying experience through an advance directive (Granda-Cameron & Houldin, 2012; Kehl, 2006). Although the notion of a “good death” is not new, there has been little or no discussion of the impact of this concept on the practice of health care providers and those they care for.

Death and dying are intertwined with sociocultural and political values and beliefs (Kellehear, 2007; van Brussel & Carpentier, 2012; Zimmermann & Rodin, 2004). These sociocultural and political values and beliefs create a discourse, in which a culturally-unique and often tacit set of attitudes and behaviors are implicitly or explicitly conveyed and maintained (Cheek, 2004). According to Cheek (2004), a discourse is a set of assumptions and social norms, which may be covert or assumed. From a Foucauldian perspective, discourses serve a purpose, which is usually related to power and its distribution in society (Cheek, 2004). The purpose of a discourse is to frame reality in a particular way: discourses "both enable and constrain the production of knowledge, in that they allow for certain ways of thinking about reality while excluding others" (Cheek, 2004, p. 1142.). By this definition, the “good death” is itself a discourse, which exists to create, to dictate, and to maintain social attitudes and behaviours surrounding death and dying. Thus it is important to explore this discourse as it will increase our understanding of its impact on persons who are dying and their family members.

The aim of this paper is to present the findings of an integrative literature review on the “good death” in contemporary western cultures. As a discourse is culturally unique, the exploration of the discourse on “good death” was limited to western cultures, as that is where the predominate literature is published in this area. The specific questions guiding this research are: how is death and dying shaped by the prevailing “good death” discourse? How does this influence the wider societal perception of death and dying, and, in turn, how do the wider societal discourses influence the care of persons who are dying? What are the implications of this socio-cultural perception for health care professionals and for dying individuals and their families?

Methods

An integrative review, which includes both experimental and non-experimental research, is most suited to a comprehensive exploration of a topic, as it promotes a wide database and seeks to uncover patterns or themes in the literature, rather than seeking to find one "right" answer (Gough, Thomas, & Oliver, 2012; Whittemore & Knafl, 2005). This relativist ontology shapes all aspects of this review process. The purpose of this type of review is to integrate diverse forms of knowledge about a particular phenomenon to reach new insights and conclusions, thus synthesizing and building knowledge (Whittemore & Knafl, 2005).

Specifically an integrative review was conducted to explore the concept of a “good death” within western cultures.

Literature Search

I conducted a literature search using the terms "good death" in the following databases: Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, PsychINFO, Academic Search Complete, and SOCIndex with full text. The search was not restricted by date, to get a sense of the evolution of the good death over time, but was restricted to academic, peer-reviewed journal articles written in English, focused on an adult population. I included studies and articles that discussed the “good death” explicitly or implicitly. I excluded articles that did not discuss the “good death” from a western perspective, those that focused on suicide, euthanasia, or assisted suicide, and those that tested tools to measure a “good death”.

The search retrieved a total of 716 articles; I deleted duplicates, book reviews, and articles not available electronically. After scanning abstracts and/or reading the full text of the article, I selected 35 articles for inclusion in this literature review. I obtained a further 4 articles by scanning the reference lists of the selected primary sources, for a total of 39 articles. Publication years for selected articles range from 1992-2014.

Qualitative studies, including media or discourse analyses, comprise the majority of the data, contributing 26 sources: 20 studies and 6 media or discourse analyses (66% total: 51% qualitative studies; 15% media/discourse analysis). Only 2 quantitative studies (5%) met the inclusion criteria. Ten sources (24%) are non-experimental or philosophical in nature; 2 (5%) are concept analyses.

The United States contributes the most sources, at 11 (28%), followed by the United Kingdom, (9 sources; 23%), Australia (8 sources; 20%), Canada (6 sources; 16%), and the Netherlands (2 sources; 5%). Belgium, Italy, and India each contributed one source (total 8%). Please see Table I for data extraction tables for the included articles.

Data Analysis

Qualitative data analysis is inductive, thus allowing findings to emerge from themes that appear in the literature, without the constraints imposed by structured methodologies (Thomas, 2006). Inductive data analysis aligns with the relativist underpinnings of this review.

Some structure is, of course, necessary to promote rigor and transparency, and to reduce the risk of bias. I combined Thomas' (2006) inductive approach with Whittemore and Knafl's (2005) data analysis method by organizing primary data sources into groups; themes were then analyzed within and between groups, using the constant comparison method to expose patterns, variations, and relationships in the reviewed literature (Whittemore & Knafl, 2005). Each article was divided into the following groups based on its primary source of information:

(Aa) Qualitative study; explored “good death” from dying participant's perspective (6);

(Ab) Qualitative study; explored “good death” from healthy participant's perspective (1);

(B) Qualitative study; explored “good death” from health professional's perspective (6);

(C) Qualitative study; explored “good death” from participant and professional perspectives (3);

(D) Qualitative study; explored “good death” in an institution (2);

(E) Media or discourse analysis (6);

(F) Quantitative studies (2);

(G) Non-experimental studies (10);

(H) Concept analysis (2).

Results

Four predominant themes were created from the review: (1) the "good death" as control; (2) the wrong "good death"; (3) the threatened "good death"; and (4) the denial of dying.

The "Good Death" as Control.

Control of death and of the process of dying emerged as the dominant theme in all the literature. It appeared in various ways, including controlling dying activities, controlling the timing and place of death, dying as form of social control, and control of unpleasant physical symptoms. For individuals at the end of life, controlling dying activities was the requirement to accept death, to make choices, and to plan and prepare for dying (Broom, 2012; Zimmermann, 2012). In the literature, this is framed implicitly, by calling an unplanned or unmanaged death a "bad" death (Seale, 2004, p. 967), or explicitly, by referring to a planned death as a "dignified" death, (Carr, 2003, p. 227; Madan, 1992, p. 431) and by urging dying individuals to get "everything in order" (Jacques & Hasselkus, 2004, p. 48).

The theme of control also manifested in the literature as controlling the place of death. The hospice ideology and, with it, the "good death", promotes the ideal of a home or "home-like" death (Borbasi *et al.*, 2005; Carr, 2003; Granda-Cameron & Houldin, 2012; Hart, Sainsbury, & Short, 1998; Ko *et al.*, 2013; Masson, 2002; Pierson, Curtis, & Patrick, 2002; Seale, 2004; Veillette, 2010; Wilson, 2009). In Wilson's (2009) study, displacement, or being moved to another community, was identified as a "bad" death: "participants made it abundantly clear that when a dying person was removed from his or her home community, it would result in a 'bad' death" (p. 28). In Seale's (2004) discourse analysis, "a death far from home is considered 'bad'" (p. 967) and in Carr's (2003) study, participants reported that "dying in a nursing home is 'bad'" (p. 217).

The “good death” as a form of social control was another manifestation of control in the reviewed literature. By providing a strong cultural script for the dying, as well as for those who care for the dying, the “good death” directed attitudes and behaviours and created a certain, socially-sanctioned way to die or to care for the dying (Broom & Cavenagh, 2010; Clarke, 2006; Goldsteen *et al*., 2006; Hart, Sainsbury, & Short, 1998; McNamara, Waddell, & Colvin, 2007; Seale, 2000, 2004; Semino, Demjen, & Koller, 2014; van Brussel & Carpentier, 2012; Watts, 2012; Zimmermann & Rodin, 2004; Zimmermann, 2007, 2012). For health care professionals, social control manifested in the literature as a requirement to internalize the “good death” ideology and act according to its ideals; indeed, implicit sanctions exist for alternative behaviours (Zimmermann, 2012). As Zimmermann (2012) reported: "health care workers appear to be caught in a disciplinary web, where acceptance is rewarded and resistance results in the label of 'denial'" (p. 223). In a hospice setting, the “good death” is an ideological model to which health care providers are expected to subscribe (Broom, 2012; Zimmermann, 2012). Within this model, a "bad" death is considered a "failure" (Broom, 2012; Carr, 2003; McNamara, Waddell, & Colvin, 1994), whereas a “good death” "validates [the nurse's] sense of self-worth and the system of values shared by hospice health professionals" (McNamara, Waddell, & Colvin, 1994, p. 231).

By subscribing to the “good death” agenda, health care professionals thus control the dying experience of individuals. Dying individuals may be pressured into behaving in a certain way, dying according to what the health care professionals consider to be a “good death”; as Walters (2004) wrote: "They like you to be quiet and grateful in hospices" (p. 406). Furthermore, in Steinhauser *et al*.'s (2000) study, participants commented that health care providers implied: "you're not dying the right way, because you're not dying the way we think you should" (p. 829). As Kaufman (2000) wrote: "Once patients and their families enter the medical world, . . . their actions are guided by the values and pervasive practices of that world" (p. 14). The “good death” was, in the literature reviewed, "an *agenda*" (Broom, 2012, p. 228; italics added).

Acceptance of death underlies this agenda; as such, the “good death” is predicated on acceptance of death and of the dying role by dying individuals, their families, and health care providers who care for the dying (Borbasi et al., 2005; Bratcher, 2010; Granda-Cameron, 2012; Hart, Sainsbury, & Short, 1998; 6; Kellehear, 2007; Ko *et al*., 2013; Pierson, Curtis, & Patrick 2002; Walters, 2004; Watts, 2012; Zimmermann, 2007; 2012). According to Zimmermann (2012), death "acceptance is a *facilitator* in the provision of end of life care" (p. 222; italics in original), as denial precludes the willingness or ability to prepare for death. The denial of death as an obstacle to a service such as palliative care tacitly ensured acceptance and acquiescence of the dying individual (Zimmermann, 2007). Denial of impending death is characterized as a "bad" death and signifies refusal to participate in the “good death” (Borbasi *et al*., 2005; Hart, Sainsbury, & Short, 1998; Zimmermann & Rodin, 2004; Zimmermann, 2007). As such, the “good death” discourse "blames the individual for the existence of denial" (Zimmermann & Rodin, 2004, p. 1777).

The Wrong “Good Death”

The wrong good death is the troubling sense that the “good death” ideal may not represent accurately what dying people consider a good death. Carr (2003), for example, explores the question "A good death for whom?", examining whether the “good death” discourse privileges the needs of the dying individual, his or her spouse, or the health care professional. The notion of the “good death” being "easier for the palliative care staff" (Zimmermann, 2012, p.

221; see also Bendle, 2001; Granda-Cameron, 2012; Hart, Sainsbury, & Short, 1998; Semino, Demjen, & Koller, 2014; Watts, 2012; Wilson, 2009) is a disturbing, yet repetitive, theme. Wilson (2009), for example, discovered that "overmedicating [occurs] to reduce demands on care staff" (p. 25), and Zimmermann (2012) reported that acceptance of death "facilitates care of the dying patient by the nursing staff" (p. 221).

In the literature, dying individuals' ideal deaths frequently did not match the “good death” ideal. In Hart, Sainsbury, and Short's (1998) study, for example, participants reported a "sense of impotence after succumbing" or agreeing to "submit" to the hospice ideal of a “good death”, in which patients are blamed for alternative views: "angry, non-accepting and non-compliant patients become deviants who are violating the established norm" (p. 69). Similarly, Gott (2008) reported that many heart failure patients want neither autonomy nor awareness of dying, both central “good death” ideals, and Goldsteen *et al*. (2006) as well as Zimmermann (2007) wrote of the disjuncture between the normative “good death” discourse and actual patient experiences.

The Threatened “Good Death”

The theme of the threatened “good death” has important implications for palliative and end of life care provision, as it underscores how social attitudes and demographics exert pressures that influence and shape the “good death” discourse and, ultimately, influence the delivery of care for the dying. The future of the “good death” is undeniably threatened by the changing trajectory of dying and demographic changes. For example, an unpredictable trajectory of dying was identified as perhaps the greatest threat to a “good death” (Kaufman, 2000; McNamara & Rosenwax, 2007; van Brussel & Carpentier, 2012; Walter, 2003). As the “good death” is predicated on the need for awareness of dying (Kellehear, 2007; Zimmermann, 2007, 2012), the unpredictable trajectory of chronic disease complicates the “good death” by making it difficult for dying individuals and health care practitioners to know when dying begins (Carr, 2003; Kellehear, 2007; Gott, 2008; Walter, 2003). Demographic changes also threaten the “good death”. Specifically, the growth of the aging population, increasing longevity of life, improved overall chronic disease management (Kellehear, 2007; McNamara & Rosenwax, 2007; van Brussel & Carpentier, 2012; Walter, 2003) and the projected increase in dementias (Carr, 2003; Kaufman, 2000; Kellehear, 2007) has resulted in a new challenge; that is "how to die well from slow, degenerative diseases of old age" (Walter, 2003, p. 219). Carr (2003) adds that: "Alzheimer's disease, delirium, or senile dementia may offer little hope of a 'good' death . . . as these illnesses may prevent the dying from establishing close and meaningful communication with loved ones and finding meaning in the dying process" (p. 227). The “good death” ideology arose from the hospice philosophy (Walters, 2004), and from oncology (Gott, 2008); death from cancers has a relatively predictable trajectory as well as predictable symptoms, which simplified the “good death” process (Gott, 2008). Though still prominent, cancer deaths are being overtaken by the slow, protracted deaths that characterize chronic illness (McNamara & Rosenwax, 2007) and with them, diverse physical symptoms. Pain, for example, once the most prevalent and "most feared" physical symptom of dying, may no longer be as significant during dying as other symptoms, particularly breathlessness (Gott, 2008, p. 1117). This will necessitate changes to the provision of care for the dying.

The Denial of Dying

As dying becomes increasingly uncertain, the revivalist “good death” is giving way to a postmodern discourse of death, characterized by fragmentation and, ultimately, by "existential uncertainty" (McNamara, 2004, p. 936). This uncertainty culminates in the theme of the denial of dying, in which the dominant discourse abandons the dying process altogether, rendering it absent, invisible through euthanasia or assisted suicide or death. For example, Pierson, Curtis, and Patrick (2002) reported that "many patients requested physician-assisted suicide" (p. 592), and Wilson (2009) wrote that participants "wanted to talk of euthanasia (referred to by one interviewee as a 'beautiful option') . . . as a way to maintain . . . control over their fate" (p. 24, 25). This need to control the timing of death (Broom, 2012; Clarke, 2006; Pierson, Curtis, & Patrick, 2002; van Brussel & Carpentier, 2012; Walters, 2004; Wilson, 2009) may indicate a significant shift within the prevailing discourse, one in which death is openly accepted--even "fashionable" (McNamara, Waddell, & Colvin, 1994, p. 1501)--but one in which the dying process is denied. Kaufman (2000) writes that the dying process is ignored in contemporary deaths: "medicine generally doesn't allow for a transition, a process, or a passage between life and death except in the most perfunctory way" (p. 17).

This theme was most explicitly addressed in the discourse or media analysis literature, illustrating the interplay between contemporary attitudes to death and dying and prominent social values, such as the right to die movement, and underscoring the dynamic nature of discourse (Clarke, 2006; Frith, 2013; van Brussel & Carpentier, 2012). That is, prominent social values are perpetuated by media and percolate throughout society, gradually changing attitudes and altering practices (Clarke, 2006; van Brussel & Carpentier, 2012). The discourse of death and dying is no exception; according to van Brussel and Carpentier (2012), "the media privilege the right to die discourse" (p. 496). Similarly, Clarke (2006), wrote that the media focus is on "those who choose to die; it is on their desire to and the means by which they'll die" (p. 163). In this discourse, then, death itself is openly discussed; it is "not random, unwelcome, or to be feared" (Clarke, 2006, p. 162), but the dying process is unmistakably missing: "there are no stories of the self-reflexive or ‘good' death, of death occurring 'naturally'. Death in communities and families is virtually absent; . . . the hospice movement and other social trends are ignored" (Clarke, 2006, p. 163). Thus the media present a portrait of an ideal death as a highly planned and tightly-controlled event that occurs swiftly and, significantly, without a dying process.

Cultural Influences on a "Good Death"

The theme of culture demands attention because although it was not a predominant theme across the literature, it did appear in data subsets and may, therefore, be a significant motif of the "good death" in some contexts. In rural areas, for example, culture was identified as a strong factor shaping the "good death". Rurality influenced death and dying experiences for both dying individuals and health care professionals; it was viewed as a "powerful cultural force" (Wilson, 2009, p. 28) that contributed a unique perspective to death and dying. Connectedness to family and, particularly, to home, including the rural community, were identified as important features of dying in rural areas, so much so that rural residents would make considerable sacrifices in their care to prevent travelling outside of their home or community (Wilson, 2009; Veillette, 2010).

For health care professionals, professional cultures influenced the "good death"; health care professionals' role designations shaped their perception of what is important during the dying process. Nurses, for example, reported regret (DeJong & Clarke, 2009) when unable to provide a "good death" for a patient, whereas physicians reported relationship conflict or "patients who don't accept the care" (DeJong & Clarke, 2009, p. 63) as factors that promote a "bad" death. A study by Steinhauser, Clipp, McNeilly, Christakos, McIntyre, and Tulsky (2000), reported that physicians' discussions of the "good death" differed significantly from other health professionals'; physicians voiced the most biomedical perspective on death and dying, whereas occupational therapists may view the "good death" as occupation, or the ability to *do* (Jacques &

Hasselkus, 2004; italics added). These differences underscore the idea that perspectives of the "good death" are socially and culturally enforced, as health care providers are each socialized into unique cultures within their profession. Two studies reported that professional roles shaped practitioners' views more significantly than sex or ethnic differences (DeJong & Clarke, 2009; Steinhauser *et al.*, 2000).

Discussion

Overall, the literature reviewed presented the idea that the revivalist "good death" discourse may not accurately reflect the realities of the dying process as it occurs or is enacted in practice, as evidenced in the four predominant themes (1) the "good death" as control; (2) the wrong "good death"; (3) the threatened "good death"; and (4) the denial of dying.

The literature reviewed portrays a picture of death and, in particular, the dying process, which is far from good. The "good death" is presented negatively as a mode for controlling the dying process for both dying individuals and those who provide their end of life care (Bendle, 2001; Granda-Cameron, 2012; Hart, Sainsbury, & Short, 1998; Semino, Demjen, & Koller, 2014; Watts, 2012; Zimmermann, 2007, 2012). Often, the literature revealed that this "good death" agenda is incongruent with dying individual's desires (Hart, Sainsbury, & Short, 1998; Goldsteen *et al.*, 2006; Gott, 2008, Zimmermann, 2007) and may, in fact, be designed to ease the care demands for health professionals (Wilson, 2009; Zimmermann, 2012). The revivalist "good death" is currently unsettled, threatened, and perhaps outgrown by an aging population, unpredictable illness trajectories (Kaufman, 2000; McNamara & Rosenwax, 2007; van Brussel & Carpentier, 2012; Walter, 2003), and diseases that prevent awareness and death acceptance (Carr, 2003; Gott, 2008; Walter, 2003), in a social context that privileges neoliberal values (Raphael, 2007, Zimmermann, 2012). This may represent a cultural shift away from the revivalist "good death" towards a postmodern death characterized by fragmentation (McNamara, 2004) and, ultimately, nihilism.

Control has a critical and complex relationship with the "good death" discourse. The preoccupation with control as a unifying aspect of the "good death" speaks to the perceived importance of neoliberal political and social values of autonomy, freedom, and choice (Balducci, 2012; Broom, 2012; Broom & Cavenagh, 2010; DeJong & Clarke, 2009; Hart, Sainsbury, & Short, 1998; Hopkinson & Hallett, 2002; Jacques & Hasselkus, 2004; Kaufman, 2000; Leget, 2007; McNamara, 2004; Madan, 1992; Pierson, Curtis, & Patrick, 2002; Raphael, 2007; Steinhauser *et al.,* 2000; van Brussel & Carpentier, 2012; Walter, 2003; Walters, 2004; Watts, 2012; Wilson, 2009; Zimmermann, 2012).

Yet within this discourse, control is paradoxical. Although the "good death" discourse overwhelmingly identified dying as an individual experience (DeJong & Clarke, 2009; Goldsteen *et al.*, 2006; Gott, 2008; Hart, Sainsbury, & Short, 1998; Hopkinson & Hallett, 2002; Jacques & Hasselkus, 2004; Pierson, Curtis, & Patrick, 2002; Veillette, 2010; Walter, 2003; Watts, 2012; Wilson, 2009), it simultaneously constrained and limited individual freedom. As Walters (2004) wrote: "in reality . . . this freedom can sometimes be compromised by the pressure of control towards what professionals consider to be a 'good death'" (p. 406).

This paradox of control and freedom co-existing in the "good death" discourse recalls Foucault's notion of governmentality, or "governing through the *freedom* of subjects" (Martin *et al*., 1999, p. 81; italics in original). Discipline in governmentalism is not achieved by traditional hierarchical power or surveillance; instead, discipline is achieved by creating, through discourse, boundaries that limit and constrict choice, while simultaneously promoting individual agency and free will. Within the "good death" discourse, dying individuals are encouraged--even coerced--to be aware, autonomous agents (Zimmermann, 2012) who make choices about their dying experience. But their repertoire of sanctioned choices is strictly limited; their power, illusory. In this view, the “good death” is a controlling, disciplinary discourse that promotes and rewards a particular way of dying or caring for those who are dying (Broom & Cavenagh, 2010; Clarke, 2006; Goldsteen *et al.*, 1998; Frith, 2013; Hart, Sainsbury, & Short, 1998; McNamara, Waddell, & Colvin, 1994; Seale, 2000, 2004; Semino, Demjen, & Koller, 2014; van Brussel & Carpentier, 2012; Walters, 2004; Watts, 2012; Zimmermann & Rodin, 2004; Zimmermann, 2007, 2012). The “good death” discourse paradoxically constrains individual freedom, by tacitly rewarding some choices over others and by dictating a certain way to die (Goldsteen *et al.*, 2006; Semino, Demjen, & Koller, 2014, Zimmermann, 2012). It "establishes stability in dying, but limits spontaneity" (McNamara, Waddell, & Colvin, 1994, p. 1506), acting as a form of social control (Hart, Sainsbury, & Short, 1998).

Within increasingly secularized western society, in which individual autonomy is a central value, the “good death” may no longer be "good enough" (McNamara, 2004, p. 929). The denial of dying represents the culmination of control and of autonomy, the apex of a neoliberal society in which "death may be purchased and consumed, valued and depreciated, managed and administered in a fashion entirely consistent with any other commodity or bureaucratic transaction under 'free market' principles, with ever-increasing superficiality and lack of lasting meaning or significance" (Bendle, 2001, p. 353). The dying process seems to have been rendered insignificant and irrelevant and has, therefore, been discarded. Though death itself is openly discussed, the dying process is so negatively characterized or perceived that it is now avoided entirely.

Contemporary western society, once a death-denying society (Aries, 1981; Zimmermann & Rodin, 2004), is now increasingly a death-accepting, but a dying-denying, society. Increasingly, the media discourse on death and dying has marginalized the dying process, rendering it invisible. Surely this negative, controlling discourse is incomplete: it presents an unbalanced and negative view of death and dying that marginalizes positive concepts, such as hope, joy, or freedom. Positive concepts were alarmingly absent from the reviewed literature, thus the "good death" is predicated not on the presence of positive symptoms, but on the absence of negative ones. The questions to ask now are: how will end of life care be shaped by this dying-denying culture? Where does this notable absence of a dying process leave the "good death"? Has the end of life care community failed to provide dying experiences that help to shape a positive discourse of dying? And, perhaps most importantly, how and where do we begin to reclaim dying, to shape a positive discourse of dying?

Limitations

This review has several important limitations. First, the literature search was restricted to electronic databases, which may have compromised the sample. A librarian may have performed a more comprehensive literature search, yet I was unable to obtain the services of a librarian. The search was also restricted to the English language, which may contribute to language bias (CRD, 2008). These literature search limitations may have altered the substantive quality of this review.

This review was completed by one individual, which poses a potential threat to rigor. My data analysis tables and drafts of this review were, however, reviewed by my academic supervisor, who contributed advice and expertise to this review.

Implications for Research, Policy, & Practice

To remain socially relevant, end of life care ideally must reflect the needs of the dying individuals and enact them through practice and policy. The findings of this literature review suggest that more research needs to explore patient perspectives of dying experiences, rather than the experiences of health care providers, and to inform care decisions that translate more effectively to practice and meet the needs of the individuals who are dying. In particular, research is needed to explore the preferences of dying persons within diverse cultural and geographic areas, as well as individuals dying of chronic diseases, including Alzheimer's and other dementias.

Most importantly, however, research must explore the positive aspects of the dying process, to reframe and reclaim dying, to move from a discourse that privileges the absence of negative aspects to one that privileges the presence of positive aspects of dying. Dying may be an important part of living; framing it as an unnecessary and meaningless part of life may have damaging consequences for individuals, for families, and for society. Denying dying may destroy individuals' opportunities to grow, to find meaning, hope, and joy, and to live fully until they die. Denying dying may preclude families from creating significant moments and from forming important memories to carry into subsequent generations. For society, denying dying and precluding positive, meaningful aspects of dying shapes and helps to perpetuate a discourse of death and dying that is unbalanced, alarmingly negative, and increasingly fragmented.

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Table 3.1

Literature Included

(Adapted from O'Rourke, H. (2014). Data Analysis Form.)

1. Author: Broom, A. Journal: *Qualitative Health Research,* *22*(2), 226-237 Title: On euthanasia, resistance, & redemption: The moralities and politics of a hospice. Year: 2012 Country: Australia	Discipline: Not specified N/S Institution: (N/S) Funding: Source: (N/S)	Type: Qualitative study N=20	PURPOSE: To explore hospice patients' experiences of inpatient hospice care, and to explore issues of euthanasia, technical control, intervention and individual versus cultural perspectives. To explore how institutional values and practices around dying and religiosity resonate and/or conflict with people's values *Hospice offers a specific model of managing dying *Revivalist GD is an "agenda" within palliative care (p. 228). *"Be strong" or "fight hard" messages that bind choice and desire, producing "good patients" as well as "good deaths"

2. Author: McNamara, B., Waddell, C., & Colvin, M. Journal: *Soc Sci Med, 39(*11), 1501-08. Title: The institutionalisation of the good death Year: 1994 Country: Australia	Discipline: Anthr., Sociology, hospice Institution: U. Western Australia Funding: N/S	Type: Qualitative study ethnography N=22 (nurses' perspectives)	PURPOSE: To investigate whether the good death ideal, central to the hospice philosophy, is compatible with the institutionalization of hospice care. *A GD used to equal a fixed moment in time; now a "fashionable" interest in death *GD establishes stability in dying, but limits spontaneity
3. Author: Cipolleta, S, & Oprandi, N. Journal: *Death Studies, 38*, 20-27.	Discipline: Psychology Public Health & Community Medicine	Type: Qualitative study N=37 (part of larger study)	PURPOSE: To explore how HCP's evaluate care at EOL and what they consider to be a good death and what constitutes good care to a dying patient. *Physicians have the responsibility but no language to communicate death; RN's have the language but no responsibility.

Title: What is a good death? Health care professional's narrations on EOL care Year: 2014 Country: Italy	Institution: U. Padova; U. of Verona Funding: Source: N/S		*What constitutes a GD is much under debate; some patients, especially elderly, prefer to stay at the hospital (p. 22)
4. Author: DeJong, J.D., & Clarke, L.E. Journal: *Journal of Palliative Care, 25(1)* Title: What is a Good Death? Stories from Palliative Care. Year: 2009 Country: Canada	Discipline: Medicine Institution: Dalhousie University Funding: Source: N/S	Type: Qualitative study (narrative thematic analysis) N=15 (purposeful; mean age not	PURPOSE: To discover the "good death" by explicating its opposite, a "bad" death. Goals of the study are to elicit stores of good and bad deaths to identify and compare themes; to illuminate subjective experience of good and bad deaths, and to determine the value of narrative methodology. To explore the experience of those who are dying and those who are attending them.

		given; mixed: patients, caregivers, nurses, doctors)	*GD: free from pain and suffering, sense of life well-lived (most prominent theme); sense of community; not dying alone *Bad death: painful, loss of control/self/freedom and independence as well as health care provider not listening or doing what's wanted *GD unique and individualised
5. Author: Gott, M. Journal: *Social Science & Medicine, 67*, 1113-1121. Title: Older people's views of a good death in heart failure: Implications for palliative care provision. Year: 2008	Discipline: Sociology/ Medicine Institution: U. Sheffield Funding: Source: (N/S)	Type: Qualitative study N=44	PURPOSE: To explore the extent to which older peoples' views and concerns about dying are consistent with the prevalent model of the good death underpinning palliative care delivery. *GD in the literature might not fit with the reality; study of heart failure patients discovered that many did not want awareness of dying or autonomy, individuality

Country: UK			*Freedom from pain as concept of GD comes from cancer deaths; this concept then may change as dying from chronic disease becomes more common. Pain is not often associated with many chronic diseases; dyspnea may become a more "feared" symptom. *Changing demographics: aging will influence the good death
6. Author: Goldsteen, M., Houtepen, R., Proot, I.M., Abu-Saad, H. H., Spreeuwendberg, C., Widdershoren, G. Journal: *Patient Education & Counselling*	Discipline: Philosophy Ethics Institution: Maastricht University Funding: Source: N/S	Type: Qualitative study N=53: patients (13) family (13)	PURPOSE: To offer insight in the way terminally ill patients talk about death and dying, and how they refer to current Western normative expectations of "a good death". *Part of a larger study: "A good death: Palliative care at home" *Disjuncture between normative "good death" discourse and actual patient experiences: patients show a clear

Title: What is a good death? Terminally ill patients dealing with normative expectations around death and dying. Year: 2006 Country: Netherlands		professional caregiver (13) bereaved caregiver (14)	diversity: they have their own ideas and standards about death and dying and . . . they each die their own unique death. What should be considered as a GD is something that cannot be defined in general terms and is not the same for everyone" (p. 384) *GD literature portrays GD as something of a higher order than merely living, whereas in reality it is "people struggling with everyday matters" (p. 383/384) *How death should not be "good" in a confining way, which may limit people's abilities and discourage other ways of dying. *GD might function as a reductionist and restrictive force in actual care for dying patients: it might function as a standard that patients are expected to live up to (p. 384)
7. Author: Kaufman, S.R.	Discipline: Anthr.	Type:	PURPOSE: To focus on advanced age in considering the problem of death in America. Specifically to explore (1)

Journal: *Journal of Aging Studies, 14*(1), 1-23. Title: Senescence, decline, and the quest for a good death Year: 2000 Country: USA	Institution: U. Cal. Funding: Source: N/S	Qualitative study ethnography N=2 (case study; part of larger study)	why the practices underlying the idea of death with dignity are so hard to achieve and (2) why the notion of death with dignity is such a prominent cultural preoccupation at the end of the 20th century. *Conceptions of "normal" and "pathological" aging, like all scientific knowledge, are not objective, natural, or given. Rather, they are constituted in particular social and political contexts. *The "problem of death in America" is not knowing when dying begins *Medicine generally doesn't allow for a transition, a process, or a passage between life and death except in the most perfunctory way" *Once patients/families enter medical world (esp. hospital), their actions are guided by the values and

			pervasive practices of that world, especially the technological imperative *Decline and death are, regularly, controlled.
8. Author: Semino, E., Demjen, Z., & Koller, V. Journal: *Discourse Studies, 16*(5), 667-85. Title: Good & bad deaths: Narratives and professional identities in interviews with hospice managers. Year: 2014 Country: UK	Discipline: sociology (linguistics) Institution: U. Lancaster Funding: Source: N/S	Type: Qualitative study N=13 (hospice managers)	PURPOSE: To explore narratives on good and bad deaths from hospice managers in UK. *Highlights the professional role in facilitating a good death and the pressure to present a unified view, which may preclude alternative perspectives *PC movement associated a "good" death with control, autonomy, and dignity; the right to die movement associated it with awareness and heroism *The politicisation of death, whether "good" or "bad" can affect the range of "acceptable" choices that patients and families are presented with

			*Hospice managers' perspectives on "good" or "bad" deaths . . . revolve around the success or failure of professional interventions (p. 670) *Strong sense of professional worth and identity associated with GD *Bad death is a challenge to the professional "face" of staff: staff prefer even to avoid using the word "bad" and instead use "difficult" or "hard" *Blaming patient: "the failure of professional intervention was explained as the result of the attitude of the people involved--namely, the patients' close relatives or . . . the patient him or herself, who either rejected help or was unable to benefit from it" (p. 678)
9. Author: Masson, J.D. Journal: *Mortality, 7*(2), 192- Year:2002	Discipline: Psychology Institution:	Type: Qualitative study	PURPOSE: To explore perceptions of a good death with patients and relatives who were dealing, or have dealt, with terminal illness in a hospice setting and to identify

Country: UK	NHS North Cumbria Funding: Source N/S	N=20	the constituent elements of a "good" death for participants. (*3 main clusters characterise a GD: 1) Tension & Paradox: what may be good for the patient might not be good for the family (and vice versa)/"death has good and bad bits in it"; 2) Contextualisation of dying within the life lived: dying is rooted in living; split between coherence (congruence with life) and contradiction, or incongruence with life lived). Usually incongruence came as a result of health care provider behaviours or attitudes; 3) Flexible realism: where you die: Most participants wanted to die at home, but not always possible. "Home-like" setting was "next best thing" *Overall notion of "good enough death" might be a more realistic concept

10. Author: Wilson, D.M Journal: *Journal of Palliative Care, 25*(1), 21-29. Title: The "good" rural death: A report of an ethnographic study in Alberta, Canada Year: 2009 Country: Canada	Discipline: Nursing Institution: U. Alberta Laval U. U Calgary U. Toronto Funding: Source: CIHR Institute of Cancer Research & Institute of Health	Type: Qualitative study Ethnography N=21	PURPOSE: To gain a conceptual understanding of the good rural death. Based on the assumption that rurality would affect perspectives on the good death. *Rurality defined as distance from a city, either geographical, or by travel time; also notion of being "sparsely inhabited": Rurality is a powerful cultural force 4 themes: 1) Rural people believe they have unique perspectives on and concerns about dying. *This "rural uniqueness" is illustrated by the most pervasive finding: dying individuals should not be displaced from their home communities *Importance of familiar faces and surrounding considered so great that some participants would not enter a hospital during their final days *Displacement and distance = seclusion and loneliness, and an increasingly negative prognosis

	Services & Policy Research		2. Rural people care deeply about their community and its members, and are highly motivated to ensure quality palliative/EOL services exist in local hospitals and other care sites *Need to maintain the dying person's functional and mental capacities for a GD *Need control over their fate; talk of euthanasia, living wills, and "natural" death 3. A loose network of Palliative/EOL providers (paid and volunteer, professional and other) has developed 4. Rural regions face unique challenges in developing and maintaining Pall/EOL care services, and thus in providing for rural GD's
11. Author: Broom & Cavenagh	Discipline: Sociology Institution:	Type: Qualitative study	PURPOSE: To discover patients' perspectives of a good death (in hospice)

Journal: *Social Science & Medicine, 71*, 869-76. Title: Masculinity, moralities, and being cared for: An exploration of experiences of living and dying in a hospice. Year: 2010 Country: Australia	U. Sydney & Newcastle Funding: Source: N/S	N=20	*Tensions about the GD: dying and caring as moral practice *GD divided into 2 realms: 1) dignity, peace, and comfort; and (2) a form of social control, which potentially marginalises divergent forms and experiences of dying *Patients' perspectives of a GD may conflict with the values of palliative care (e.g. many older patients do not actually want to die at home)
12. Author: McNamara, B. Journal: *Social Science & Medicine, 58,* 929-38. Title: Good enough death: autonomy and choice in Australian palliative care. Year: 2004	Discipline: Anthropology Institution: U. Western Australia	Type: Qualitative study ethnography (observations of HCP's in 2 settings)	PURPOSE: To trace the changing notions of a good death (in Australian hospices) *Traces the development of a GD in Western (Au) culture; the division between hospice and palliative care (emot/spiritual vs. medicalized, with emphasis on managing physical symptoms)

Country: Australia	Funding: Source: N/S		*Notion of a "good enough death": a death that will ultimately support the choices of the individual and the perceived certainty of medical practice *The element of individual choice is a reflection of a broader "postmodern condition" and within this context, postmodern deaths typify a fragmentation of ideas and behaviours; a multivocality of responses; and, ultimately, an existential uncertainty"
13. Author: Veillette, AM. Title: La belle mort en milieu rural: a report of an ethnographic study of the good death for Quebec rural francophones. Journal: *Journal of Palliative Care, 26*(3), 159-166.	Discipline: Nursing/ Medicine Institution: Laval University U. Alberta U. Calgary	Type: Qualitative study (ethn) N=70	PURPOSE: To obtain perspectives on what constitutes a good death from persons living in rural Quebec. *4 themes for "good" death: (1) physical dimension (pain control/dyspnea/fatigue/bedsores/a quick death); (2) emotional/psychological dimension (serenity, peace, security, not being a burden, dignity); (3) social dimension (communicating with and being listened to by family, friends, and hc workers; being lucid; being able to

Year: 2010 Country: Canada	share thoughts and feelings; being surrounded by family; being able to say farewell and obtain closure; existing in a quiet, private atmosphere; (4) spiritual dimension (accepting death, finding meaning in one's life and death, transcending physical discomfort and finding peace, focusing on spiritual beliefs, and having freedom of choice) *Specificities of rural environment: proximity of family and friends versus the proximity of formal health care and other services; staying in a home environment versus entering a hospital; the solidarity and mutual support offered in a rural community versus the supposed individualism of the urban way of life; the sense of security versus insecurity that comes from travelling to an urban centre; generalist community organisations that

			serve rural communitites versus the specialized services that can be found only in large cities *Good death is individualised, but predominant wish is to die at home, even at the expense of foregoing specialised urban treatments.
14. Author: Pierson, CM; Curtis, JR; Patrick, DL Journal: *AIDS Care, 14*(5), 587-98 Title: A good death: A qualitative study of patients with advanced AIDS. Year: 2002 Country: USA	Discipline: Medicine Institution: U. Washington Funding source: N. Washington Royalty Research Fund/ U.	Type: Qualitative study (GT) N=35 (mean age 41)	PURPOSE: To identify and describe the domains that define a "good" versus "bad" death from the perspective of patients with advanced AIDS. To explore not the quality of life, but the quality of dying in this patient population. *12 main domains: 1) symptoms, primarily pain; 2) QOL: no suffering, no prolonging life; 3) people present; 4) dying process; 5) location (home preferred); 6) sense of resolution (time to make preparations, say farewells; 7) patient control of treatment (including being involved in treatment decisions and ceasing treatment if desired); 8)

	Wash Centre for AIDS Research/Open Society Project on Death in America Faculty Scholars/Parker B. Frances Fellowship		spirituality (mainly religious); 9) death scene (quiet and peaceful at time of death); 10) Physician assisted-suicide; 11) aspects of medical care (including access to care/good relationship with physician/treated as an individual or whole person/felt as if they were receiving quality medical care; 12) acceptance of death *Key findings included considerable individual variation/variability in what constituted a "good" death, and the requests for physician-assisted suicide (article stated "many patients" but did not specify how many patients reported this).
15. Author: Ko, E., Cho, S., Perez, R, Yeo, Y., & Palomino, H.	Discipline: SW Nursing Anthr. Institution:	Type: Qualitative study (GT: Glaser & Strauss)	PURPOSE: To identify and describe the domains that define a good death from the perspective of healthy Mexican Americans

Journal: *Journal of Gerontological Social Work,* *56*(6), 6-25. Title: Good & Bad death: Exploring the perspectives of older Mexican Americans. Year: 2013 Country: USA	San Diego U. Mokpo Nat'l U (S. Korea) U.S. Carolina Funding: Source: N/S	N=18	*Population recruited from a larger study (N=122) on advance care planning. population for this study self-identified as Mexican; mean age 77; healthy; 2/3 women. Good death comprised of 5 categories: 1. No suffering: most prominent theme: referred mostly to physical suffering and wish to die in sleep; 2) Living life with faith: predominantly organised religion; death a positive thing, the opportunity to meet God; 3. Having time for closure with family; 4. Dying at home; 5. Natural death: no reliance on medicine/medical technology and dying as part of the course of life *Acceptance of death is an integral part of life and as an entrance to the afterlife are predominant features of Hispanic culture; good death is culturally diverse

16. Author: Bratcher, J.R. Journal: *Critical Care Nursing Quarterly, 33*(1), 87-99 Title: How do critical care nurses define a "good death" in the intensive care unit? Year: 2010 Country: USA	Discipline: Nursing Institution: Veterans Admin; Reno NV Funding: Source N/S	Type: Qualitative study N=15	PURPOSE: To explore and describe the characteristics of a good death as defined by 15 critical care nurses in ICU in mid-sized urban city 3 main themes characterise a good death in ICU: 1. the person does not die alone 2. the person does not suffer (pain) 3. Acceptance of death by patient and loved ones Data collection by interview: mean age of sample 50; no details on rigor/coding/method (other than "qualitative exploratory) given
17. Author: Jacques, N.D., & Hasselkus, B.R. Journal: *OTJR: Occupation, Participation, & Health, 24(*2), 44-55.	Discipline: OT Institution: U.Wisconsin	Type: Qualitative study (ethn) N=30	PURPOSE: To gain further understanding of occupation as it is created and experienced by people who are dying and those who care for them. Research questions: What is the meaning of occupation for all those involved in the dying process? How does occupation change during the

Title: The nature of occupation surrounding dying and death Year: 2004 Country: USA	Funding Source: U.Wisconsin Caroline Goss Thompson Distinguished Grad. Fellowship/American OT Foundation Student Grant Program	(25 staff; 5 residents)	course of the dying experience? How does occupation support EOL care? *Occupation and Good death: 4 themes: 1. Doing things that matter/continuing life; 2. Getting everything in order; 3. It takes so long to die: waiting; 4. Gentle Goodbye: death and after death *"Occupation is the good death: the context of dying provides a unique temporal and sociocultural experience, remaking the "ordinary" into "extraordinary"
18. Author: Hopkinson, J., & Hallett, C.	Discipline: Nursing Institution:	Type: Qualitative study	PURPOSE: To explore understandings of personal ideal of a good death voiced by 28 staff nurses who were caring for dying people in hospital. Sub-purpose is to

Journal: *International Journal of Palliative Nursing* Title: Good Death? An exploration of newly-qualified nurses' understanding of a good death Year: 2002 Country: UK	U. Southampton U. Manchester Funding: Source: N/S	N=28	uncover whether there is a clear common understanding of a good death. *Concept of a good death is perhaps a reduction that leads to an incorrect assumption of a shared understanding of the acceptable way to care for a dying person *Commonalities in findings, yet each nurses' perception coloured by own death experiences (family, friends, etc). Good death is variable. Commonalities: time to spend with patients/peace/comfort/dignity/expected death/someone present/good symptom control *Reconceptualisation of a good death as a "personal ideal of death" could facilitate the acceptance of a new shared set of values that acknowledge a diverse range of deaths that can be perceived to be acceptable according to individual perspectives.

			Methods: phenomenology (van Manen); mean age of participants 22-24; open interviews.
19. Author: Steinhauser, KE, Clipp EC, McNeilly M, Christakos NA, McIntyre LM, Tulsky JA Journal: *Annals of Internal Medicine, 132*, 825-32 Title: In search of a good death: observations of patients, families, and providers. Year: 2000 Country: USA	Discipline: Medicine Institution: U. Chicago; Duke U; Vets Affairs Medical Centre Funding: Source: Project on Death in America/Vets Affairs	Type: Qualitative study N=75	PURPOSE: To gather descriptions of the components of a good death from patients, families, and providers through focus group discussions and interviews participants were MD's, RN's, SW's, chaplains, hospice volunteers, patients, recently bereaved family members 6 major components of a good death: 1. Pain and symptom management; 2. Clear decision making (esp. communication); 3. Preparation for death (knowing what to expect); 4. Completion (meaning at EOL, farewells, closure); 5. Contributing to others (gifts, time, or knowledge, including being able to tell others the purpose of life); 6. Affirmation of the whole person

	Health Services Research Career Dev. Award/Robert Wood Johnson Generalist Physician Faculty Scholars Award		**Physician's discussions of a good death differed greatly from those of other groups; physicians had the most biomedical perspective; SW had case mgmt perspective *Participants cautioned hc providers against implying "you're not dying the right way because you're not dying the way we think you should" (p. 829); "patients and families feared bad dying more than death" (p. 829) *Social and professional roles shaped the views of participants more significantly than sex or ethnic differences
20. Author: Borbasi, S., Wotton, K., Redden, M., Chapman, Y.	Discipline: Nursing Institution: U. Adelaide	Type: Qualitative study N=17	PURPOSE: To explore the views of nurses on EOL care for patients with end stage heart failure *Descriptive exploratory study (subset of larger study)

Journal: *Australian Critical Care, 18* (3), 104-113. Title: Letting Go: A qualitative study of acute care and community nurses' perceptions of a 'good' versus a 'bad' death. Year: 2005 Country: Australia	Funding: Source: Flinders Medical Centre Foundation		*GD themes: 1. Defining a good death: including patient and family in decision-making; keeping patients and families informed; patients and families' acceptance of death; appropriate environment of care/adequate staffing; 2. Dying as one has lived: "congruent death": not so much about dying with dignity than dying with integrity; 3. Involvement of the Palliative Care Team: "essential" if a good death was to be "achieved"; 4. Symptom control, particularly pain and dyspnea. Discussed by all nurses but not given the same prominence as other factors. Bad death themes: 1. Unexpected death, "conspiracy of denial; "not letting go; 2. Fear of discussing death; 3. Imposition of health care provider values; 4. Lack of resources;
21. Author: Kehl, K.A.	Discipline: Nursing	Type: Concept	PURPOSE: To analyze the concept of a good death.

Journal: *American Journal of Hospice & Palliative Medicine, 23* (4), 277-87. Title: Moving toward peace: An analysis of the concept of a good death Year: 2006 Country: USA	Institution: U. Wisconsin Funding: Source: National Institute of Nursing Research	analysis	*Roger's evolutionary model; N=42 (restricted 1973/1995-2004; English; adults; MEDLINE; CINAHL; PUBMED *Strong agreement that a good death is highly individualised, changeable over time (dynamic) and based on perspective and experience Attributes: being in control/being comfortable/sense of cosure; affirmation/value of dying person recognised; trust in care providers; recognition of impending death; beliefs and values honoured; burden minimised; relationships optimised; appropriateness of death; leaving a legacy; family care. Antecedents: no universal agreement, but patient/family must have wishes honoured. Others included place/level of consciousness at time of death/who is to be present at time of death/ability to communicate preferences

			(therefore Alzheimer's/dementia deaths not considered "good" as person cannot communicate preferences) Consequences: professional satisfaction/sense of integration/learning from experience/understanding self and others better/being more comfortable with own mortality/being more connected to family and friends/feeling privileged/
22. Author Granda-Cameron, C. & Houldin, A. Journal: *American Journal of Hospice & Palliative Medicine, 29*(8), 632-39. Title: Concept Analysis of good death in terminally ill patients	Discipline: Nursing Institution: Drexel U, Philadelphia Funding: Source: N/S	Type: Concept analysis	PURPOSE: To analyze concept of good death in terminally-ill patients. *Roger's CA *Very little in the literature of the good death is from patients, most is from hc provider's *Attributes: pain and symptom mgmgt, patient dignity (not defined); family presence; family support; awareness of death; good communication *GD is subjective and context-laden/dependent

Year: 2012 Country: USA			
23.Author: Zimmermann, C. Journal: *Social Science & Medicine, 75*, 217-224. Title: Acceptance of dying: A discourse analysis of palliative care literature Year: 2012 Country: Canada	Discipline: Medicine Institution: U. Toronto Funding: Source:	Type: Discourse Analysis N=40	PURPOSE: To examine the use of the term "acceptance" of dying in the palliative care literature from 1970 to 2001. (Foulcauldian DA lens) *Acceptance is a critical component of the good death *The theme of acceptance is integral to pall care, which had subthemes of acceptance as a goal of care, personal acceptance of healthcare workers, and acceptance as a facilitator of care; For patients and families, death acceptance is a goal that they can be helped to attain; for pall care staff, acceptance of dying is a personal quality that is a precondition for effective practice *Acceptance not only facilitates the dying process for the patient and family, but also renders care easier

			The discourse on acceptance of dying represents a productive power, which disciplines patients through apparent psychological and spiritual gratification, and encourages participation in a certain way to die.
24. Author: Zimmermann, C. Journal: *Sociology of Health & Illness, 29*(2), 297-314 Title: Death denial: obstacle or instrument for palliative care? Year: 2007 Country: Canada	Discipline: Medicine Institution: U Toronto Funding Source N/S	Type: Qualitative study (thematic analysis) N=30	PURPOSE: To examine the theme of denial as an obstacle to palliative care. Two dominant themes: 1. denial as a psychological coping mechanism; 2) denial as an obstacle to palliative care *Denial is perceived to be standing in the way of several components of palliative care, including: a) open discussion of dying; b) dying at home; c) advance care planning; d) symptom mgmt; and e) stopping "futile" treatments *These components form a "proper way to die", which in turn represents a managed death.

			*Rather than being an obstacle to palliative care, death denial--and indeed its very conceptualisation as an obstacle--may be seen as a construction that is instrumental in upholding the "way to die" and efficiently manage the dying process
25. Author: Seale, C. Journal: *Nursing & Health Sciences, 14,* 488-94. Title: Media constructions of dying alone: a form of "bad death" Year: 2004 Country: UK	Discipline: Sociology Institution: U. London Funding: Source: N/S	Type: Discourse analysis N=90	PURPOSE: To analyze newspaper articles about dying alone. *More violent deaths reported in newspaper ("newsworthy") *Moral lesson evident in newspapers: death isn't merely a medical event, but is heavily moralized. *Dying alone is stigmatised, and can be deserved (ie for people of "poor" moral character) *Death alone is framed as a punishment for moral failings *Social death: experienced by many elders, and is a modern version of being buried alive

			*Newspaper writers are bearers of moral messages and guardians of the community aligned with an official morality about how such a society ought to behave.
26. Author: Clarke, M.N. Journal: *Omega, 153-167.* Title: Death under control: Portrayal of death in mass print English language magazines in Canada Year: 2006 Country: Canada	Discipline: Humanities Institution: Funding: Source: Social Science & Humanities Research Council of Canada	Type: Qualitative media analysis; CDA N=63 (from 1991, 1996, 2001)	PURPOSE: To explore the portrayal of death in popular English language magazines in Canada. What is newsworthy is the notion that death is a choice, along with the control of its timing, the pace, and reasons for death. Speaks to cultural and social value of autonomy. Control over death is the prevailing underlying frame or discourse *No stories of the self-reflexive or good death. The focus is not on the lives of those who are choosing to die or how they have made their lives meaningful; instead it is on their desire to and the means by which they'll die. Death is not random, unwelcome, or to be feared. It is not conveyed in the context of prevention, suffering,

			palliation, or community supports. Death in communities and families is virtually absent. Bereavement and strategies to support the bereaved, the hospice movement, and other social trends are ignored. 3 dominant discourses: 1. Death is the result of active medical intervention (medicide); 2. Individuals and individualism: focus on the rights of the individual to select to live, to die, to live longer, or to choose death; 3. Importance of celebrity and with it wealth, athleticism, and attractiveness.
27. Author: Carr, D. Journal: *Journal of Health & Social Behaviour, 44*(2), 215-32 Title: A good death for whom? Quality of Spouse's	Discipline: Sociology Institution: Rutgers University	Type: Quantitative study N=210 151 women; 59 men	PURPOSE: Studied the importance of a "good death" on bereaved spouses grief process. Used data from Changing Lives of Older Couples (survey) to investigate 1) frequency and predictors of 8 conceptually-derived aspects of death quality; and 2)

death and psycho-logical distress among older widowed persons Year: 2003 Country: USA	Funding: Source: Grant from National Institute on Aging	(part of larger study; N 1532)	whether and how spousal death affects psychological distress 6 months post loss *Dying in a nursing home is an indicator of a "bad" death *Death quality is stratified by social class *Critical components of a GD: having led a full life, accepting death, not being a burden Qualitative aspects of dying well are best predicted by objective characteristics of death, including its cause, suddenness, and timing. *Religion shapes EOL experience (may provide meaning) GD is upheld as an ideal toward which care providers, the dying, and their kin should strive" *Advanced medical technologies allow the dying elderly to increase the length, though not necessarily the quality, of their lives.

			*Alzheimer's: not aware therefore cannot find meaning in death.
28. Author: McNamara, B. & Rosenwax, L. Journal: *Health Sociology Review, 16,* 373-83. Title: The mismanagement of dying Year: 2007 Country: Australia	Discipline: Anthr., Sociology & OT Institution: U. Western Australia & Curtis Inst. of Technology Funding: Source: N/S	Type: Quantitative study N=1071	PURPOSE: To examine death certificates and documents to discover the quality of dying in Australian in-patient units; how death and dying are characterised in hospitals. *dying is mismanaged in hospital in-patient units Value of autonomous agent who is able to take control of his/her affairs, make informed choices, or delegate same; the notion of self-managed dying. *The slow death of chronic illness has changed the concept of the good death and of dying itself *The irony of a well-managed death is that one needs reasonable health to achieve it" (Kellehear, 2007, p. 149)
29. Author: Seale, C.	Discipline: Sociology	Type:	PURPOSE: To explore the changing patterns of death and dying in Western culture.

Journal: *Social Science & Medicine, 51,* 917-30. Title: Changing patterns of death and dying Year: 2000 Country: UK	Institution: U. London Funding: Source: N/S	Non-experimental	*Tension between religious and scientific views of dying in Western culture *The ambitions of humans to control death and relieve suffering becomes almost limitless *Medical treatment largely involves an anaesthetic solution to suffering, which encourages the view that pain and grief are illegitimate disturbances to the normal pain-free existence everyone has the right to expect
30. Author: Hart, Sainsbury, Short Journal: *Mortality, 3*(1), 65-80 Title: Whose dying? A sociological critique of the "good death". Year: 1998	Discipline: Sociology/ Medicine Institution: U. Newcastle U. Sydney U. NSW	Type: Non-experimental	PURPOSE: Two key questions: 1) whose interests does the prevailing ideology of the good death serve; and (2) how are the choices of dying people increased or constrained by the idea of a good death? *Acceptance was uncritically received socially as a key component of a good death GD in hospice is a victory for hospice staff and for the ideology of hospice

Country: Australia	Funding: Source: N/S		*Bad deaths relate to wider society being in denial of death (are never a fault of hospice staff): "Angry, non-accepting and non-compliant patients become deviants who are violating the established norm" (p. 69).
31. Author: Frith, H. Journal: *Sociology of Health & Illness, 35*(3), 419-33. Title: Making death 'good': instructional tales for dying in newspaper accounts of Jade Goody's death. Year: 2013 Country: UK	Discipline: Sociology Institution: N/S Funding: Source: N/S	Type: Media analysis	PURPOSE: To explore media coverage of the death of a young celebrity to uncover how dying is framed and shaped by popular media/discourse *Deaths are neither good nor bad; they require cultural labour to be "made over" as good *Popular culture offers moral instruction in dying well, which resonates with the messages from palliative care *Facilitating a good death is a central goal for professional practice.
32. Author: van Brussel, L., & Carpentier, N.	Discipline: Sociology Institution:	Type: Discourse analysis	PURPOSE: Discourse analysis of newspaper articles on good death

Journal: *Journal of Language & Politics* Title: The discursive construction of the good death and the dying person: A discourse theoretical analysis of Belgian newspaper articles on medical EOL decision-making. Year: 2012 Country: Belgium	Vrije Universiteit Brussel Funding: Source: N/S		(note no search strategy or discussion of included articles provided). *Good death= control, autonomy, dignity, awareness, and heroism *Right to die is privileged in articles, along with the extraordinariness and heroism of dying; subject who autonomously chooses how and when to die and preferably dies "in a state of full awareness so he can die with dignity" *Death is "loaded with meaning" and cannot be detached from processes of social construction.
33. Author: Leget, C. Journal: *Medicine, Health Care, & Philosophy, 10,* 313-19.	Discipline: Philosophy Institution:	Type: Non-experimental	PURPOSE: To explore the ethics of good death *Lack of common perception of dying well across cultural boundaries

Title: Retrieving the *ars moriendi* tradition. Year: 2007 Country: Netherlands	Radboud University Funding: Source: N/S		* Strong emphasis on autonomy to determine meaning of one's own death hides contemporary cultures' incapacity to give support to those who are confronted with mortality and suffering
34. Author: Bendle, M.F. Journal: *Cultural Values, 5(*3), 349-67. Title: The contemporary episteme of death Year: 2001 Country: Australia	Discipline: Sociology Institution: N/S Funding: Source: N/S	Type: Non-experimental	PURPOSE: Discussion of the changes in cultural attitudes to death and the good death. *Death is militarized and medicalized The good death is a professional standard of performance aspired to by doctors and specialists.
35. Author: Balducci, L. Journal: *Annals of Oncology, 23* (Supp 3), iii 56-iii61 Title: Death and dying: What the patient wants.	Discipline: Medicine Institution: N/S	Type: Non-experimental	PURPOSE: To explore, in cancer patients, what a "good death" looks like. Emphasised that autonomy, personal relationships, personal concerns (spiritual elements) are critical to a good death.

Year: 2012 Country: US	Funding: Source: N/S		
36. Author: Madan, T.N. Journal: *Social Science & Medicine, 35*(4), 425-432. Title: Dying with Dignity Year: 1992 Country: India	Discipline: N/S Institution: Institute of Economic Growth Funding: Source	Type: Non-experimental	PURPOSE: To reexamine the good death and the "indignity of death". *Death secularised in 18th Century: amenable to human manipulation, management and medicalisation *Promotes cultural and individual autonomy and familial responsibility, so that death is considered a normal part of living and is encompassed by life, thus not its simple opposite. *Calls attention to holism in midst of fragmentation that characterises modern life.
37. Author: Walter, T. Journal: *BMJ*, 327, 218-220.	Discipline: Sociology Institution:	Type: Non-experimental	PURPOSE: To explore the salient cultural features of a "good death".

Title: Historical and cultural variants on the good death. Year: 2003 Country: UK	U. Reading Funding Source: N/S		A good death is culturally-bound and depends on: 1) extent of secularisation; 2) extent of individualism; 3) how long a typical death takes *GD depends on culture and changes over time Religion and secularisation influence ideas regarding the good death *Individualistic societies promote personal autonomy of the dying, including palliative care and euthanasia *Challenge now is how to die well from slow, degenerative diseases of old age" (p. 129)
38.Author: Walters, G. Journal: *Palliative Medicine* Title: Is there such a thing as a good death? Year: 2004 Country: USA	Discipline: Medicine Institution: Funding: Source: N/S	Type: Non-experimental	PURPOSE: To explore the concept of the "good death" in hospice. *Aim of hospice is to make dying "better" GD is associated with the development of hospice, holistic care, and dignity *GD predates medicine and has religious beginnings.

3 types: 1) the death that doesn't happen yet; 2) the death that isn't seen to happen; 3) the death that happens without my noticing

*Post modern GD: death in my control, openly discuss death; acceptance: nowhere is this more evident than the right to die movement

*Hospice is still focused on control, but over symptoms, not timing, of death. Hospice arose from the refusal to accept death as a failure.

*Commonalities of palliative care/euthanasia: "both products of the same cultural mind-set: both insist on acknowledging the existence of death and placing it at the forefront of consciousness while using modern medical science to control it"

39. Author: Watts, T. Journal: *European Journal of Cancer Care* Title: EOL care pathways as tools to promote and support a GD: a critical comment Year: 2012 Country: Wales (UK)	Discipline: Nursing Institution: U. Swansea Funding: Source: N/S N/S	Type: Non-experimental	PURPOSE: To explore how EOL care pathways influence understandings of and facilitate health care providers' ability to provide a good death. *Achieving a GD is a prominent social and political priority and an ideal that underpins the philosophy of hospice and palliative care, but it's a nebulous and fluid concept EOL care pathways may facilitate a certain kind of good death: one that is associated with the dying process and framed within biomedicine

Chapter 4: Paper 3: The role of transcripts in interpretive description

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The role of transcripts in interpretive description

Qualitative researchers depend on transcripts to facilitate the working and re-working of data, thus the creation of transcripts has important implications for data quality, for analysis, and, ultimately, for the study findings. Different qualitative research methods are predicated on particular philosophical and epistemological underpinnings and, as such, have different data analysis methods. Like all elements of a well-designed qualitative study, transcripts must be congruent with the methodological foundations of the design. Interpretive description (ID) is a qualitative research framework designed from within the nursing discipline for the purpose of exploring questions that pertain to nursing practice (Thorne, 2016). In ID, data and findings are co-constructed through an interpretive process in which the researcher examines the data in context while exploring his or her own contribution to its analysis. Thorne (2016) suggests that data in ID studies should include multiple sources of data. Interviews, one data source, are typically audio recorded and transcribed verbatim. Ideally, transcripts for an ID study are interpretive, naturalistic documents that clearly express verbal as well as contextual data, thus facilitating analysis and promoting rigour. In this paper I will explain the process of knowledge development in ID and explore the interplay between data and data analysis by examining the role of transcripts in the context of an ID study. Though many similar principles apply to transcripts of video recordings, the focus in this paper is on transcripts of audio recordings of individual interviews.

ID: An overview

ID is predicated on the axioms of naturalistic inquiry (Thorne, 2016), and is underpinned by three core assumptions. The first assumption—that reality is complex, contextual, constructed, and ultimately subjective—indicates a relativist ontological stance. The second assumption is that the inquirer and the “object” of inquiry interact to influence one another, indicating a constructivist epistemology. The third assumption is that for the resulting description to be valid, it must be grounded in the data (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004; Thorne, 2016). ID is not a prescriptive method; rather, it is an “operating logic” (Thorne, 2016, p. 81), through which researchers use various data collection and analytic strategies, which are bound by their shared ontological and epistemological underpinnings as well as the purpose and aims of the study (Thorne, 2016).

As a framework for developing knowledge, ID is, at least in part, pragmatic, and is focused on creating useful knowledge for clinical practice (Thorne, 2016). Similar to what Risjord (2010) calls “the nursing standpoint”, (p. 67), the disciplinary focus of nursing provides the “theoretical scaffold” (Thorne, 2016) or analytic framework on which ID is built. This scaffold helps to make theoretical assumptions, biases, and preconceptions explicit (Thorne, Stephens, & Truant, 2016). Rather than relying on or using a theoretical framework borrowed from other disciplines, Thorne (2016) calls for nurse researchers to rely instead on the disciplinary perspective of nursing to frame knowledge development intended for nursing practice. In this way, the discipline of nursing, with its tacit understanding of how knowledge is used in the clinical setting, is the dominant discourse in ID research (Thorne et al., 2016).

Building knowledge that is useful for nursing practice, then, demands a tacit understanding of nursing practice. Nursing is an applied discipline, which means that knowledge from basic and social sciences must be applied to individual situations and contexts, while remaining true to nursing’s “moral imperative” (Thorne & Sawatzky, 2014, p. 16) and embedded values (Risjord, 2010). Nursing knowledge is complex and relies on multiple ways of knowing to cover “the full spectrum from cell to soul” (Thorne & Sawatzky, 2014, p. 7). Practising nurses actively engage with and interpret multiple forms of data at once, relying on pattern recognition, common sense, skill, a sense of salience, and deliberate rationality to answer questions in practice (Benner & Tanner, 1987). Clearly no one view or type of knowledge development can account for the knowledge needed for nursing practice, therefore the common purpose that links knowledge for nursing is its usefulness and applicability to nursing practice (Risjord, 2010; Thorne, 2016). Because the processes used to develop knowledge in ID have been primarily developed from within nursing, ID provides a strong foundation for studying research questions relevant to nursing practice.

Transcripts for analysis in ID

In ID the researcher approaches a transcript in the same way a practising nurse approaches a patient. The researcher views the transcript as a whole, looking for salient words or ideas, recognising patterns, and considering alternative explanations. Unlike patients, however, transcripts are static documents that are tasked with capturing the richness of the data at one point in time and presenting them in such a way that makes them amenable to analysis.

Many different types of transcripts exist, along a spectrum from simple to complex. Simple or "naturalised" (Bucholtz, 2000, p. 1440) transcripts privilege content of conversation over structure, using conventional spelling to record only speech while leaving out para-verbal behaviours such as intonation, pauses, and "filler" words such as "um" or "okay" (Henderson, 2017). Complex transcripts appear foreign to the untrained eye, as they record words, often in phonetic spelling, and detailed descriptions of speech, including syllable length and accents, intonation, inflection, pauses, and all para-verbal and para-linguistic behaviours (Henderson, 2017). A naturalised transcript is too simplistic for an ID study, as it would remove potentially important contextual details that may add depth to the analysis; a complex transcript is too detailed for an ID study, as its linguistic details are not necessary for the analytic processes used in ID. (Bucholtz, 2007, p. 795).

In comparison, a "broad transcript" (Henderson, 2017, p. 147) fits somewhere in the middle of the simple-to-complex transcript continuum. It includes not only words, but pauses, coughs, pitch, and tempo (where appropriate), as well as other para-linguistic behaviours (such as throat clearing or sniffing). It more closely meets the needs of an ID study, as it facilitates deep, contextualised data analysis while preserving readability; it is, in short, a *useful* transcript. Including para-verbal and para-linguistic sounds and behaviours is important in an ID study, as they not only provide contextual information, but may provide valuable cues that point to otherwise hidden meanings. In this excerpt, for example, the pauses and emphasis lend a different meaning than the words alone:

> P: Yeah I love this place I really do love this place. The staff is nice, everything is very very clean. The food is very good, the cook is a very good cook. It's … like … [2s] … being in a home … [2s] … it's just … [2s] … not *too* bad you know.

Ensuring that the transcript type best meets the needs of the study helps to ensure methodological congruence. Methodological congruence refers to "fit" between the research question and the way in which the research is enacted (Mayan, 2013; Morse & Singleton, 2001). The validity of the findings depends in part on methodological congruence. Transcripts are a tool that researchers use to monitor methodological congruence between the research question and the methods used to conduct the study, from the research question, to data collection, analysis and presentation of results.

Transcripts are, at least in part, interpretive documents (Bird, 2005; Davidson, 2009; Durante, 2006; Henderson, 2017; Lapadat, 2000; Ochs, 1979), as their preparation requires many analytic decisions (Davidson, 2009; Jaffe & Walton, 2010). To say that a transcript is interpretive does not mean it is a work of fiction, it simply highlights the processes of interpretation and judgment required on the part of the transcriptionist (Hammersley, 2010). The choices transcriptionists make can alter the participants' meaning and may, therefore, have implications for data analysis and study findings. The ways in which non-verbal data are conveyed can change the inferred meaning. Laughter, for example, can be represented in a transcript simply as [laughter], yet this does little to convey the participant's meaning and demands further interpretation, as [laughter] could refer to a hearty belly laugh, an ironic chuckle, or a nervous giggle (Bailey, 2008).

In addition to non-verbal communication, choosing to spell words according to standard spellings ("you know" or "should have") or non-standard, individualised spellings ("yuh know" or "shoulda") can also have implications for data analysis. When reading a transcript, it is possible that researchers may make subtle and unconscious judgments regarding the socioeconomic status, race, and education level of speakers based on the written word used (Jaffe & Walton, 2000). These judgments may in turn affect the analysis of the data and may lead to unintended misrepresentations. Clearly, then, the interpretation of the participant's intended meaning and, by extension, the veracity of the findings, depend to some extent on the type of transcript (e.g., simple, broad, or complex), the way words are spelled, and the inclusion of paralinguistic features.

Engagement with transcripts

Thorne (2016) writes only briefly about transcription, but encourages "engagement in the transcription process as a means to enforce that shifting pace of attention that characterises so much of our scholarly reading and reflection" (p. 158). Transcribing encourages immersion in the data, as it demands a different kind of listening than ordinary conversation (Davidson, 2009; Hammersley, 2010; Henderson, 2018; Thorne, 2016). Thus, transcribing may encourage or inspire ID researchers to view data from a different and, perhaps, richer perspective than that gained from reading the transcript alone.

Transcription done by the researcher is ideal, but transcription is a time-consuming task, and it may be unrealistic for all researchers to transcribe all interviews. Alternative suggestions include selecting transcriptionists carefully and ensuring that they are aware of the study methods and purpose. Also important is deciding what type of transcript to create: what elements of speech and, particularly, non-verbal data to include in the finished transcript, and whether to use standard or non-standard spelling. Transcription decisions should be revisited as data analysis progresses, because what needs to be included or excluded from transcripts may change as the researcher explores new insights (Hammersley, 2010). The importance of the researcher returning to the data—listening to the audio recordings—whilst reading the transcripts, cannot be overemphasised, because it may illuminate errors as well as areas of divergence from participants' intended meanings. At a minimum, re-reading transcripts while simultaneously listening to the audio recordings provides the researcher with the opportunity to immerse him or herself in the data and pay attention to the context in which the interview occurred. As Olson (2011) notes, data analysis should not begin until the researcher has verified the transcripts.

Data in ID are deeply contextualised; their analysis consists of the researcher exploring overall meaning, looking for patterns, and, importantly, deviations from patterns, while consistently asking "what are the data telling me or not telling me"? (Thorne, 2016, p.174). Thorne (2016) encourages researchers to "explore alternative angles of vision" (p. 173) throughout the data analysis process, but provides little in the way of direction for *how* to explore alternative views. Peshkin (2001), however, explained the similar process of deliberate and disciplined "planned ways of perceiving" (p. 242) or the process of choosing various lenses through which to explore data and enhance their analysis. He was an American anthropologist, who used ethnographic methods to study schools in the USA, and became interested in exploring his subjectivity as it occurred to understand its influence on the research process (Bradbury-Jones, 2007; Peshkin, 1988). Peshkin (2001) used the analogy of a walk in the country to explain the process of exploring alternative views. He described his deliberate decision to focus on the entire landscape by bringing different elements, such as sounds or textures, from the margins to the forefront of his awareness at different times. This encouraged "a wealth of perceptions" (p. 239) that would otherwise have been impossible without the deliberate attention to different angles of vision.

Peshkin's (2001) process for exploring alternate views is similar to what Benner and Tanner (1987) term "deliberate rationality" (p. 28), which they describe as "trying on alternatives" (p. 29) to clarify a nursing decision by considering how different perspectives may extend interpretive possibilities. Each category or each angle of vision simply forefronts a different perspective, while maintaining the integrity of the whole.

Viewing data from different angles is not the same as disassembling or "fracturing" the data, as Thorne (2016) explicitly advises against this practice. Instead, Thorne (2016) recommends reading in broad, generic "meaning units" (p. 160) rather than fragmenting or fracturing the data through micro-analysis. This again speaks to the parallels between ID and nursing practice, in which nurses approach problems "with perceptions of the situations as wholes rather than as combinations of elements, bits, and cues" (Benner & Tanner, 1987, p. 29).

For example, reading the first sentence of the following excerpt without considering the rest of the paragraph would convey a different meaning than reading the paragraph in its entirety:

> P: Um, well the first thing that comes to mind is there's not a lot of joy here, . . . a lot of our patients come in quite sick now; maybe they're too sick to feel joy. This one lady, her daughter came in, got her into the wheelchair, and took her outside, where her granddaughter was waiting for her in her wedding dress. Definitely a lot of joy in that moment. So, yeah, the more I think about it . . . I would have said originally there are more patients who don't have joy, but when I think about it, more do.

If this passage were coded line-by-line, the researcher may conclude that "there's not a lot of joy" or "patients are too sick to feel joy". Reading the entire passage, however, gives a different meaning as the participant articulates, at the end of the paragraph, how she came to realise that patients do in fact experience joy in this setting.

The ability to adopt a different lens is inextricably bound to the practice of reflexivity. Unlike reflection, which involves looking back at past experience to promote learning (Horton-Deutsch & Sherwood, 2008), reflexivity is a conscious and deliberate critical self-examination of how the researcher affects and is affected by the research process and outcome (Berger, 2015; Bradbury-Jones, 2007; Olson, 2011). Reflexivity involves looking within and reflecting critically on ourselves as researchers, and asking how our own subjectivities affect our decision-making in research (Berger, 2015; Bradbury-Jones, 2007; Olson, 2011).

Reflexivity is an important component of both the analysis process and rigour, because it exposes the creative and interpretive nature of analysis and makes researcher subjectivity explicit throughout the research process (Bradbury-Jones, 2007; Olson, 2011). This monitoring of self-as-researcher provides the opportunity to catch and manage threats to reliability or credibility before they occur (Morse, Barrett, Mayan, Olson, & Spiers, 2002; Olson, 2011). This ensures that rigour is an integral component of the study as it is taking place, rather than a post hoc assessment.

Conclusion and Implications

ID is predicated on a naturalistic, relativist ontology, a constructivist epistemology, and is inherently pragmatic, focusing on developing useful practice knowledge from within the disciplinary epistemology of nursing. This inherent pragmatism demands a transcript that includes all verbal data and captures salient contextual features, while preserving the veracity of the participant's contributions.

Transcripts reflect the ontological and epistemological assumptions embedded in the research question; researchers can monitor the rigour of a study as it is being conducted by using the transcripts to check the connections between the research question and the approaches used to conduct the study. The inclusion of contextual information within a transcript further assists the researcher in monitor this process. ID requires transcripts in which the data are contextualised but are unencumbered by linguistic details, which may disrupt the flow of the language. Striking a balance between too much and too little contextual data is essential to facilitate data analysis.

For qualitative researchers, understanding the influence of transcripts on the study findings is critical. Transcripts are critical components of an ID study, as they transform multidimensional, contextualised speech into unidimensional, static text (Lapadat, 2000). Researchers may rely on transcripts without fully understanding their interpretivist nature, and may be unaware of the role of the transcriptionist in the co-creation or representation of data. Whereas accuracy of what is said during an interview is important to avoid misrepresenting participants' contributions, transcripts are not strictly verbatim accounts of interviews, as they typically broad rather than complex in nature. Qualitative researchers need to be aware of the interpretive nature of transcripts and consider decisions pertaining to transcripts early in the study planning process (Jaffe & Walton, 2000). In ID, as with other qualitative methods, the responsibility for the truthfulness and quality of the overall study findings and, by extension, the development of relevant and useful nursing knowledge, hinges on the researcher's careful attention to nuanced, reflexive, and interpretive analysis of transcripts.

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Chapter 5: Paper 4: "Being alive": An interpretive description of joy at the end of life in hospice

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“Being alive”: an interpretive description of joy at the end of life in hospice

The concept of joy has received little attention in the palliative care literature, which is dominated by concepts such as pain, suffering, and existential distress (Boston, Bruce, & Schreiber, 2011; Nakashima & Canda, 2005). Although palliative care research is growing in areas such as meaning, spirituality, hope, and quality of life (McClain, Rosenfeld, & Breitbart, 2003; Nakashima & Canda, 2005; Kylma, Duggleby, Cooper, & Molander, 2009), the dominant research landscape remains embedded primarily in the management of physical symptoms McNamara, 2004; Nakashima & Canda, 2005). Although much has been written on death and dying, little has been written on joy during the dying process, even in the context of “the good death”. As nursing involves caring for individuals experiencing all facets of the human condition (Meleis, 2012), and because the goals of palliative care are to improve the quality of life for people with advanced illness (CHPCA, 2015; Pickett, Cooley, & Gordon, 1998), further exploration into experiences related to quality of life is necessary.

The aim of this study is to better understand and describe the concept of joy as experienced by adults with advanced cancer in hospice. By making joy visible within palliative care, this study aims to help nurses see ways to encourage joy in hospice patients.

Joy as a concept is poorly understood. Though it is colloquially often included under the broad rubric of happiness, joy is vastly different. Joy may be defined conceptually as a spontaneous, sudden, and transient feeling of elation and delight, which is associated with connection, awareness, insight, and freedom (Cottrell, 2016). Exploring and making explicit patient experiences of joy at the end of life may influence and direct nursing care, thus improving patients’ quality of life.

Literature Review

Joy in Palliative Care

The concept of joy is rarely the focus of a palliative care study, but has emerged in the work of a few research groups (Lin, 2003; Olsson, Ostlund, Strang, Grassman, & Friedrichsen, 2011; Soares, da Silva, Santos, & Depianti, 2016). These authors discussed joy as a benefit of working in palliative care, but were focused on joy in health care providers (Lannie, 1978; Twycross, 1997; Dunne, 1999; Gibson, 2004; Puchalski, 2004; Kirkland, 2016), volunteers (Muckaden & Pandya, 2016), or family caregivers (Gauger, 2014; Horsfall, Noonan, & Leonard, 2012; Magill, 2009).

Only two studies explored the concept of joy from the perspective of individuals with advanced illness. Banos et al. (2013) explored the participants' experiences of joy through a virtual reality experiment in 19 hospitalized patients with advanced cancer using a mixed methods design, and found that joy increased positive emotions while decreasing negative emotions. Using an interpretive phenomenology analysis methodology, Linge (2011) discovered that hospital clowns could encourage joy in children with advanced cancer in a study of 20 paediatric health care providers. Study findings suggested that participants associated joy with "possibilities and a feeling of freedom" (p. 7).

Joy has been alluded to in two other palliative care studies. Lee and Pilkington (1999) explored Parse's (1997) related concept of joy-sorrow in a case study of a Korean woman with advanced cancer. In another study, Horsfall, Noonan, and Leonard (2012) wrote that caregivers reported "joy and grey hollows" (p. 378) when caring for relatives with advanced illness, which is similar to Parse's (1997) concept of joy-sorrow.

These few studies of joy within palliative care contribute to our understanding of joy in this population. This study was designed to help fill the gap in knowledge about joy from the standpoint of individuals in the context of hospice. This understanding will provide a foundation that can be used by nurses to encourage joy in this population.

Method

The question guiding this exploratory interpretive description study was “how can we better understand the experience of joy in individuals with advanced cancer in the context of hospice?” Interpretive description (ID) was selected as the approach for this study because it addresses the research question with the first author’s interest in exploring joy through a nursing lens. ID is an approach to qualitative inquiry that arose from within the discipline of nursing and is designed to explore practice problems from the gaze of the nursing discipline (Thorne, 2016). The question underlying this study arose from the first author’s experiences as a practising nurse, in which she observed joy in individuals with advanced illness, yet found a disjuncture between what was witnessed in practice and the descriptions of hospice patients’ experiences in the literature. ID provided a flexible and pragmatic method to explore this nursing practice problem. As a design, ID offers “the potential to deconstruct the angle of vision upon which prior understandings have been erected and to generate new insights that not only shape new inquiries but also translate them into practice” (Thorne, 2016, p. 40).

Credibility was enhanced throughout this study by using Thorne’s (2016) criteria of epistemological integrity, representative credibility, analytic logic, and interpretive authority. Epistemological integrity was determined by ensuring strong links between the research question and the way knowledge was generated in this study. Specifically, because the research question focused on how patients viewed joy, data were collected using an unstructured interview format in which participants were invited to describe their experience in detail. Participants were also invited to photograph, draw, or produce a picture or artifact that represented joy for them.

Representative credibility was augmented by considering alternative angles of vision and by the use of alternative data sources as a collateral approach (Thorne, 2016). Nurses provided collateral data by describing not their own experiences, but their observations of patients' experiences, which helped to affirm representative credibility, as did the analytical process of considering alternative angles of vision. Analytic logic was maintained by researcher reflexivity throughout the data analysis process, which included maintaining an audit trail of decisions made. The findings in this report are supported by *in vivo* data from study participants, which illustrates the researcher's commitment to interpretive authority.

Study findings were developed from within the disciplinary standpoint of nursing (Risjord, 2011; Thorne, 2016) and, as such, are directly relevant to and useful in the practice of nursing and to the population (adults with advanced cancer in hospice). In addition, these findings adhere to the principle of probable truth, which means that they do not seek "truth", but reflect meaning derived from within a particular place and time (Thorne, 2016). As knowledge is continually evolving, the findings of this study represent one interpretation of the meaning of these study participants' experiences of joy.

Ethical approval for this study was obtained from the University of Alberta Research Ethics Board (REB File#Pro00064093).

Study Participants

Participants were recruited from a free-standing not for profit hospice in an urban western Canadian city. Potential participants were identified and initially approached by hospice staff, who asked if they were willing to meet with a researcher. The researcher met with interested potential participants to discuss the study and provided an opportunity to answer any questions about the study. Those willing to take part provided written consent, and appointments for interviews were scheduled, though on one occasion a participant requested to be interviewed immediately after providing consent. A total of seven patients were recruited: three males and four females. The average age was 68 (range 60-75; SD 4.8). All participants had a diagnosis of cancer. Only one participant was married; one was a widower; two were single and three were divorced. Regarding religion, three participants were Roman Catholic (two "non-practising"); two stated they had "no religion"; one was a non-denominational Christian, and one was a Wikka practitioner. Level of education ranged from Grade 8 to graduate studies.

Demographic data portray just one view of the study participants and omit contextual factors that add depth and perspective to the study findings. Participants in this study all lived in East Vancouver, an area historically associated with ethnic diversity and lower-than-average income (Statistics Canada, 2011). Prior to coming to hospice, three study participants were precariously housed, living in single room occupancy hotels; they described themselves as "loners" or "drifters". Four participants had worked at odd jobs in restaurants and bars or as general labourers, though three participants had had professional careers. Most participants reported having had tumultuous lives, and six of the seven participants described their childhoods as "horrific" or "terrible". They shared stories of psychological, physical, and sexual abuse and violence in childhood (and, for some, into adulthood), and spoke of how the neglect and fear they felt as children had profoundly affected them throughout their lives. Three participants disclosed that they had struggled with addictions. One participant fled his home country, where he described living with a "constant fear" of being persecuted for being homosexual. All of the participants had difficult family circumstances, and were either estranged from their families or had no close relationships. The one participant who was married at the time of the study stated that she had lost her sister and her daughter to "drugs and prostitution”. Two participants had restraining orders preventing family members from visiting the hospice.

In addition to patient participants, six hospice nurses were recruited to provide collateral data, as described previously. Thorne (2016) wrote that using the experiential knowledge of practitioners who have “seen many cases over time” (p. 93) provides a “rich source of insight about clinical patterns and themes that would not [be] accessible through other available data sources” (p. 93) and, “may help to counterbalance the known limitations of the data source and provide at least one additional angle of vision” (p. 92).

A combination of methods was used to recruit nurses. The inclusion criteria stipulated that nurses must have one year of full time practice, or its equivalent, to provide the opportunity for them to have observed cases over time. The researcher relied on others to identify nurses who were considered experts or outstanding hospice nurses, as suggested by Morrison & Symes (2011). As such, three nurses were recommended by the nursing manager at the hospice, and three nurses were recruited from other local hospices after recommendations from colleagues. Nurses were purposively selected from outside the patient recruitment site to obtain observations of joy from a different practice setting, as recommended by Thorne (2016). Five nurses were female and one was male; the mean age was 47.5 (range 27-71; SD 14.7). With respect to educational preparation, one nurse was a licensed practical nurse; five were degree-prepared registered nurses, one of whom had Canadian Nurses’ Association specialty certification in hospice palliative care. One nurse had a Master’s degree; one, a PhD. Years of experience in hospice and/or palliative care nursing ranged from 1.5 to more than 25 years. Two of the nurses were previous acquaintances, but not colleagues, of the researcher.

Data Collection

Data were collected during face to face audiotaped semi-structured interviews, which lasted from 40 minutes to 1.5 hours (See Appendix I for interview guides). Patient participants were interviewed at the hospice, either in patient rooms, in the lounge area, or outside in the garden. Three participants were well enough to participate in a second interview for a total of 10 patient interviews; the second interviews were shaped by the data analysis process, and served to clarify meanings and provide direction for further interviews. Nurses were interviewed at a location outside of the hospice, after providing written informed consent. Nurse interviews lasted from 45 minutes to two hours.

In addition to interviews, patient participants were encouraged to use visual elicitation methods, such as participant-provided artifact, participant drawing or photography, or participant description of an image that represented joy to them (see Appendix II for participant images). This approach was used because joy may be an intimate topic (Potkay, 2007), and thus participants may find it difficult to articulate their experience using words alone. Visual elicitation methods are thought to help participants "express the unsayable" (Guillemin & Drew, 2010, p. 179), and are considered less tiring and repetitive than conventional interviews (Harper, 2002). For this reason, they may also provide data that are different from or unavailable through words alone (Harper, 2002). Despite reports that adults may find the creative process embarrassing or awkward (Guillemin & Drew, 2010), four participants chose to participate in the visual elicitation component: two took photographs, one drew a picture, and one participant produced a computer-generated image. Participants were invited to participate in the visual elicitation component during the first interview. Initially the researcher asked participants if they would be willing to draw, photograph, or produce an image of joy; this was later revised to ask participants to visualise a joyful experience, and then describe or draw what they visualised. All materials were provided by the researcher. One participant drew whilst being interviewed; one took a photograph near the end of the interview, and another asked the researcher to take a photograph for her. The participant who provided a computer-generated image asked for time to consider what to include as an image of joy, so the researcher met with her the following day to discuss the image she had chosen. Participant-derived images were discussed during the interviews; thus the data pertaining to images was incorporated into the overall analysis.

Data Analysis

All interviews were audio recorded, transcribed, and cleaned by the researcher. Data analysis followed Thorne's (2016) procedures. For example, the research purpose—to illuminate relevant patient insights about joy in this context—was forefronted in the data analysis process; as such, transcripts were analysed concurrently with data collection, and interview questions were revisited and revised throughout data collection and analysis.

The researcher read all of the transcripts several times prior to coding to get an overall sense of the participant's meaning, considering broad questions such as "what am I seeing or not seeing here?" and "what are these data telling or not telling me?" This helped to keep the analysis process open and the researcher's analytic vision broad, rather than focusing immediately on the minutiae of the data. Transcripts were coded inductively, in blocks of text rather than line-by-line, which helped to keep the coding process centred on the study purpose; that is, to better understand the ways in which participants describe joy, how joy feels when it is happening, and how it occurs. Initial codes were broad, and involved grouping together related ideas and thematic patterns, which were later re-examined and tested to see how they fit within the pattern and within each other. Codes were checked several times before tentatively grouping them into preliminary themes or categories. Preliminary themes were then re-examined and deconstructed, by exploring alternative explanations and comparing accounts from hospice participants with accounts from nurses (Thorne, 2016).

Initially, all data sources (patient and health care provider transcripts) were analysed separately. Health care provider data were used to inform patient data and the patient voice was predominant in the analysis. Tables were created according to data source and preliminary theme. Tables were then combined to create matrices according to themes. Conceptual mapping or diagramming was used to visualise relationships within and between themes. Data organised into tables or diagrams added a visual dimension through which strengths and weaknesses in the analysis became evident, thus inviting re-analysis until reaching the final description.

Visual elicitation data were integrated into and analysed with participant transcripts as participants described how the image captured or embodied joy. Three participants' images represented things that brought them joy—a flower garden, family members, and dancing—whereas one participant's image—bubbles—represented how joy made her feel. In addition to participant's descriptions, field notes describing the participant's body language and mood during the process of creating the image, as well as the actual image, were included in the analysis of visual elicitation data.

Findings

Context

Thorne (2016) suggests that all data are analyzed within the context of the participants' lives. Each individual's life journey is unique, yet these participants all lived in a liminal space, at the threshold between life and death in a setting that was neither home nor institution (Broom & Cavenagh, 2011; Ho et al., 2013). Hospices are not neutral places, but are imbued with meaning (Broom & Cavenagh, 2011); they are places where the living come to die. The context of hospice was potentially a significant actor that may have shaped study participants' experiences of joy.

Joy

The following description of joy is a synthesis, created from patterns and themes of study participants' descriptions of joy in hospice. Participants described the experience of joy as a sudden "moment in time in which everything comes together" and from which comes strength, freedom, and the feeling of being alive. Participants associated joy with an intense feeling of deep connection. Participants' descriptions of joy had three dependent, interconnected themes: a) "being aware"; b) "being with"; and c) "being alive". Being alive was the central theme, in which being aware and being with culminated, and represents the moment of joy (See Figure 5.1). Though discussed as separate entities, all of these themes were interdependent and inextricably linked. Participants experienced joy not as a linear process, but as a sudden moment in which they oscillated amidst and between themes.

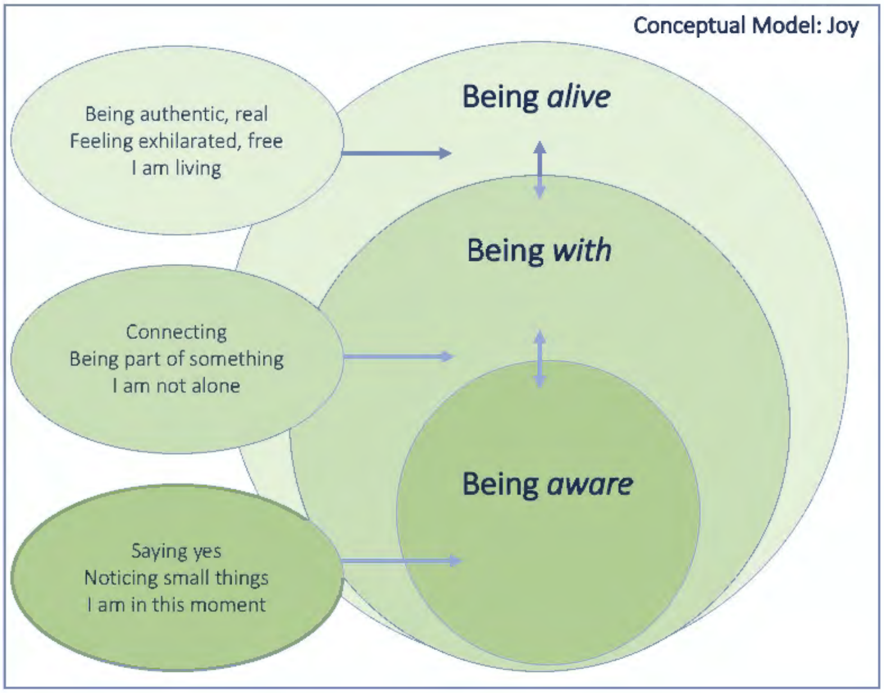

Figure 5.1: Conceptual Model: Joy

Being aware. Being aware included the subthemes of “saying yes”, “noticing small things”, and “I am in this moment”.

Saying yes. Participants spoke of “putting yourself in a position to have joy” as necessary to experience joy. As one participant said:

> I chose to be positive, to choose *possibility*. I realised that I said no to everything to protect myself. And I thought “ok I’m going to spend one year saying yes.” And I did. And I realised that as long as I said yes to joy it said yes to me.”

Saying yes did not mean conjuring a joyful moment or experience; it simply meant to be in a position where joy may occur. Although participants said they could not conjure a moment of joy, they made a conscious choice to “say yes to the possibility of joy”.

Noticing small things. Through being aware, participants described a new awareness of their surroundings, an appreciation of the kindness of others, and an acceptance of the importance of each moment. Perhaps the knowledge of their imminent death sharpened participants’ appreciation for the world; one participant mentioned that “I have had much, much more joy in this time of my life, since knowing I was going to die, than I ever had before”. This heightened sense of awareness brought participants a sense of joy in everyday, ordinary things, such as birds, the sound of children’s laughter, the kindness of others, and nature, or “the beauty of the place”. Two participants recounted stories of watching hummingbirds bathing, which brought them intense joy; one stated: “a little hummingbird would come every day and have a shower and a bath and that’s joy to me”. Collateral data supported this finding, as nurses described patients experiencing joy as “nothing remarkable, just very ordinary. It’s just an observation of something that’s being reflected from the inside out”. Another nurse described witnessing patients’ joy as “being aware of the sacred or preciousness of life, a sense of what matters, even the smallest things". Though joy was found in small things and in ordinary, everyday moments, it was extraordinary and powerful.

I am in this moment. Being aware meant noticing, being in, and accepting each moment. The acceptance participants articulated was not defeat or resignation; to the contrary, participants gave the sense that acceptance meant savouring each moment, and coming to accept themselves. One participant spoke of accepting his situation: "you have to enjoy the moment that you have, whatever it is". Another said: "This joy of being honest with myself, you know this is just where I'm at and that's ok. All I got is right now" (P5). For another participant, acceptance was a challenge: "But it was HARD, it was really hard knowing that I couldn't do anything. I couldn't do *anything*. I have a beautiful family, still got lots of years left right you know? But it's not gonna be that way, right? So I just do the best I can the way it is now". "Being aware" brought to participants a sense of appreciation for each moment; it made the ordinary extraordinary and joyful.

Being with. Being with represented an intense feeling of deep connection with self, others, and with the universe. As one participant described when she experienced joy:

> It was just a feeling; it's hard to describe, but we all felt it at the same time. We were sitting in the car and as soon as [my daughter] said it, we *knew*. We could feel it; the air . . . was charged, there was an energy. I turned around and we all looked at each other, our eyes met. No one said anything, but we all had this moment of togetherness, like aha!—a moment of connecting, of coming together. It was powerful. And then it was just . . . gone. But we all felt as if we'd shared something big.

Though not distinct sub-themes, as they are too closely interrelated, connecting, being part of something, and I am not alone represent this theme. Participants described joy as a relational concept; joy is about being with and connecting: with self, with others, with nature, or with God. When asked what joy looks like, one nurse described patients connecting with themselves: “It’s all in the eyes, just settling down into their being, and there’s a real sense of here’s a total being. It’s a real inner groundedness”. The primary thrust of the connection was external, focused on connection with and to others.

Participants described connecting with others through kindness, generosity, and a feeling of being cared for. Being with included feeling gratitude**,** as participants noticed and were surprised by the kindness and generosity of others. One participant stated he found joy “in the kindness of everyone here, it’s unbelievable”. Another participant became emotional when discussing “how *generous* everyone is”; he tearfully recounted narratives of how staff members and other patients’ family members brought him food and small gifts, and spent time with him, taking him out for car rides and trips to the store. He noted that he had never before felt deserving of care or kindness, and feeling the generosity of others was an emotional experience. He said “maybe this is what joy is for me”. Several other participants shared similar stories about “feeling cared for” and one nurse mentioned “the joy—you see it in patient’s eyes—when you do something, even something so small for them”.

Participants found joy by being with their families, God, or nature, by being a part of something. One participant described finding joy “in beauty—the ocean, the trees, the mountains”. Other participants found joy through their relationship with God; one described joy as “sitting quietly here and connecting with God”. Connecting with loved ones was important; one participant said she found joy in “looking at those pictures of my grandson”. The walls of her small room were covered with photographs of her children, her husband, and her grandson, whom she had raised from infancy. One participant said that "being with children and animals and people is joyful to me", and another participant described "my relationship with my partner" as "the joy of my life". When asked what brought him joy, one participant described his experience of learning to connect: "now I'm finally letting people in a little bit . . . and it's a brand new thing". During his hospice stay, he had reconnected with his ex-wife from whom he had been estranged for more than 20 years. He said that this had been "probably one of the most real and joyful things in my life. I told her I loved her … and it was the first time I meant it".

Collateral data supported the importance to joy of being with. One nurse shared her description of a patient's joy; she said that joy is "just being ordinary, but by sitting together so you can feel my spirit and I can feel yours. It's those little things, those shared moments". Another nurse described joy as "having that moment to connect and dance with people, to touch and let go", while another said "joy is about connection, and being together". Nurses described situations from their practice that described families coming together, rekindling, and sharing.

Being alive. Being alive was the central, unifying theme and represented the culmination of the joy experience, a moment in which being aware and being with came together and manifested as a sense of exhilaration, energy, and freedom. Being alive included the subthemes of feeling exhilarated, free and being authentic, real.

Some participants felt that "joy is just being alive". When asked if having or feeling joy makes you feel alive, another participant replied: "oh, you *want* to be alive . . . you *want* to be alive!" Participants described the vitality and energy they received from moments of joy. One participant described joy as a transformative experience; it was a new beginning, a new start, a new life. He stated:

> what I’m experiencing now is something that I didn’t think I ever would . . . this change of heart, how I [pause] my emotions, my feelings, how everything changed all at once. That’s something I didn’t expect to ever happen to me.

Collateral data provided further examples of joy as a sense of being alive. One nurse, for example, described the joy a young hospice patient experienced when creating a memory journal for her family. The nurse said that the patient expressed joy “through her energy, her strength, and her ability to go on living—she would do her hair up and she *engaged* in life”. Another nurse recalled a story of a blind patient, who endured being carried to the window to “see” the harvest moon. Tucking the patient back into bed, the nurse remembered the patient was blind, and apologised for the ordeal. The nurse described the patient’s response: “with a face filled with joy, she told me ‘I felt the light on my face, and I heard your description of the scene. I lived!’”.

Feeling exhilarated, free. Joy had a visceral quality and was felt physically, which speaks to the interconnection of the body and soul. One participant stated “with joy you just feel *wow*! You’ve got this thing like fluttering in your stomach or your heart; it’s just beating or fluttering. It’s got *oomph* to it, like oh *wow*; it sorta floods through you”. One participant drew a picture of joy: a whirling, slender ballerina leg, and described it as her “dance through life with joy”, adding that “I feel joy when I move my body”. Other participants stated: “I just felt bubbly” and: “you lift up, and you come from the heart [gestured to chest/heart]”. Other participants cried when discussing joyful experiences, or became excited and animated whilst discussing joy. One participant stated that joy is “feeling the world with all of my senses, being truly in it’. Notably, several participants’ joyful experiences included references to the senses: in addition to seeing beautiful things, they described sounds, tastes, and smells that brought or rekindled joy.

Being authentic, real. Many participants spoke of the need to be true, real, authentic. One participant talked about “learning to express what’s underneath, not phony positive, but *real*.” For one participant, joy itself was authentic: “You can’t make that up. Joy has to be real. How else can it be so powerful?” Collateral data supported this sub-theme; one nurse stated: “there is joy in being authentic. People have their own way to die, there is freedom in that. Allowing themselves to *feel* is joy; people not being afraid to be themselves, and to have families and loved ones.” Another nurse described joy as: “it’s when someone is just themselves. It’s not a big opera production, it’s a very humble thing; you feel someone just settled inside themselves. It’s just being ordinary, and being inside themselves and with others.”

Authenticity was connected to a sense of freedom; for one participant, joy meant freedom to live life; she described joy as “learning to become free”, and the absence of joy as “dark, stiff, cold, restrained”. Another participant mentioned that “joy is freeing to my soul”, while another described the absence of joy as “losing freedom . . . to life.”

Discussion

The purpose of this study was to better understand and describe the concept of joy as experienced by adults with advanced cancer in hospice. Findings from this study suggest that the experience of joy begins by being positive, or what participants described as “saying yes to joy”. A positive attitude or outlook may function as an antecedent to joy, and it may be a personality trait (Alessandri, Caprara, & De Pascalis, 2015; Cann, Stilwell, & Tako, 2010; Csikszentmihaly & Hunter, 2003; Steger et al., 2008) or an enduring quality (Martin et al., 2003). Positive personality traits are related to both extraversion and being open to experience (Isik & Uzbe, 2015), and may have a direct relationship with health and with overall psychological resistance (Cohen et al., 2003; Cohn et al, 2009). Positive personality traits were linked to joy in the literature (Consedine, Magai, & King, 2004; Cottrell, 2016), though the relationship between joy and personality traits has not been studied empirically.

By being aware, participants described being in the moment, taking it in with all of their senses and rendering each moment significant. Through being with, participants described the importance of connecting with others, of being a part of something, of not being alone. Being alive represented for participants a moment of embodied joy, as they felt the connection they had to themselves, to others, and to the world. The three themes coalesced in a sudden moment of joy, a moment in which participants described feeling acutely aware of being alive—feeling truly alive, free, and connected to something larger and outside of themselves.

The concept of connection resonates throughout the research on joy. Findings from the concept analysis of joy and happiness (Cottrell, 2016) support connection to self and, particularly, to others, as an important aspect of joy. Empirically, Magill's (2009) study and Linge's (2011) work noted a relational component to joy, and much of the anecdotal and non-empirical work recounts the importance of connection as a component of joy. For example, Kirkland (2016) wrote that finding joy in palliative care medical practice is based in part on collaboration and shared experiences; Dunne (1999) wrote of the joy she received simply by being with and sharing stories with a dying woman. According to Hale (2013), belonging is a compelling human need, through which we feel a part of the whole. The findings of this study posit that connecting through joy is healing, as it overcomes—if even for a moment—the existential alone-ness of the individual (Hale, 2013).

Because of its association with spiritual integrity, as well as its links to religion, joy is often associated with or viewed as synonymous with spirituality (Blinderman & Cherny, 2005). Spirituality may be an antecedent to joy (Cottrell, 2016; McEntee, Dy-Liacco, & Haskins, 2013) and joy and spirituality have in common the experience of connection to self, others, and the universe, or something larger than themselves (Wills, 2007). Yet participants in this study described joy as something quite distinct from spirituality. Spirituality is an active process, a conscious quest to construct meaning, which is realised, in part, as the quest itself (Tanye, 2002; Wills, 2007). Unlike spirituality, joy can be neither conjured nor sought, but simply arrives, unsummoned. Joy *is* meaning, it is not the quest for meaning.

The presence of joy at the end of life may have implications for the western "good death" ideal. This "good death" ideal may be viewed as an increasingly medicalised, controlling discourse that has contributed to shaping an unbalanced and negative view of dying (Cottrell & Duggleby, 2016). Acknowledging the presence of joy at the end of life may help to create a positive view of the dying process, and may help to reshape a more positive discourse of dying.

Limitations

This study has several important limitations. First, recruitment was more challenging than originally anticipated, therefore the hospice participants were obtained through convenience, rather than purposive, sampling. Despite this, they represent a diverse mix of individuals. The study participants were drawn from one hospice, which limits the findings, though collateral data from nurses in other hospices suggests that the experiences of the participants in this study are not unlike those of patients in other hospices. In addition, the participants' characteristics, particularly their histories of abuse and challenging family circumstances, likely shaped their view of joy. Participants from different socioeconomic backgrounds, with less turbulent lives, may articulate a different view of joy. With regard to age, none of the participants were in the oldest old (>80 years) age group; most were, in fact, from among the youngest old (65-75 years). A purposive sample with a more diverse range of ages may have provided different insights and experiences of joy. It was also difficult to interview participants more than once due to the nature of the serious illness of participants, a common challenge to researchers working with individuals at the end of their lives.

Implications for Nursing Research and Practice

The findings of this study offer an initial insight into how joy is experienced by hospice patients, and illuminate areas for future exploration. The concept of joy has direct implications for palliative care nursing research and practice. Understanding the ways in which positive concepts may have value for patients at the end of life is essential to broaden the palliative care discourse and reframe the end of life experience for patients. Further research to explore joy in settings outside of hospice is necessary to further define and refine the concept of joy. Exploring the links between personality traits and joy may be important to ascertain if a positive outlook is a necessary precursor to the development of joy.

For nursing practice, the findings of this study illuminate the significance of joy at the end of life and pinpoint ways in which practising nurses can encourage patients to experience joy. Nurses may encourage joy in patients through small yet significant acts, such as providing compassionate care and by honouring a patient's wishes whenever possible. Nurses can also encourage joy by being truly *with* patients—connecting—as well as listening to and demonstrating authentic kindness, which are simple yet extraordinarily powerful actions. Nurses can also ask patients directly what brings them joy, and encourage them to talk about joyful moments in their lives. This may encourage those individuals who are unable or unwilling to discuss deeper concerns to access their core and experience joy, even for a moment. These actions may transform a patient's dying experience and create a space in which patients feel aware, connected, and alive through joy.

Conclusion

The findings of this study are in no way meant to undermine the importance of astute symptom management in palliative and end of life care. These participants experienced pain, nausea, breathlessness, and other often debilitating physical symptoms, as well as fear, suffering, and despair. But they also experienced joy. They found delight, wonder, moments of freedom, and a profound sense of being alive through joy. The findings of this study suggest that experiencing moments of joy may help patients feel cared for, alive, and connected to themselves and to others. Moments of joy may help those individuals with advanced illness who experience dislocation and alienation associated with liminality; joy may provide the connection that protects from despair and alienation and fosters healing. Being alive through moments of joy is an affirmation of the strength of the human spirit; at the end of their lives, these participants chose joy. In the midst of their dying, they chose to live.

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Chapter 6: Summary, Conclusions and Recommendations

By focusing on joy from the perspectives of people with advanced illness in hospice, I generated new knowledge about the concept of joy for this population in this setting. In this final chapter, I will summarise my overall findings and highlight conclusions, strengths, and limitations of my work to better understand my participants' experiences of joy. I close with implications of this work for future research, clinical practice, and policy.

Summary of Findings

In this dissertation, I focused on understanding the experience of joy from the perspective of participants with advanced cancer in hospice. The theme of discovery was an underlying motif of this work; I discovered that although joy may be a silent discourse in the palliative care literature, its presence was prevalent in the experience of my study participants. This finding—the presence of joy—is not entirely absent in the literature; Banos (2009), Linge (2003) and Magill (2011) described joy as being important to palliative care patients and their caregivers. Joy was also seen as important in the context of palliative and end of life care in a small selection of non-empirical literature (Gauger, 2014; Kirkland, 2017; Lammie, 1978; Twycross, 1997; Witt-Sherman, 2015). In the empirical as well as non-empirical literature, joy was a positive concept that contributed to feelings of safety and/or freedom (Linge, 2003 Magill, 2011), connection to self, others, and/or the universe (Linge, 2003) and improved quality of life (Banos, 2009). Despite these positive findings, research on joy is limited, particularly in palliative and end of life care.

This study suggests that joy may be prevalent in and valued by hospice patients, yet most of the nurse participants in this study were surprised to realise its presence and its importance to their patients and to their practice. Several nurse participants voiced initial scepticism about the presence of joy in hospice patients, yet realised during their interviews that many patients did, in fact, experience joy. This speaks perhaps to the power of qualitative research, and to the ways in which interviews may provide participants who are health care providers with an opportunity to reflect on their practice. Jack (2010) wrote that through interviews, research participants may find new perspectives and validate their experiences. Thus for the nurse participants, it is possible that it was through reflection that they realized their patients did experience joy. Joy in palliative care has been a silent or missing discourse; as a result, the presence of joy has been ignored, and nurses working in the field may be largely unaware of its presence.

There are several possible reasons for the paucity of literature about joy in palliative care. First, joy at the end of life may be hidden given the current scientific, managed approach to care of the dying (Gott, 2008; Kellehear, 2007; McNamara, 2004; Seale, 1998; Walters, 2004). Whereas the philosophy of hospice and in particular the "good death" ideal strove initially to forefront dying as a natural and positive part of life, hospices have gradually become increasingly medicalised (Gott, 2004; McNamara, 2004; Seale, 1998) and discussions of dying are seldom found within the social discourse (Cottrell & Duggleby, 2016).

Second, joy may be an uncomfortable or disquieting concept. On many occasions during the course of this work I was asked—primarily by nurse participants—why I chose to study joy, as it was "a tricky word". Due to its colloquial association with religion, joy may be an uncomfortable concept in an increasingly secularised society (Crowther, 2012). Joy's lack of conceptual clarity is another possible reason that joy is understudied. The literature review and concept analysis revealed how joy is often subsumed by or used synonymously with other concepts, such as spirituality, peacefulness, happiness, or meaning. Joy is undoubtedly related to each of these concepts, yet is markedly different. Unlike joy, happiness is pursued, and is a long-lasting, stable mental state associated with virtue and self control (Cottrell, 2016). Spirituality is, like joy, related to connection; a substantial body of work on spirituality describes connection "to self, others, and/or the universe" (Wills, 2007, p. 423) as an important component of spirituality. Yet spirituality and joy are not identical concepts. They share common threads of connection and meaning; although spirituality may be contained in moments of joy, joy is not necessarily a component of spirituality. Spirituality is associated with peace (Wills, 2007); joy, with vitality (Cottrell, 2016).

These differences and similarities between joy and its related concepts raise several questions: What does joy bring to individuals living with life-limiting illness that its related concepts do not? What specific purpose might the presence of joy at or near the end of life serve? Does joy serve a purpose? Perhaps the purpose of joy is to remind us that we are alive.

Joy is a capricious emotion. In the course of this study, I learned that it cannot be "caused" or forced: real joy is unsummoned, but it is possible to create situations in which joy may more easily surface. Participants articulated that being real, being authentic, being cared for, being loved, experiencing kindness and generosity, as well as being in nature or with their families or God, all contributed to their joy.

Implications for Research

Perspectives of patients who are at the end of life are important because they help researchers frame directions for future studies in palliative and end of life care. Based on the findings of this study, possible directions could include an exploration of the experience of joy in patients with advanced illness living in the community, in 24-hour care facilities, or in hospitals. Exploring joy in other populations is also important, particularly in individuals with dementia and in caregivers, either those who care for relatives with dementia or those nearing the end of life, and in various settings, such as home or 24-hour care facilities.

Exploring the relationships between joy and spirituality is another important direction for research. In this exploratory study I did not explore the links between joy and spirituality in detail with study participants. Understanding the points of similarity and divergence between the two concepts may help to guide research and plan interventions in both of these areas.

In this study, none of the participants related their experiences of joy directly to suffering, though this was not a specific aim of this study. These participants were, however, dying of advanced cancer and may have been experiencing significant physical and existential suffering during the course of this study. They had also lived difficult lives, and thus it is also possible that each had a significant history of suffering, which may have affected their experiences of joy. Parse (1997) and Frankl (1946) both explored the juxtaposition of sorrow or suffering and joy or meaning; both authors concluded that the paradoxical concepts are interdependent and each relies upon the other for its existence. It is, however, unclear if to experience joy human beings need to have experienced suffering. Future research could explore the relationship between suffering or sorrow and joy, and this information would be useful in developing effective interventions.

Understanding the potential links between joy and personality traits or characteristics, such as positive outlook, resilience, or hardiness, may also be important. It is not clear if the ability to "say yes" or choose to be positive is an intrinsic trait or if it is learned behaviour. Future work in collaboration with psychologists, counsellors, or psychiatrists may help to build knowledge in this area, from which more focused interventions could be planned.

Implications for nursing practice and policy

As joy was important to these participants at the end of life, it is important to find ways to provide environments—both physical and emotional—that are conducive to the development of joy at the end of life. The nature of joy—how it arrives—makes it difficult to develop an intervention to increase joy in persons at the end of life. Nurses cannot simply bring joy to patients, as it is intrinsic in nature. More research should be conducted in a variety of settings to determine those factors most salient to the development of joy. For example, this study found that physical environments that provide access to nature and space for family members may contribute to patient experiences of joy. This has implications for hospice design: to build physical spaces that are conducive to joy, with attention given to windows, plants, light, and space. Relational spaces, in which families can gather together, are also important and may help to encourage joy.

Emotional environments are critically important. To encourage joy, emotional environments should be places that support nurses to provide compassionate and authentic care. Ideally, nurses need to have sufficient time to allow patients to make choices and to talk to patients about life experiences, both positive and negative. Many nurse participants spoke of the lack of time and the pressure to complete tasks rather than taking time to engage with and get to know their patients.

It is easy to support the idea that nursing practice should be shaped by the needs of patients rather than by staff shortages and budget constraints, but much more difficult to actually do this amidst competing system-wide challenges and busy clinical agendas. It may be possible to generate new approaches that could be tried, however, by establishing discussion groups on this topic that include clinical staff, patients, and families. Areas for initial discussion could include ways to make real, authentic care possible. Participants also spoke about noticing the kindness and generosity of others, so work environments that value these elements are critical. Finally, I encourage practising nurses to look for joy in their patients, and to *expect* to find it. Often, what we are not looking for goes unnoticed. By looking for joy, I think we help to bring it to the surface and allow it to breathe, to exist.

Summary of Personal Learning

Through this dissertation, I learned that joy is possible for adults with life-limiting illness in the context of hospice. I learned how these participants experienced joy, about how joy made them feel present, connected, alive. I learned that joy is important to people at or near the end of their lives; as one participant stated, “joy is *always* important”.

I learned that building relationships is fundamental to research, but that building relationships as a researcher is very different from building relationships as a nurse. Walking into a patient room as a nurse is an entirely different experience from walking into a patient room as a researcher. I noticed how relationships with participants were not immediately encased in and built upon trust, as they were in my experiences as a bedside nurse. As a nurse, I was trusted immediately; as a researcher, I had to work to build trust. Perhaps my former experience as a nurse intensified this experience, and I wonder if researchers without nursing backgrounds would share a similar experience.

I found my clinical background challenging at times; it was hard not to be a nurse, but at the same time, it was a strength. My disciplinary scaffold rooted in nursing helped me to keep searching and not to decide immediately that the first thing the participant said was the most important. Often, I learned, that participants saved the important things for the middle of the conversation, or the end, after they had learned to trust me.

My nursing self predominated during the visual elicitation component of the study. I journaled about my reluctance to ask participants to complete a task, noting that my nursing self felt guilty for requiring participants to do or to provide something for the study. I felt that I should be caring for and providing for them, rather than asking them to provide for me and the study. This gave me with a great deal of insight about my transition from nurse to researcher, as I gradually learned alternative methods of negotiating with participants (with assistance from my supervisor and committee members).

Through the visual elicitation component of this study, I also learned an important lesson about assumptions. I designed the visual elicitation component primarily as a prompt to aid participants to express their feelings, ideas, and thoughts about joy. I assumed that joy would be a difficult or awkward concept to discuss. Yet all of these study participants talked freely about joy; none required additional prompting. I learned from one participant how asking to produce or describe an image on demand contradicted the nature of joy; she asked for time alone to produce an image of joy, stating that "I can't force it; it has to come to me". From this I learned an important lesson about the necessity to be flexible and responsive in research and to see my own assumptions and their impact on my research more clearly .

I also learned about ID as a method, particularly its similarities to nursing practice. Having started this study using Charmazian grounded theory, I found the differences between methods startling and significant not only in the analysis process, but also when developing the findings and, ultimately, when exploring the applicability of the findings to the practice context.

Strengths and Limitations

Strengths

This study was the first of its kind to explore joy in hospice patients. Patients at the end of life have historically been excluded from research as they have been viewed as too vulnerable to participate (Terry, Olson, Ravenscroft, Wills, & Boulton-Lewis, 2006). This particular cohort of participants, with their difficult histories of substance abuse and precarious housing, may represent a population that is not often included in research studies. This study provided an opportunity for their voices to be heard and shared. The findings contribute to the understanding of joy at the end of life and show that, at least for the participants in this study, joy can exist when a person is dying.

The ID approach used in this study provided an opportunity to develop an understanding of joy that was both descriptive and interpretive. Thorne, Stephens, and Truant (2016) assert that nurse investigators are "rarely satisfied with description alone" (p. 3) but require interpretation to yield findings that are useful "to guide and inform disciplinary thought in some manner" (Thorne et al., p. 3). Interpretation results in thicker findings than description alone. I am looking forward to sharing these findings with nurses and talking with them about ways they think they can use them in their clinical practice.

Limitations

This work was hampered by several important limitations. The study population and setting limit the findings in several ways. First, the sample size itself was small, with seven patient participants, though additional data were provided by nurses who worked in palliative and end of life settings. The patient participants were recruited from one site, all had cancer, and were in-patients in a small hospice. The recruitment of participants from one site may result in a sample that may be demographically more homogenous than it would be had participants been recruited from multiple sites. As mentioned in Chapter 5, participants in this study shared a background of emotional hardship and, often, substance abuse. Replication of this study in other settings is needed to confirm study findings.

Culture was a related limitation: the recruitment site was situated in an urban western Canadian city, which has, like every city and area, its own unique culture. The literature reviewed throughout this dissertation was published in English. Joy is undoubtedly a universal phenomenon, but limiting the literature in this study to English may be a significant limitation to my understanding of the concept.

The main method of data collection, individual interviews, may be a limitation. Interviews provide a snap-shot, a moment in time, and are dependent on many different variables, including the relationship between the interviewer and the participant, moods, time of day and other factors. Further research into joy may benefit from diverse data collection methods, such as observation, rather than relying only on interviews for data collection purposes.

Conclusion

This dissertation promotes an initial understanding of joy at the end of life. I explored the concept of joy within the literature and from the perspective of adults with advanced cancer in the context of hospice. The findings from this study, that joy is a moment of awareness in which participants felt truly alive and connected, provide important information that could be used to structure nursing care for hospice patients and to frame future research questions. It was significant that these participants all experienced joy in the context of a predominantly joyless palliative care discourse. If palliative care is focused on relieving suffering and improving quality of life, these concepts must be broadened to include the importance of joy. To reframe and reclaim dying, we must focus on encouraging joy at the end of life.

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Appendices

Appendix I: Ethics Approval

Notification of Approval

Date:	May 4, 2016
Study ID:	Pro00064093
Principal Investigator:	Laura Cottrell
Study Supervisor:	Wendy Duggleby
Study Title:	Joy at the End of Life: A Constructivist Grounded Theory Study
Approval Expiry Date:	Wednesday, May 3, 2017

Approved Consent Form:	Approval Date	Approved Document
	4/6/2016	Information & Consent Form

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

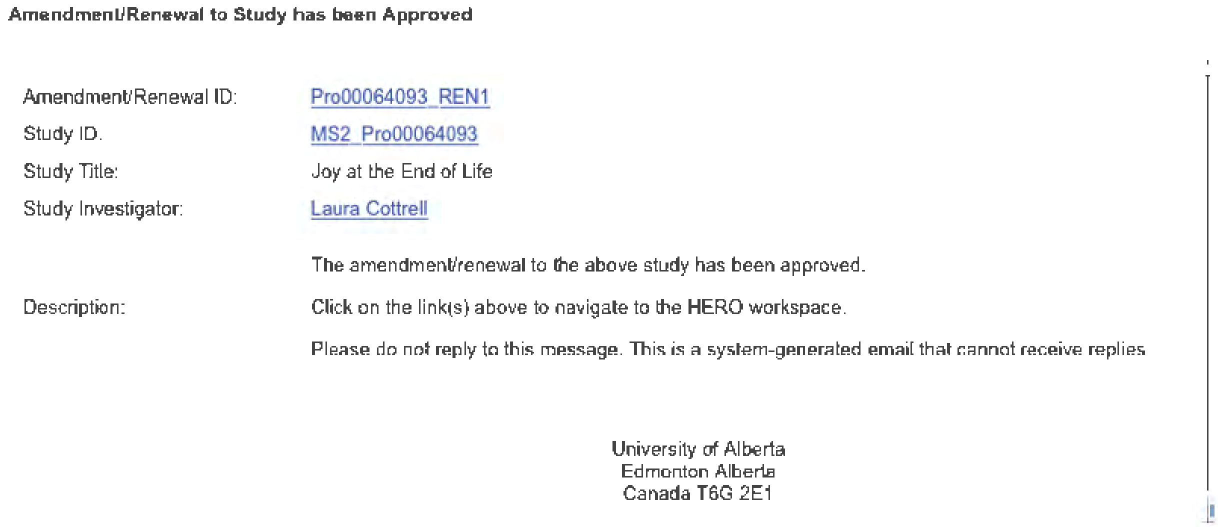
A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Anne Malena, PhD
Chair, Research Ethics Board 1

Note: This correspondence includes an electronic signature (validation and approval via an online system).



Amendment/Renewal to Study has been Approved

Amendment/Renewal ID:	Pro00064093_REN1
Study ID:	MS2_Pro00064093
Study Title:	Joy at the End of Life
Study Investigator:	Laura Cottrell
	The amendment/renewal to the above study has been approved.
Description:	Click on the link(s) above to navigate to the HERO workspace.
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University of Alberta
Edmonton Alberta
Canada T6G 2E1

Appendix II: Interview Guides

a) Patient Participants

Study Title	"Joy at the End of Life: An Interpretive Description"	
Principal Investigator	**Laura Cottrell, PhD (c), RN** Faculty of Nursing University of Alberta	lcottrel@ualberta.ca

I. First Interview (Formal, Unstructured)

Initial open-ended questions:

- To begin, I'd like you to tell me a little bit about yourself and how you came to be here.
- Can you tell me about joy? What is it like for you?
- Have you had experiences of joy since you came to hospice? Can you tell me about those experiences?
- Have you noticed any changes in your experiences of joy? If so, what were/are these changes like?
- Is there anything in particular that influences your joy? What makes you joyful? What makes you not joyful?
- Tell me about a specific experience in which you experienced joy.

Optional Questions:

- In what ways does joy influence your day-to-day life?
- Do you think joy is important for you? Do you think joy is important at this time in your life?

Final Questions:

- Is there anything else you would like to add about your experience of joy?
- Is there anything you would like to ask me?
- What has it been like for you to participate in this study?

II. Second Interview (Formal, Semistructured)

Initial open-ended questions:

- Tell me about this photograph/drawing/object/description
- In what ways does this represent joy for you?
- Is there something else you would like to photograph/draw/bring or describe if you had the opportunity?
- Can you tell me about the thoughts or feelings you had while you were drawing/taking this photograph/searching for or looking at or thinking about an object/or describing an image of joy?

b) Nurse participants

Nurse Interview Guide

Study Title	"Joy at the End of Life: An Interpretive Description	
Principal Investigator	**Laura Cottrell, PhD candidate, RN**	
	Faculty of Nursing University of Alberta	lcottrel@ualberta.ca Phone:

I. First Interview (Formal, Unstructured)

Initial open-ended questions:

- Can you tell me about experiences you have had as a nurse working in hospice in which you have witnessed patients' joy?
- Can you tell me about things you have seen that may help patients in hospice to feel joy?
- Can you tell me about things you have seen that may influence hospice patients *not* to have joy?
- Do you think that the hospice environment influences or hinders the development of joy in patients? In what ways?

Appendix III: Participant Images

Image I: Participant 01

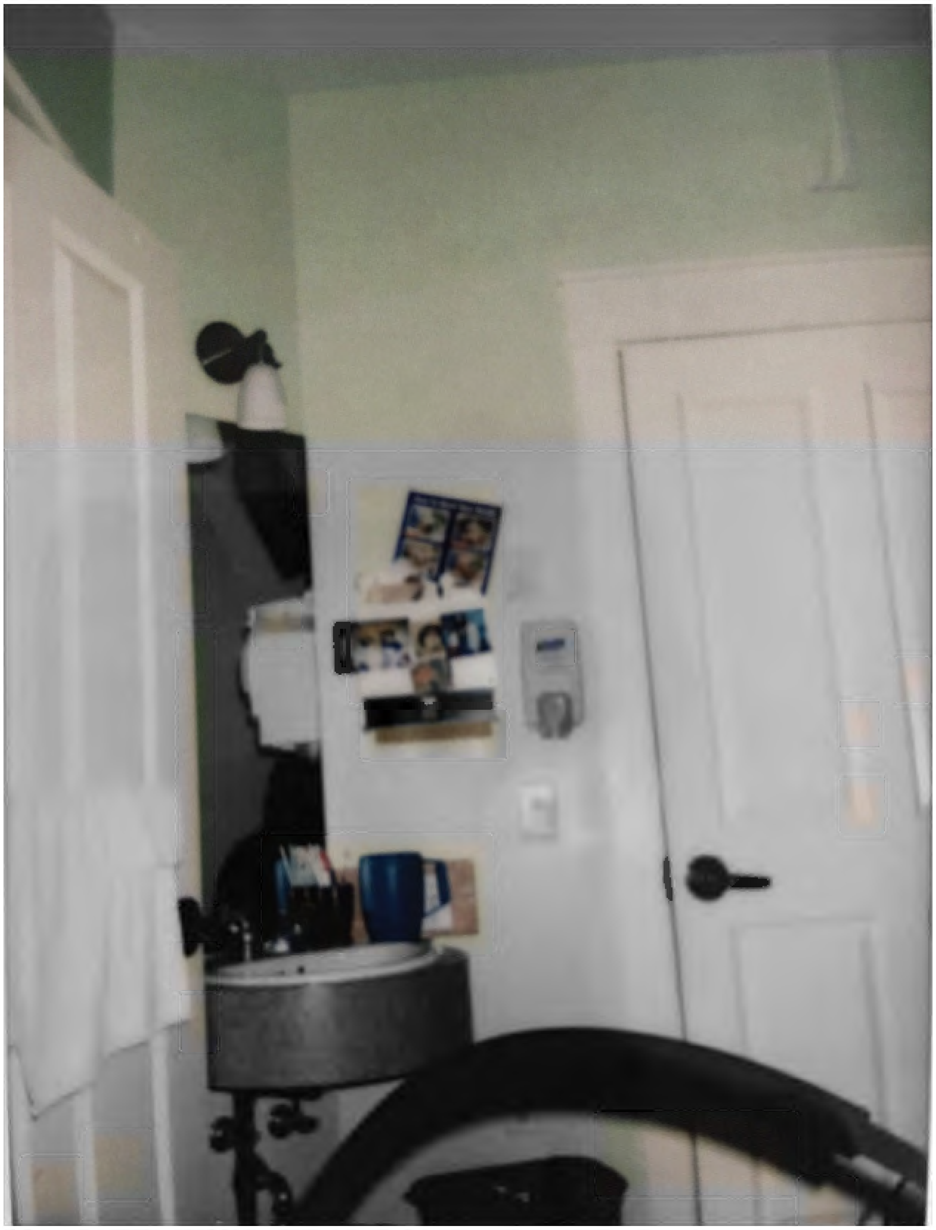

Image II: Participant 02

Image III: Participant 04

Image IV: Participant 06

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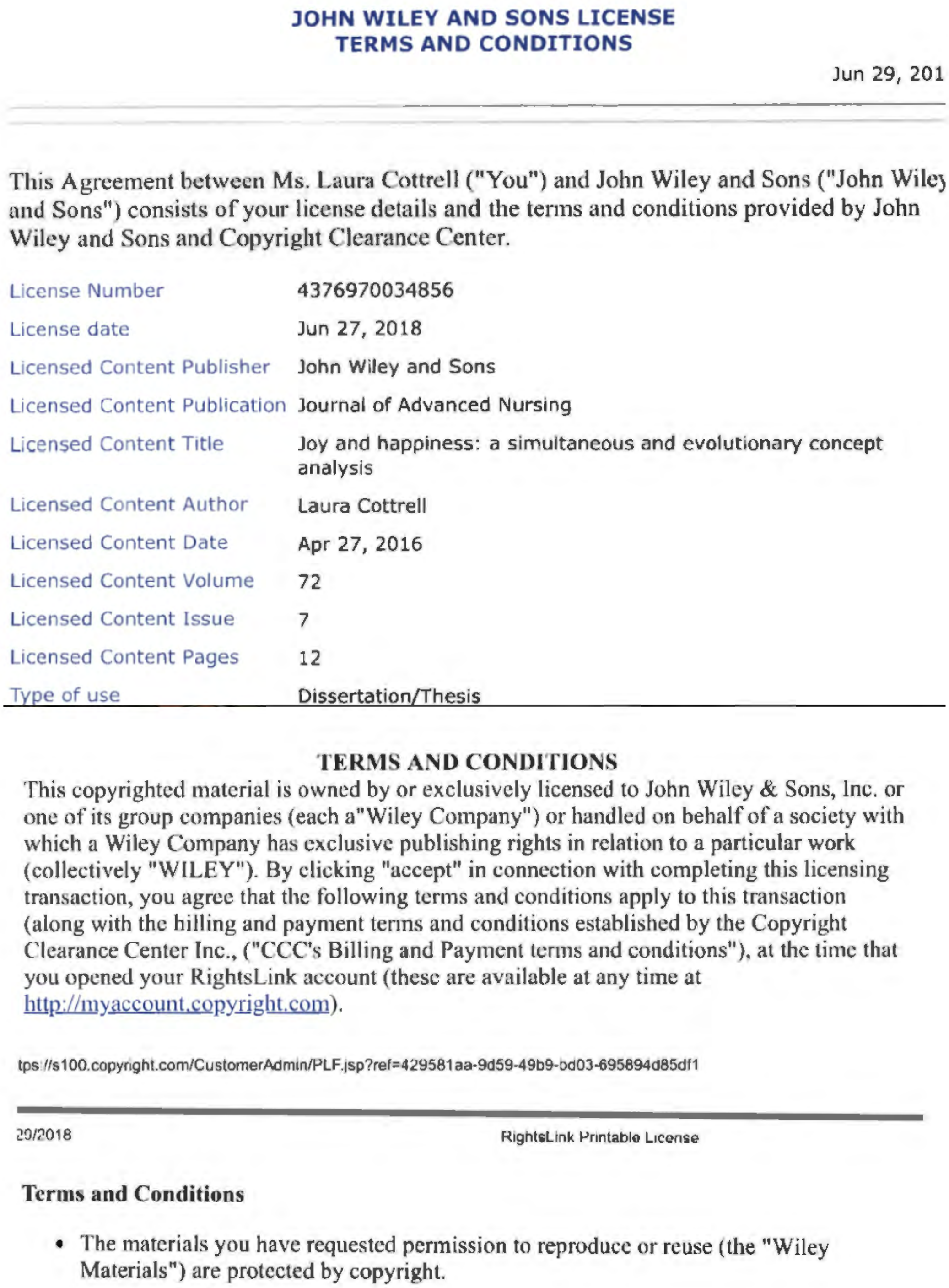

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Licensed Content Author	Laura Cottrell
Licensed Content Date	Apr 27, 2016
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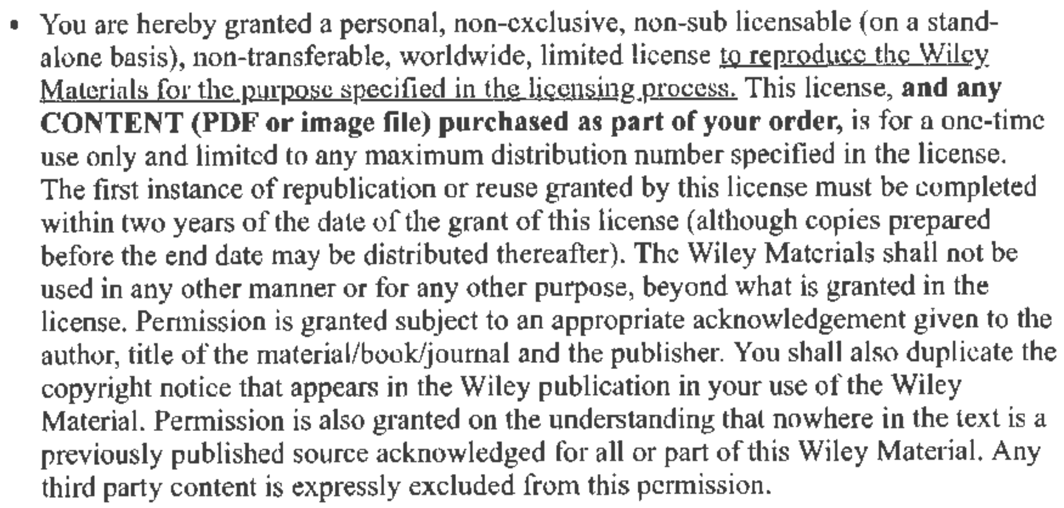

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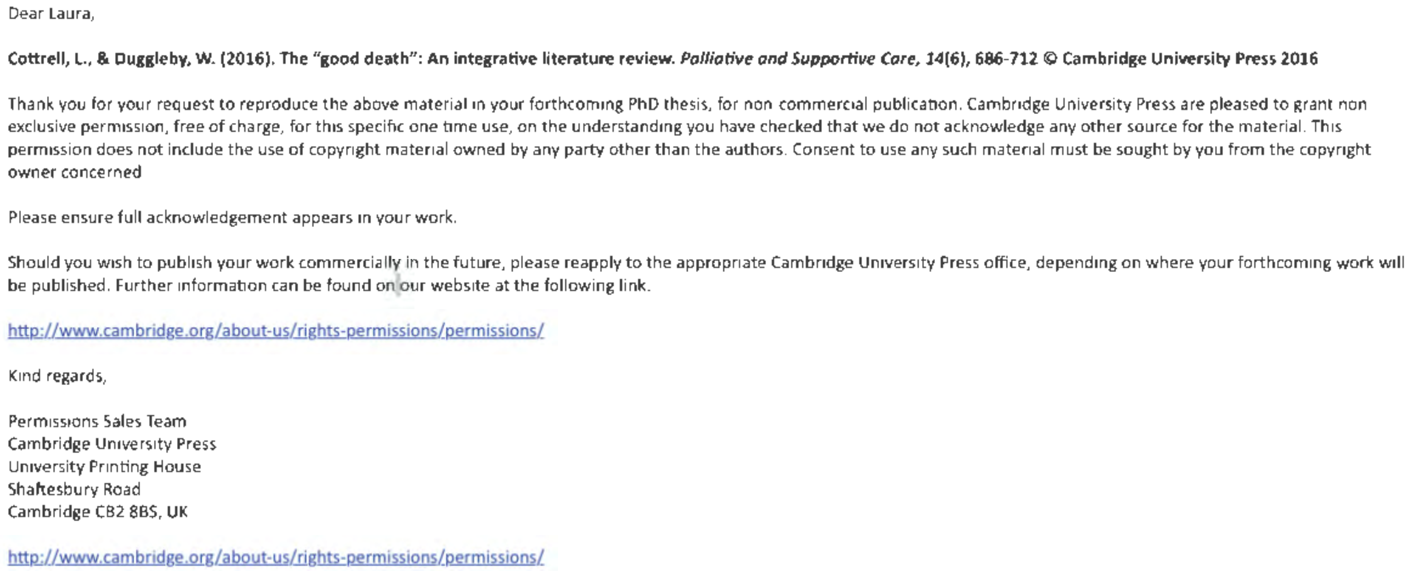

Dear Laura,

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