Is the Waiting the Hardest Part?: How Cancer Family Caregivers Experience Quality of Care at the End of Life

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HOW CANCER FAMILY CAREGIVERS EXPERIENCE QUALITY OF CARE AT THE END OF LIFE

A dissertation
by

PHILIP CHARLES HIGGINS

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Abstract

Cancer caregivers are key stakeholders across the cancer trajectory, particularly in the final weeks of life and the bereavement period that follows. Current measures are limited in capturing caregiver assessment of the quality of end-of-life (EOL) care. Because none include caregiver perception of patient suffering or prolongation of death, the author sought to develop and validate a new measure of caregiver-perceived quality of EOL care that includes these dimensions. Data for this study comes from Coping with Cancer (CwC), a multisite, prospective, longitudinal study of advanced cancer patients and their caregivers (N=275 dyads). CwC investigators interviewed cancer patients and caregivers prior to the patient's death, and then caregivers again following the patient's death, on a range of psychosocial issues related to EOL care and bereavement. The present study represents a refinement of the author's previous work in developing and validating the Caregiver Evaluation of Quality of End-of-Life Care (CEQUEL) scale, a comprehensive measure of caregiver-perceived quality of EOL care. Factor analysis revealed four distinct factors: Prolongation of Death, Perceived Suffering, Shared Decision-Making, and Preparation for the Death. Each item loaded strongly on only a single factor. The author examined the new measure's factor structure, and evaluated its reliability (using Cronbach's α) and convergent validity (via associations between CEQUEL and key EOL outcomes). CEQUEL and its subscales showed moderate to acceptable Cronbach's α (range: 0.52-0.78). Higher scores (indicating better perceived quality of care) were positively associated with therapeutic alliance (ρ=.13; $p \leq .05$) and hospice enrollment (z=-2.09; $p \leq .05$), and negatively associated with bereaved caregiver regret (ρ=-.36, $p \leq .001$) and a diagnosis of Posttraumatic Stress Disorder (z=-2.06; $p \leq .05$). Scores did not vary by caregiver characteristics other than religious affiliation, with Catholics scoring lower than non-Catholics, and those without religious affiliation scoring lower than those with an affiliation. Models predicting CEQUEL scores were compared using multiple regression analysis and AICc values. In unadjusted analyses, dying in a hospital, inpatient hospice length of stay (LOS) < 1 week, patients feeling seen as a whole person by their physician, and caregiver religiosity predicted CEQUEL scores. Only dying in a hospital (B=-1.65, SE=0.42, p=0.000) and inpatient hospice LOS < 1 week (B=-1.87, SE=-.69, p=0.008) remained significant in adjusted analysis. These findings suggest that CEQUEL is a brief, valid measure of quality of EOL care from the caregiver's perspective. This study also identifies key factors that can be modified to improve caregiver evaluation of quality of care and associated bereavement outcomes. CEQUEL is the first scale of its kind to include perceived suffering and prolongation of death. If validated in future work, it may prove a useful quality indicator for the delivery of EOL care and a risk indicator for poor bereavement adjustment. Implications for research, clinical practice and policy are discussed.

DEDICATION

In memory of Elma, the patient who taught me when to laugh,
and Veronica, the patient who taught me when to stop,
and all of the men and women who have bravely and gracefully
followed in their footsteps.

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With gratitude,

Phil

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Chapter I. Introduction

Study Background and Purpose

Cancer caregivers are key stakeholders not only in active cancer care, but also in terminal care and bereavement. With the evolution of patient-focused, family-centered care at the end of life, caregivers – defined here as those family members or other loved ones providing the majority of a patient's unpaid, informal care – play an increasingly central role as patients come closer to death (Teno, Casey, Welch, & Edgman-Levitan, 2001a). "Dying," Stewart, Teno, Patrick, and Lynn (1999) write, "redefines the family as a direct participant rather than an intermediary for the patient, thus, the family's present and future well-being is strongly affected by the care given to the patient" (p.94). Caregivers provide an important perspective on, and reliable assessment of, the quality of end-of-life (EOL) care patients receive (Zhang, Nilsson, & Prigerson, 2012). Caregiver perception of the quality of care provided to a dying loved one impacts not only the health care team's ability to provide good EOL care, but also the caregiver's own mental health during the dying process and in bereavement (Barry, Kasl, & Prigerson, 2002; Hanson, Danis, & Garrett, 1997; Koop & Strang, 2003; Wendler & Rid, 2011; Wright et al., 2008).

Research has identified factors important to dying patients and their caregivers, including avoidance of prolonged death or suffering, shared decision-making, communication with providers about patient wishes, awareness of prognosis and preparation for death (Emanuel, Alpert, Baldwin, & Emanuel, 2000; Gutierrez, 2012; Russ & Kaufman, 2005; Steinhauser et al., 2000b; Teno et al., 2001a). Instruments designed to measure the quality of EOL care (Hales, Zimmermann, & Rodin, 2010) usually elicit patient experiences via patient or proxy response, rather than the caregiver's personal experience of the care provided by the health care team (Byock & Merriman, 1998; Curtis et al., 2002; Steinhauser et al., 2002; Teno et al., 2004). Existing caregiver measures typically assess caregiver burden, quality of life (QOL), or satisfaction with care, but not perceived quality of care to the dying patient (Hudson et al., 2010). Measures that do focus on caregiver-perceived quality of care have failed to include two key factors identified as important to dying patients and their caregivers: perceived patient suffering and prolongation of death (Engelberg et al., 2010; Teno et al., 2001a). Perceived suffering versus perceived peacefulness during the dying process may have a profound impact on caregiver mental health in the final days of a patient's life and during bereavement, as may their experience of the 'emotional limbo' that ensues as they wait for a death that is inevitable as an outcome but uncertain in its timing.

The foundation for the present study lies in an initial scale development performed by the author (Higgins, 2012a). Using Coping with Cancer (CwC, described below) study data from 271 patient/caregiver dyads, the author conducted an exploratory factor analysis that produced a 13-item Caregiver Evaluation of Quality of End of Life Care (CEQUEL) scale. CEQUEL items loading strongly and uniquely on four distinct factors: Prolongation of Death ("Prolongation"), Perceived Suffering ("Suffering"), Shared Decision-Making/Advance Care Planning ("Care Planning") and Preparation/What to Expect ("Preparation"). CEQUEL scores ranged from 13 to 23 out of a possible 26 points (M=15.4, SD=2.2, Median=15), with higher scores signifying perceived poor quality of care. CEQUEL demonstrated acceptable reliability (Cronbach's

α=0.692, mean corrected item-total correlation (ITC)=0.32). Prolongation and Suffering also had acceptable α's of 0.782 (ITC=0.62) and 0.730 (ITC=0.56), while Care Planning and Preparation had moderate α's of 0.520 (ITC=0.32) and 0.553 (ITC=0.38) (Cortina, 1993).

In convergent validity analyses conducted as part of the author's initial study (DeCoster, 2005), higher CEQUEL scores (signifying perceived poor quality of care) were correlated negatively with hospice enrollment, and positively with caregiver regret, hopelessness and trauma symptoms. Higher Suffering and Prolongation scores (signifying greater perceived suffering and prolongation of death) were positively associated with caregiver fear, regret and negative religious coping. Higher Suffering scores were also negatively associated with length of inpatient hospice enrollment and positively associated with helplessness, while higher Prolongation scores were positively associated with trauma symptoms.

These initial findings suggested that CEQUEL was a reliable and valid measure of quality of EOL care from the perspective of cancer caregivers. The data also corroborated the author's hypothesis that perceived suffering and prolongation of death were key factors in the final week of life, with important implications for bereaved caregiver adjustment. Post-hoc analysis revealed four CwC items related to focus on the dying patient as an individual (described in more detail below) that were not included in the initial analysis, but which were relevant to perceived quality of care and merited inclusion in further scale refinement. The author also discovered data for four additional patient-caregiver dyads not included in the initial analysis, as well as items related to patient-physician therapeutic alliance that were deemed important variables to include in convergent validity analysis. These discoveries, together with important feedback about the scale's practical utility – including the intuitive benefit of reversing the scale so that higher scores signified perceived *better* quality of care – suggested that further refinement and expansion of the CEQUEL scale was warranted.

The purpose of the present study was to develop a comprehensive, reliable and valid measure of caregiver-perceived quality of care at the end of life (i.e. a refined CEQUEL scale), with particular attention paid to previously underexamined factors of perceived suffering and prolonged dying. Furthermore, this study aims to expand upon the author's previous work by identifying those factors most predictive of perceived good quality of care at the EOL (i.e. higher CEQUEL scores), and finally to consider the implications of these findings for social work and healthcare research, practice and policy.

Definitions of Key Concepts

As in any field of study, there is considerable variation in the oncology, palliative care and end-of-life literature with regard to what language is used to define various EOL concepts. Clear definition and application of terms is critical to conducting and interpreting research, comparing findings across studies, and applying these findings to the spheres of clinical practice and health care policy.

Caregivers

One key conceptual issue has been choosing consistent terminology to identify those members of a patient's support network who provide day-to-day care and other assistance as the patient faces a cancer diagnosis. This is illustrated by the broad variation in terms used from one study to the next (e.g. *loved ones, family*, *caregivers*, *surrogates,* *proxies*). Stewart et al. (1999) have defined *family* broadly: “the person or persons who are intimately involved with the patient, are concerned and aware of the patient on a regular basis, and who love the patient” (p.95). The present study uses the CwC definition of *caregiver*: the person (typically a family member or friend) identified by a patient as providing the majority of his/her unpaid, informal care.

End of Life

End-of-life researchers and writers have also struggled to define what it means to be *dying* or at the *end of life*. Teno and Coppola (1999) have termed this the ‘denominator problem’: in measuring EOL care, how do researchers identify the dying patient, and when does a patient transition from ‘not dying’ to ‘dying’? Patrick, Engelberg, and Curtis (2001) have suggested that while a focus on the final week of life is somewhat arbitrary, it also allows for standardization of measures. Owing to the logic of this argument as well as the nature of CwC variables available for analysis, this study’s author developed the CEQUEL measure using data specific to care in the final week of life, and defines *end of life* as such where CEQUEL data is concerned.

Quality of Life, Quality of Death, and Quality of Care

While acknowledging their inescapable overlap, researchers have argued for clearer delineation between the oft-blurred concepts of *quality of life*, *quality of dying*, and *quality of care at the end of life* (Hales, Zimmerman, & Rodin, 2008). Patrick et al. (2001) write that differentiating between these three concepts and measuring them independently are necessary first steps toward identifying the components of a positive dying experience and developing effective EOL interventions. Field and Cassel (1997) have defined *health-related quality of life* as “physical, mental, social, and role functioning; sense of well-being; freedom from bodily pain; satisfaction with health care; and an overall sense of general health" (p.25). Patrick et al. (2001) have defined *quality of dying and death* as "the degree to which a person's preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others" (p.721). Similarly, Stewart et al. (1999) define quality of dying as "a personal evaluation of the dying experience as a whole….according to one's expectations and values" (p.104). Field and Cassel (1997) have suggested that *quality of care at the end of life* "stresses the link between the structures and processes of health care and outcomes…. High-quality care should contribute to the quality of living and the quality of dying but is not synonymous with them" (p.25). Stewart et al. (1999) have suggested a close association between *quality of care* and *satisfaction with care*. According to Teno (1999), "the most important outcome variable for examining the quality of care of the dying is whether health care providers understood and responded to the expectations and preferences of the dying patient and their loved ones" (p.169). Steinhauser et al. (2000b) echo this sentiment: "Physicians also should recognize that there is no one definition of a good death. Quality care at the end of life is highly individual and should be achieved through a process of shared decision-making and clear communication that acknowledges the values and preferences of patients and their families" (p.2482).

Hales et al. (2008) suggest that quality of life, quality of dying and death (QODD), and quality of EOL care exist along a continuum, with each incorporating the last. According to these authors, quality of life encompasses the physical, psychological, social and spiritual or existential domains of the patient's experience. Quality of dying and death incorporates these domains but also includes the nature of health care, life closure and preparation for death, and the circumstances of the death, and is further distinguished by its focus on the period of time immediately preceding the death. Quality of EOL care again incorporates each of these QOL and QODD domains, but focuses on the perceived impact of health care structures and processes on EOL outcomes. Even as frameworks such as this have been proposed, there remains a lack of clear consensus regarding the definition and measurement of quality of dying versus quality of care. Thompson, Bott, Gajewski, and Tilden (2012), for example, cite the unique culture of nursing home care when they define quality of care according to 'system-level factors' such as the prevalence of advance directives, hospice enrollment, rehospitalizations and feeding tube placement, while characterizing quality of dying by resident or family outcomes such as symptom distress, caregiver strain, adherence to EOL preferences, resident- and family-centered care, and satisfaction with care. Such a framework situates quality of care as the degree to which certain objective EOL outcomes are achieved rather than as a subjective evaluation of care by individual caregivers, and may be more appropriate for system-level quality improvement efforts. The present study defines *quality of dying* as the lived (or observed) experience of dying, and *quality of care at the end of life* as the caregiver's perception of the health care team's contributions to a loved one's quality of dying during the final week of life.

Prolonged Dying and Suffering

There is general consensus that dying patients and their caregivers wish to avoid prolonged dying and suffering, but the way in which these factors are presented in the literature varies. The absence of prolonged death and suffering in existing quality-of-care measures is particularly perplexing given their prevalence in the research literature, where the two are often discussed hand-in-hand. Meeker and Jezewski (2009), for example, write about complex EOL decision-making “where the likelihood of any meaningful recovery is weighed in relationship to the risk of increased suffering and prolongation of dying” (p.163). There are persons for whom some level of suffering may feel redemptive, perhaps because of their religious conviction that suffering is an acceptable sacrifice for the promise of eternal salvation. For others, prolongation of dying may not feel like a negative, but like a positive. Clinicians are familiar with caregivers who say, “Do whatever you have to do to keep him alive, every minute is precious,” even when it is clear to the health care team that the patient is dying. These are an important subset of caregivers for clinical focus, as providers may perceive a patient to be suffering or experiencing a protracted death in a way that caregivers do not, creating a situation that is ripe for caregiver-team conflict. For the purposes of this study, however, questions related to suffering and prolonged dying are phrased in a way that clearly positions them as negative rather than positive aspects of care. It is safe to assume, therefore, that caregivers endorsing these ‘problem’ areas feel that they are, in fact, problematic.

Perceived Prolongation of Death. Researchers including Singer, Martin, and Kelner (1999) have long referenced the “inappropriate prolongation of dying”, presenting the negative implications of the phenomenon as a given rather than as a subjective interpretation. Despite this consensus, the idea of prolonged dying as fundamentally negative is complicated by research highlighting caregiver ambivalence when asked to make decisions that could prevent prolonged dying (Rothchild, 1994; Swigart, Lidz, Butterworth, & Arnold, 1996), particularly in the absence of clear advance directives (Tilden, Tolle, Nelson, & Fields, 2001). A clear definition of prolonged dying has been stymied by an increase in “ambiguous dying” owing to patients living longer with life-limiting, chronic diseases where immediate prognosis is often unclear (Bern-Klug, 2004). Patients and caregivers facing such illnesses, where the certainty of death is inevitable but the timing is uncertain, often find themselves in the position of wanting to avoid prolonged dying, yet not knowing when the ‘dying’ has begun (Davison, 2001; Kutner & Kilbourne, 2010). At the other end of this spectrum are families holding bedside vigil for patients who are clearly dying, and for whom all potentially death-prolonging interventions have been stopped, but who then linger on for days or even weeks. While research focused on this ‘emotional limbo’ is lacking, clinicians involved in direct patient care often observe caregivers responding with a broad range of emotions, including the belief that death is being prolonged regardless of whether or not patients are actively receiving life-sustaining treatments. The present study uses CwC language to define *prolongation of death* as a caregiver’s subjective perception that death was prolonged by medical interventions despite awareness that the patient was dying, and in a way that may have increased the patient’s suffering.

Perceived Suffering. It is nearly impossible to find an EOL research article that doesn’t make some allusion to suffering, a concept whose mutability as a very narrowly- or broadly-focused phenomenon allows it to be applied in any number of situations. While suffering is often conflated with unrelieved physical distress, increasing awareness of the concept of *total pain* – meaning pain rooted not only in physiology, but also in psychosocial or spiritual distress – has helped to broaden understanding of the more far-reaching implications of suffering. As Stewart et al. (1999) have written, “For dying patients, suffering is not just based on physiologic abnormalities, but on the social or psychological distress from the knowledge of the destruction of oneself. Even when no symptoms are present, a dying person may suffer greatly" (p.102). Cherny (2005) defines suffering as "an aversive experience characterized by the perception of personal distress that is generated by adverse factors that undermine quality of life" (p.7). Of key import to the present study, Cherny also proposes a "triangular model of suffering" in which perceived distress of patients, family members or health care providers may amplify the distress of the others. Cassel (1982) highlights the relationship between suffering and personal integrity when he defines suffering as "the state of severe distress associated with events that threaten the intactness of the person" (p.640). It is important to recall that caregivers may not view a loved one's suffering merely as an abstract state of distress, but may strongly attribute it to a failure by the health care team. Cassel touches upon this idea when he writes, "Physicians' failure to understand the nature of suffering can result in medical intervention that not only fails to relieve suffering but becomes a source of suffering itself" (p.639). Using CwC language the present study defines *suffering*, in part, as the degree of peacefulness (versus violence) of a patient's death as perceived by caregivers.

Study Significance

Cancer is the second most common cause of death in the United States, with an estimated 1.66 million new cases and 580,350 cancer deaths expected in 2013 (American Cancer Society, 2013). Even when prognosis is poor, many cancer patients and their families continue to receive aggressive care at the end of life (Goodman et al., 2010). Donaldson and Field (1998) observed that problems with quality of EOL care fall within three categories: overuse, underuse and poor practitioner (including physicians, nurses and social workers) skill. Recent Dartmouth Atlas Project (DAP) data from 2003 to 2007 illustrates this classification, detailing high use of aggressive interventions at the end of life and relatively poor utilization of palliative interventions. According to nationwide DAP data, 29% of Medicare-age advanced cancer patients died in hospitals, 24% were admitted to intensive care in the last month of life, 9% received life-sustaining treatments such as cardiac resuscitation and ventilator support, and 6% received chemotherapy in the last two weeks of life (Goodman et al.). Despite research suggesting that less aggressive EOL care leads to improved QOL and better adjustment for bereaved caregivers (Teno et al., 2004; Wright et al., 2010b; Wright et al., 2008), patients in the Dartmouth report spent an average of 5.1 days in the hospital during their last month of life, and in at least fifty academic medical centers less than half of these patients were referred to hospice (Goodman et al.).

These data corroborates previous findings from the seminal SUPPORT (Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment) study, which documented significant underuse of palliative interventions at the end of life, including inadequacies in pain and symptom management, physician-patient/family communication, and shared decision-making at the end of life (Baker et al., 2000; McCarthy, Phillips, Zhong, Drews, & Lynn, 2000). Other recent studies have highlighted similar findings. In their survey of family members of 1578 decedents across 22 U.S. states, Teno et al. (2004) found that almost 70% of decedents died in an institution, and only half of those dying at home were enrolled in hospice. One quarter died with unrelieved pain or dyspnea, and one quarter of family members reported inadequate communication with physicians. Family members of patients dying in nursing homes or hospitals cited significantly more concerns with quality of EOL care than those dying at home on hospice. In a study using Coping with Cancer data, Mack, Weeks, Wright, Block, and Prigerson (2010a) found that only 68% of patients received EOL care consistent with their wishes, with receipt more likely for patients who recognized their terminal illness and/or discussed their EOL wishes with their doctor. Burt, Shipman, Richardson, Ream, and Addington-Hall (2010) surveyed 1266 bereaved relatives in England and found that cancer decedents had significantly worse pain and other symptoms than non-cancer decedents, but less than half received adequate pain medication.

A Good Death

There has been an upsurge in attention paid to death and dying in the last three decades, with particular focus on care in the final weeks of life (Plonk & Arnold, 2005) and how to achieve a *good death* (Steinhauser et al., 2000a), defined by Field and Cassel (1997) as one "free from avoidable distress and suffering for patient, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards" (p.24). Smith (2000) has cited twelve principles of a good death which include knowing when death is coming and what to expect, retaining control over what happens, having control over pain and symptoms, being able to issue advance directives to ensure that wishes are respected, and not having life pointlessly prolonged. Interest in improving EOL care evolved within the distinct medical and fiscal realities of the 1980s and 90s, including increased wariness of the 'new way of dying' in America, whereby new technologies enabled people to live longer and die slower from chronic and progressive illness, but also left them more vulnerable due to physical frailty and shifting social support systems; prominent debates over physician-assisted suicide; increased financial scrutiny by health care payers; and the troubling SUPPORT study data (Donaldson & Field, 1998; Freeborne, Lynn, & Desbiens, 2000; Lynn, 1997; Rudberg, Teno, & Lynn, 1997).

Concurrent with a renewed interest in how Americans die has been a push to characterize and measure EOL constructs in ways that are scientifically sound. In addition to defining a *good death* and identifying those factors that patients, caregivers and health care professionals deem critical to achieving such a death, research has focused on the distinctions between quality of life, quality of dying, and quality of care at the end of life (Field & Cassel, 1997; Hales et al., 2008; Patrick et al., 2001) and how best to measure the quality of EOL care (Addington-Hall & McPherson, 2001; Fowler, Coppola, & Teno, 1999; Hinton, 1996; Tilden, Tolle, Drach, & Hickman, 2002). "The potential for better care will be realized only if the systems measure quality and implement improvements" (p.526), wrote Lynn (1997) in an early call to action, suggesting ten domains of quality EOL care: physical and emotional symptoms, support of function and autonomy, advance care planning, aggressiveness of care near death, patient and family satisfaction, global assessment of QOL, family burden, survival time, provider continuity and skill, and bereavement. Many of these are echoed in more recent documents such as the National Consensus Project for Quality Palliative Care (Ferrell, 2005), which includes the following suggested domains of EOL care: structure and process of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious and existential aspects of care; cultural aspects of care; care of the imminently dying patient; and ethical and legal aspects of care.

Caregivers Matter

The research literature is clear on cancer caregiver vulnerability to mental health distress, both during active EOL caregiving and in the ensuing bereavement period. Research suggests that while a significant number of caregivers meet criteria for anxiety, depressive and other psychiatric disorders while caring for their dying loved ones, many forego mental health support (Hudson, Thomas, Trauer, Remedios, & Clarke, 2011; Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Unaddressed mental health needs may not only impact caregivers themselves, but also their perception of and satisfaction with the care provided to patients (Fleming et al., 2006). Studies have also found significant rates of complicated grief and depression in bereaved caregivers, many of who do not access mental health services (Cherlin et al., 2007; Guildin, Vedsted, Zachariae, Oleson, & Jensen, 2012; Lichtenthal et al., 2011). Mental health vulnerability may increase for caregivers with less social support, psychiatric histories, poor physical health, pessimistic thinking, poor coping skills, and multiple stressful life events or prior losses (Brazil, Bédard, & Willison, 2002; Burton et al., 2008; Kelly et al., 1999; Tomarken et al., 2008). The field has responded with an increase in interventional studies aimed at improving mental health outcomes for cancer and palliative care caregivers (Harding, List, Epiphaniou, & Jones, 2011), but caregivers remain at high risk for mental health distress during EOL care and bereavement.

Despite the overwhelming evidence that cancer caregivers matter – not only in terms of their influence on patient care at the end of life, but also their own vulnerability to poor mental health outcomes – there remains a significant gap in the research literature with regard to caregiver perceptions of quality of care at the end of life (Teno et al., 2001a). The foundation for this endeavor has been set: there is good consensus on those factors most important to patients and their caregivers at the end of life (Clayton, Butow, Arnold, & Tattersall, 2005; Downey, Engelberg, Curtis, Lafferty, & Patrick, 2009; Singer et al., 1999; Steinhauser et al., 2001; Teno et al., 2004), and a growing body of research has described the impact on EOL care and bereaved caregiver adjustment when those factors are not achieved (Buss et al., 2007; Gries, Curtis, Wall, & Engelberg, 2008; Hebert, Schulz, Copeland, & Arnold, 2008; McDonagh et al., 2004; Ott, Lueger, Kelber, & Prigerson, 2007; Wright et al., 2010a). Existing measures of caregiver-perceived quality of EOL care have also laid the groundwork for further scale development, most notably the After-Death Bereaved Family Member Interview from the Toolkit of Instruments to Measure End-of-Life Care (TIME) (Teno, Claridge, Casey, Edgman-Levitan, & Fowler, 2001b), which measures eight domains of caregiver-perceived quality of care in the final week of life: patient physical and emotional comfort, shared decision-making, focus on the individual, attendance to family needs, coordination of care, encouragement of advance care planning, support of family self-efficacy, and patient-focused/family-centered care. The TIME instrument is a broad and clinically relevant instrument that has offered the best means by which to measure caregiver evaluation of EOL care. Its utility is illustrated in part by its adaptation for the CwC study as well as the number of TIME items that have been incorporated into CEQUEL (described in more detail below). The TIME interview's omission of perceived patient suffering and prolongation of death, however, make it an incomplete measure.

Hudson et al. (2010) offer the following caution regarding instrument development:

> While there will be circumstances where an existing instrument does not meet the specific needs of clinicians or researchers, we recommend that caution prevail before embarking upon the development and subsequent testing of new instruments. Another option is to modify existing tools; however….[i]t is the responsibility of authors to demonstrate the psychometrics of these new instruments created from old ones. (p.664)

Having carefully considered such advice from these and other researchers (Williams & McCorckle, 2011), the author of the present study feels that development of the CEQUEL measure – a new instrument, to be sure, but also a modification of the TIME instrument – is well-justified based on the absence of caregiver-perceived suffering and prolongation in TIME and similar measures. Inclusion of these key factors in CEQUEL, and use of CEQUEL to explore key correlates and predictors of caregiver-perceived quality of care, promises a better understanding of the caregiver's experience at the end of life and improved opportunities to mitigate caregiver distress and negative bereavement sequelae.

Specific Aims and Research Hypotheses

This study has several aims and will test three hypotheses. First, it seeks to identify those factors comprising the broader construct of quality of care at the EOL and to develop a comprehensive measure of this construct (i.e., a refined CEQUEL scale), with a particular focus on examining the heretofore overlooked factors of perceived suffering and prolongation of death. Identification of factors and development of the refined CEQUEL scale will be achieved via exploratory factor analysis (EFA), and will build upon the author's previous research by including a larger sample and a larger initial pool of EFA items.

Hypothesis I: Variables related to caregiver-perceived quality of care in the final week of life will load significantly and uniquely on a set of distinct factors that include perceived suffering and prolongation of death.

Second, this study will test the reliability and convergent validity of the refined CEQUEL measure. The study will draw upon the existing research literature to identify key variables related to EOL care or bereaved caregiver adjustment, and will test for significant associations between these variables and bereaved caregiver CEQUEL scores. The study will also examine the unique associations between these variables and perceived suffering or prolongation of death, and will further build upon the author's initial research by adding new EOL variables to validity analyses.

Hypothesis II: The refined CEQUEL scale, as well as its Suffering and Prolongation subscales, will demonstrate acceptable reliability (via Cronbach's alpha and mean item-total correlation) and convergent validity (via significant associations and correlations with key EOL variables).

Third, this study moves beyond refinement of the CEQUEL scale to examine the set of variables most predictive of perceived quality of care at the EOL. Identification of potential predictors will be informed by the research literature as well as the convergent validity analyses described above. The author will model this analysis on two recent CwC studies, applying the refined CEQUEL scale in comparative fashion to Garrido and Prigerson (2013) and Zhang et al. (2012), who identified parsimonious models of factors predicting bereaved caregiver mental health and patient quality of life at the end of life, respectively.

Hypothesis III: Caregiver-perceived quality of care at the end of life can be significantly predicted by a unique and parsimonious set of EOL factors.

Finally, the author will consider the research and clinical implications of the above findings, and will make recommendations for clinical practice and health care policy to improve the experience of caregivers in the final week of life and during bereavement.

Chapter II. Literature Review

Conceptual Frameworks

Conceptual frameworks for care at the end of life have relied heavily on Donabedian's (1966) model of quality of care, which suggests three domains for quality measurement: care *structures* (e.g. access to care, formal support services available, physical care environment), care *processes* (e.g. provider clinical skills, communication, counseling) and care *outcomes* (e.g. satisfaction with care, quality of life). Stewart et al. (1999) have built upon the Donabedian model by situating *contextual patient factors* (e.g. socioeconomics, clinical status, social supports) as a distinct but related component of this structure/process/outcome framework, and further differentiating structure and process of care from *quality of care*, the latter being determined by external judgment of the former. Patrick et al. (2001) have provided a critical expansion upon these models by emphasizing the interplay between patient and family EOL preferences and the *unavoidable circumstances of death* (e.g. unexpected clinical complications, or a prolonged dying process even in the absence of any life-sustaining interventions) that determines what a death looks like and how bereaved caregivers ultimately rate the quality of death. This addition is important because it highlights that even the highest-quality care may not be able to control for all aspects of death and dying. Caregivers watching a loved one die, however, are likely to struggle to separate what is controllable and what is not. In such situations, the onus is on the care team to help caregivers make this distinction and to subsequently shape how caregivers frame what quality of care truly means.

Another key aspect of current conceptual models of EOL care is their emphasis on aspects of care beyond pure physiology. Byock (1999) has suggested that an ideal conceptual model should consider the “full range of emotional, psychosocial, and psychospiritual states of persons living with physical discomfort, functional decline, and awareness of impending death” (p.85). Emanuel and Emanuel’s (1998) conceptual framework for a good death similarly emphasizes the need for a holistic, multidimensional lens in evaluating *modifiable dimensions of care* at the end of life, a lens that moves beyond physical pain and symptoms to include social supports, hopes and expectations, psychological symptoms, economic demands and caregiving needs, and spiritual or existential needs. The authors situate these modifiable dimensions as separate from, but informed by, fixed patient characteristics such as clinical status or sociodemographics. As used in the present study, the term *modifiable* reflects the degree to which social workers and other health care clinicians can effect change in a given end-of-life variable, be it patient-, caregiver-, or care-based. Innate patient or caregiver characteristics such as self-efficacy or sense of optimism, for example, may be more ‘hard-wired’ and less amenable to change via clinical intervention. So, too, are certain unavoidable aspects of care at the end of life, such as the exact timing of death. This leaves a number of factors, however, whose characteristics – and, by extension, whose impact on the caregiver’s perception of care – *are* potentially changeable. Patient and caregiver behaviors, mental health, health care utilization and various aspects of coping all present opportunities for social work intervention at the end of life, as do various care structures and processes including hospice utilization and place of death.

Emanuel and Emanuel also propose several tiers of “care-system interventions” at the individual provider as well as the institutional level, all of which interact to produce good or bad outcomes with the dying experience. In a second iteration of this model informed by longitudinal patient interviews and subsequent factor analysis, Emanuel et al. (2000) propose the following eight modifiable dimensions of EOL care: Patient-clinician relationship, social connectedness, caregiving needs, psychological distress, spirituality or religiousness, personal acceptance, sense of purpose, and clinician communication. Importantly, physical pain and symptom management were not included in the revised model due to low reliability during factor analysis.

These conceptual models are helpful in framing the present study, which seeks first to isolate those health care *structure and process* components of EOL care (e.g. suffering, prolongation of death) that caregivers evaluate in determining *quality of care* at the end of life, and then to identify potentially *modifiable* care structure and process factors, patient contextual factors, and/or caregiver contextual factors that best predict caregiver perception of quality of EOL care (Figure 1).

Theoretical Frameworks

In studying how caregivers perceive the quality of care provided to their dying loved ones, and how these perceptions shape outcomes such as bereavement adjustment, it is helpful to draw upon established psychosocial theories such as the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). According to this model, the way in which one appraises a potential stressor determines the degree to which one adapts to or copes with that stressor. This includes *primary appraisal* of the circumstances – the severity of threat and one’s susceptibility to that threat – as well as

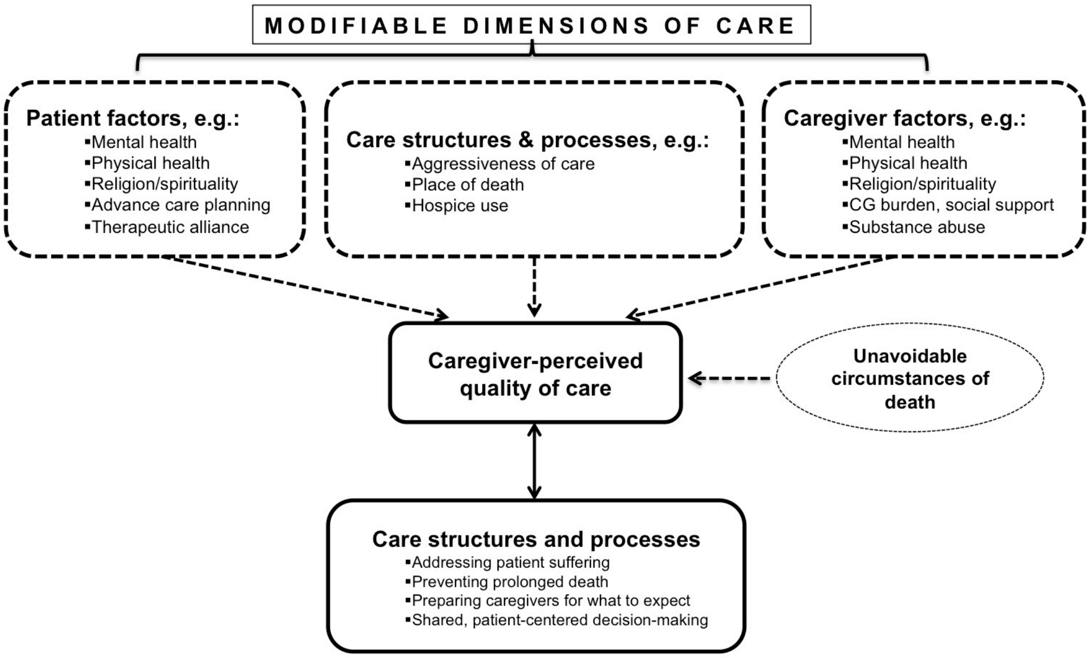

Figure 1. Conceptual model of caregiver-perceived quality of care at the end of life.

secondary appraisal of one's internal resources to respond to the stressor by changing either the situation itself or one's emotional response to the situation. The Transactional model assumes that stress is determined by one's ability to cope with a stressor, and emphasizes the possibility of learning how to cope with stressors by drawing upon one's internal resources. Applied to the present study, any of the identified domains of quality of care at the end of life (e.g. suffering, prolongation of death) may be a potential stressor to cancer caregivers at the bedside. The way in which caregivers perceive and cope with these scenarios is likely informed by the degree of perceived threat to their loved ones' 'good death', as well as by the caregivers' own internal problem-solving or emotion-regulating resources.

In her theory of Uncertainty in Illness, Mishel (1988) echoes the Transactional model in suggesting that the way in which patients manage medical uncertainty determines their ability to adapt to and make meaning of that uncertainty. A critical element of care at the end of life is the pervasive sense of uncertainty faced by caregivers, be it uncertainty about the dying patient's physical comfort or uncertainty about when death will come. According to Mishel, appraisal of uncertainty as a danger (i.e. likely to have a harmful outcome) is associated with attempts to reduce uncertainty (via *mobilizing* strategies such as vigilance or information-seeking) and manage emotion (via *affect-management* strategies such as faith or disengagement). Appraisal of uncertainty as an opportunity – perhaps an appraisal that accepting the uncertainty of prognosis is preferable to acknowledging the certainty of impending death – is associated with *buffering* strategies such as avoidance and selective ignoring. Mishel's theory has clear implications for the way in which cancer caregivers perceive and cope with quality of EOL care within the broader context of uncertainty, and such a theoretical lens is critical to the team's ability to mitigate caregiver distress around quality-of-care issues.

Review of the Literature

Caregivers Matter at the End of Life

While cancer caregivers often derive meaning and satisfaction from caring for a loved one (Wolff, Dy, Frick, & Kasper, 2007), caregiving at the end of life also presents significant risk to caregiver physical health, mental health, social activities, relationships and financial security (Girgis, Lambert, Johnson, Waller, & Currow, 2012; Williams & McCorckle, 2011). Those caring for patients with worse quality of life, symptom burden or depression; perceived unmet needs at end of life; or perceived lack of respect from health care providers are at increased risk for caregiver burden and stress (O'Hara et al., 2010). While caregivers are clearly impacted by their caregiving role as well as the clinical care provided to their dying loved ones, they also play a fundamental role in shaping what EOL care and the dying process look like. This active role at the bedside is illustrated by Tschann, Kaufman, and Micco (2003), who found that seriously ill patients with family present at time of death were more likely to forego resuscitation, to have unhelpful treatments withdrawn, and to receive necessary pain medication.

Leaders in end-of-life care have long been advocating for an increased focus on the role of caregivers at the end of life, both in the clinical realm of assessment and intervention as well as in the development of research measures. In their systematic review of EOL measures, Mularski et al. (2007) cite a significant gap in measures relating to caregiver wellbeing. Donaldson and Field (1998) have argued that measurement of quality of care at the EOL should extend beyond patients to their families and loved ones. Rudberg et al. (1997), too, have advocated for the family caregiver perspective at the end of life: “Family perceptions and reactions are not just surrogates for the patient but rather constitute another important piece in the mosaic of care that occurs at the end of life” (p.529). “What is fundamental to caring for such a vulnerable population,” writes Teno (1999) “is acknowledging the need to listen to both the dying person and their family about both technical and caring aspects of medical care” (p.168). Teno et al. (2001a) have also cited as a significant barrier to improving EOL care the paucity of valid and reliable measurement tools to evaluate care as perceived by patients and their loved ones.

What Matters to Caregivers at the End of Life

As caregivers have gained more prominence in the EOL research literature, consensus has developed regarding what matters most to caregivers facing the death of a loved one. Much of this research has sought input from patients and caregivers together, and in some instances from health care providers as well. Based on interviews with seriously ill patients, Singer et al. (1999) proposed five domains of quality EOL care: pain and symptom management, avoiding prolonged dying, achieving a sense of control, relieving family burden, and strengthening relationships with loved ones. Steinhauser et al. (2000a) used focus group data from hospice patients, caregiver and team members to identify six components of a good death including effective pain and symptom management, clear decision-making and communication with physicians, preparation for death, completion, contributing to others, and affirmation of the whole person. Importantly, while all six of these themes emerged with patients, family members and non-physician team members, physicians tended to provide more biomedical than psychosocial-spiritual responses, highlighting the lack of congruence that may exist between the EOL priorities of patients, caregivers and physicians. This data informed a larger study in which patients, bereaved family members, and health care providers ranked 44 aspects of EOL care (Steinhauser et al., 2000b). Families rated ten items as most important for dying patients: being kept clean, naming a decision maker, feeling comfortable with one’s nurse, having someone who will listen, maintaining one’s dignity, trusting one’s physician, having family present, being free of pain, having financial affairs in order, and having physical touch. The majority of patients and family members felt it was important for family to be prepared for death and for patients not to be connected to machines.

When Heyland et al. (2006) asked seriously ill hospitalized patients and their family caregivers what was most important at the end of life, their findings echoed those of Steinhauser and colleagues. Caregivers prioritized trust in physicians; avoiding life support when there was little hope for meaningful recovery; honest physician communication about the disease course; adequate home care services; pain and symptom relief; time to strengthen relationships with the patient; physician access to patient information when transitioning from home to hospital; completing tasks, resolving conflicts and saying goodbye to the patient; adequate information about treatment risks and benefits; and trust in nurses.

In a qualitative study of terminally ill cancer patients, caregivers and health care professionals, Clayton et al. (2005) found that while many patients did not want detailed information about future symptoms, they did value knowing broadly what to expect with their disease course and reassurance of clinical support. Caregivers wanted to feel prepared and to have a more detailed sense of what to expect. Physicians and nurses highlighted the importance of preparing families for a drawn-out dying process, as families often expect patients to die quickly. Downey et al. (2009) found that the top priorities for seriously ill patients and family members were spending time with family and friends and effective pain control. Other priorities included breathing comfort, dignity/self-respect, being at peace with dying, human touch, avoiding strain on loved ones, and avoiding life support. Healthy and ill patients alike have prioritized quality of life over prolongation of death. Bryce et al. (2004) asked healthy respondents about the extent to which they would trade life expectancy for better EOL care, and found that three-quarters would trade longer life expectancy for better care if they were dying.

Several studies have focused specifically on what patients and caregivers expect from physicians at the end of life. Curtis et al. (2001) found agreement between patients, families and health care providers on the most important qualities of physicians caring for the dying: communication, emotional support, accessibility and continuity. In a small qualitative study of ICU family members, Gutierrez (2012) heard from most respondents the need for honest, realistic, and compassionate communication about prognosis, especially when prognosis was poor. Importantly, families emphasized the importance of both content (i.e. accurate information) and process (i.e. sensitive delivery) in delivery of bad news.

Communication

In their extensive review of communication in end-stage cancer, Trice and Prigerson (2009) juxtapose the conflict between what is said by physicians and what is heard by patients and their loved ones, as well as between health care providers wanting to minimize patient and caregiver distress while also needing to provide clear information about prognosis. Wright et al. (2008) found that EOL discussions between patients and physicians were not associated with higher rates of major depressive disorder (MDD) or worry, but were associated with lower rates of ventilation, resuscitation and ICU admission and earlier hospice enrollment. These findings are particularly important given the authors' additional findings that more aggressive EOL care was associated with poorer patient QOL and higher rates of MDD in bereaved caregivers, and that better patient QOL was associated with better caregiver QOL in bereavement.

A recent review by Wendler and Rid (2011) evaluated 40 studies (29 qualitative, 11 quantitative) and found that many surrogates experience negative emotional burden including stress, doubt and guilt, a burden that decreased when patient wishes were known. Importantly, nine studies identified beneficial effects of decision-making on surrogates, largely related to their satisfaction in being able to advocate for patients' wishes. The health care team has a significant role to play in clarifying EOL wishes with patients prior to decline, facilitating communication of wishes between patient and caregiver, or helping caregivers to reflect on patients' wishes when patients are no longer able to participate in decision making. In a qualitative study by Hebert et al. (2008), bereaved caregivers identified a number of factors through which medical providers can facilitate decision-making and improve caregiver outcomes, including preparing caregivers for the loss, providing prognostic information, employing interdisciplinary team support, and being available to listen to and answer caregiver questions.

Several studies have highlighted discrepancies between provider and family perceptions of team communication, as well as the impact of poor communication on caregiver outcomes. In one-third of the cases examined by Fried, Bradley, and O'Leary (2003), physicians and family caregivers gave conflicting reports on whether there had been a discussion about dying patients' condition or prognosis. Almost half of the bereaved family members in a study by Hanson et al. (1997) identified communication issues with providers during EOL decision-making, with almost a quarter reporting no discussion of treatment options with the patient's physician. Gries et al. (2008) found higher levels of family satisfaction with decision-making in the ICU when physicians made clear recommendations for withdrawal of life support and included discussion of patients' wishes.

Smaller, qualitative studies have also highlighted the role of team communication in EOL decision-making and subsequent bereavement. Many of the bereaved family members interviewed by Russ and Kaufman (2005) reported that physicians had waited too long to discuss patient prognosis, and then pressed families to make decisions when patients were already dying and such decisions felt meaningless. Norton, Tilden, Tolle, Nelson, and Eggman (2003) found that families experiencing conflict with their health care team expressed a need for more timely, honest, clear and consistent communication, and improved listening from team members. Radwany et al. (2009) found that 70% of ICU families had lingering questions after a patient's death and/or resentment about the care received, and 40% felt residual guilt about decisions made.

Preparation

Russ and Kaufman (2005) use the term "death without dying" to describe the experience of caregivers who don't know their loved one is dying until death is imminent, leaving them to confront their loss with inadequate preparation and adjustment. The authors suggest that this phenomenon is multifactorial, with caregivers receiving conflicting messages about treatment plan and prognosis – citing Christakis' (1997) concept of *prognostic abandonment* – at the same time as they are ambivalent about wanting to hear about prognosis. Barry et al. (2002) found that families who felt unprepared for a death were more likely to experience complicated grief (CG) at four months post-loss, and both CG and major depressive disorder at nine months post-loss.

Steinhauser et al. (2001) have found consensus as well as variation between health care providers, patients and caregivers regarding which aspects of preparation are most important at the end of life. Most respondents agreed on aspects of preparation including naming a surrogate decision-maker, knowing what to expect about physical condition, and family preparation for the likelihood of death. There was less consensus on the importance of knowing the *timing* of death, which was endorsed by almost half of patients and caregivers but only a quarter of physicians. This discrepancy has important implications for caregivers who may want to receive information about immediate prognosis but are not given the opportunity to do so.

Hebert, Prigerson, Schulz, and Arnold (2006) have proposed a theoretical model linking caregiver-team communication, feelings of preparedness, and outcomes including caregiver satisfaction, mental health and adjustment. Caregiver interviews supported this model, with caregivers reporting the need for prognostic information and clear team communication in order to manage uncertainty and prepare for a loss (Hebert, Schulz, Copeland, & Arnold, 2009). Almost all of the surrogate decision makers interviewed by Apatira et al. (2008) felt that discussion of prognosis was critical to preparing for a loved one's death and that avoidance of these discussions in order to maintain hope was not acceptable. Biola et al. (2007) found that half of their bereaved caregivers felt they didn't receive information on what to expect and didn't understand what the physician was saying about what to expect.

Suffering

The broader research literature has tended to reference the term *suffering* in conjunction with pain rather than as a phenomenon in its own right (Desbiens & Wu, 2000; Kutner & Kilbourne, 2010; Meeker & Jezewski, 2005; Mori, Elsayem, Reddy, Bruera, & Fadul, 2012). A key exception is Cassel's (1982) seminal piece "The Nature of Suffering and the Goals of Medicine", which criticizes the medical field's historical, artificial separation of physical and nonphysical suffering, as well as its prioritization of the former over the latter. Cassel suggests that suffering is not confined to physical symptoms, that it results not only from disease but also from the treatment of disease, and that it can only truly be assessed by asking patients directly about their experience. He further emphasizes the distinction between physical distress and suffering:

> Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it….Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner. (p.639-640)

Cassel also emphasizes the role of transcendence and meaning in ameliorating the patient's experience of suffering. Transcendence, he writes, "locates the person in a far larger landscape" than his/her own personal suffering. "[S]uffering is reduced when it can be located within a coherent set of meanings…It is more tolerable for a terrible thing to happen because of something that one has done than it is to be at the mercy of chance" (p.644). Cassel underscores the temporal nature of suffering, in that one of its chief components is fear of its continued, unabated existence. Finally, he highlights the complicit role of physicians and other members of the health care team in unwittingly amplifying patient and caregiver suffering by failing to understand its origins.

Subsequent literature has echoed many of Cassel's ideas. Byock (1999) has advocated for a broad definition of suffering "not completely tied to pain or the pathophysiology of….disease" (p.85). Ferrell and Coyle (2008) describe suffering, in part, as "pain that persists without meaning" (p.246). Mori et al. (2012) discuss the multidimensional nature of pain, which often includes underlying psychosocial or spiritual distress. It is this distress that the authors define as "a patient's inner state of suffering resulting from physical, psychological, social, spiritual, and/or practical issues" (p.238), and which must be accurately assessed in order to distinguish it from physical pain. Stewart et al. (1999) have also written about the multiple factors that may contribute to a patient's suffering beyond physical discomfort: "Even when no symptoms are present, a dying person may suffer greatly" (p.102). Emanuel and Emanuel (1998) define patient suffering more broadly as a failure on any dimension of their proposed framework for a good death.

Cherny (2005) has further broadened the model of suffering to a triangular one that includes not only patients but also their loved ones and members of the health care team, all of whom may interact in a way that amplifies the distress of the others. He suggests that Saunders' (1964, 2001) concept of *total pain* – which posits that pain may have multiple sources including physical, psychological, social and spiritual – should be applied to patient, caregiver and health care provider alike. Cherny posits that coping and growth are possible in the face of suffering, but only if adequate relief is achieved from the overwhelming demands of the situation. His suggestion that suffering is defined in part by "the presence of perceptual capacity (sentience)" (p.7) is limiting, in that it restricts the phenomenon of suffering to the person who is conscious enough to experience it, and leaves unclear the role of caregiver perception of suffering in a loved one. The present study's definition of suffering as the perceived violence versus peacefulness of a patient's death is borne out in the research literature. Barry et al. (2002), for example, found that bereaved family members who perceived a death as violent were more likely to experience major depressive disorder at four months.

Akiyama, Numata, and Mikami (2010) have found that perception of a peaceful death is associated with decreased caregiver bereavement regret.

Prolonged Dying

Much like suffering, the concept of prolonged dying has been a mainstay within the EOL professional literature, but has not often been a focus of targeted study. Many authors have relied on anecdotal ‘knowledge’ that prolonged dying is something to be avoided. Reference to this knowledge has been at times casual – “Dying can be a prolonged and difficult process for some chronic dialysis patients, with many suffering needlessly” (Davison, 2001, p.41) – and direct – “[Physicians are] reasonably aware of the fact that human beings do not want to suffer at all if they can avoid it – and you don’t have to be a rocket scientist to figure out that no one wants to experience prolonged agony while dying” (Curtin, 1996, p.59). In an early commentary on the “dilemma of prolonged death”, Stewart (1975) described patients facing this dilemma as “trapped in life by the proficiency of modern science” (p.172).

A clear definition of prolonged dying has been elusive, muddied by ambiguous prognoses for an increasing number of patients with life-limiting illnesses (Bern-Klug, 2004) and concomitant ambiguity regarding when the dying process begins (Kutner & Kilbourne, 2010; Davison, 2001). Much of the current data has come from the intensive care literature, which has examined the impact of improved team communication or identification of dying patients on outcome such as withdrawal/withholding of life-sustaining treatments and ICU length of stay (Campbell & Guzman, 2003; Curtis et al., 2005; Lilly et al., 2000). These studies have been critical to understanding the intersection of intensive care and EOL care in avoiding prolongation of death, but they have not tended to address the *meaning* of prolonged dying to caregivers, or its impact on their mental health.

Many dying patients and their families cite avoidance of prolonged death as a priority at the end of life (Downey et al., 2009; Heyland et al., 2006; Singer et al., 1999; Steinhauser et al., 2000b), and health care providers have highlighted the importance of preparing families for the likelihood that a loved one's death may feel prolonged (Clayton et al., 2005). Many of the public hospital patients in a qualitative study by Dzul-Church, Cimino, Adler, Wong, and Anderson (2010) found the idea of a prolonged death more frightening than that of a sudden death. Prolonged death was one of the chief components of a 'bad death' identified by the terminally ill men in another qualitative study by Vig and Pearlman (2004). Many of the Christian clergy and congregants interviewed by Braun and Zir (2001) talked about the importance of avoiding inappropriate prolongation of death, and a study by Bradley, Wetle, and Horwitz (1998) found that the most common reason for completion of advance directives among nursing home residents was having witnessed the prolonged death of a loved one. Still, when caregivers are faced with treatment decisions that might curtail prolongation of death, they often experience ambivalence or internal conflict (Rothchild, 1994; Swigart et al., 1996; Tilden et al., 2001).

Existing Quality-of-Care Measures

In contrast to the large body of measures designed to assess quality of life at the end of life (Jordhoy et al., 2007) and quality of dying and death (Hales et al., 2010), there are relatively few that gauge caregiver perceptions of quality of EOL care. Of the measures that do exist, most are restrictive in their focus (e.g. specific to evaluation of physician care, or tested only in long-term care or VA settings) or were designed specifically for quality improvement rather than for clinical assessment or basic knowledge building. There is also a subset of instruments designed to measure suffering, but these are variable in how they conceptualize suffering, most are directed at patients rather than their caregivers, and none address caregiver-perceived patient suffering as part of the broader construct of quality of care at the end of life (Krikorian, Limonero, & Corey, 2013).

The most comprehensive and utilized quality-of-EOL-care measure to date is the After-Death Bereaved Family Member Interview from the Toolkit of Instruments to Measure End-of-Life Care (TIME) developed by Teno et al. (2001b). Based on the existing literature as well as focus group interviews, the authors identified five key elements of quality care in the final week of life, and organized them into questions along eight care domains: informing and making decisions; advance care planning; closure; coordination of care; achieving control and respect; family emotional support; self-efficacy; and patient-focused, family-centered care. Teno and colleagues (2001b) evaluated the TIME measure's reliability and validity by administering it to 156 bereaved family members of patients dying on home hospice, in a hospital, or in a nursing home. The authors cite satisfactory psychometric properties for five of the eight domains: informing and making decisions; coordination of care; achieving control and respect; self-efficacy; and patient-focused, family-centered care. Importantly, they imply that the TIME interview may be more suitable for quality improvement initiatives than for knowledge building, and acknowledge the need to further test the measure's validity with other samples. A subsequent study (Teno et al., 2004) exploring perceived quality of

EOL care in home- versus institution-based settings appears to use the initial five elements of quality EOL care cited in Teno et al. (2001a) rather than the TIME interview itself. Moreover, the hospital version of the TIME measure appears to be an amalgam of the two, containing seven of the validated domains but replacing the closure domain with patient physical comfort and emotional support. While a number of studies, including Coping with Cancer, have adapted portions of the TIME interview (Arcand et al., 2009; Casarett et al., 2005), subsequent testing in other samples has questioned its validity and reliability compared to other measures (van Soest-Poortvliet et al., 2012).

Casarett et al. (2008) have developed the Family Evaluation of Treatment at End of Life (FATE) survey within the Veterans Administration (VA) system, a 32-item measure that includes nine QOC domains as rated by caregivers: patient well-being and dignity, information and communication, respect for treatment preferences, patient and family emotional and spiritual support, management of symptoms, choice of inpatient facility, care around the time of death, access to VA services, and access to VA benefits after the patient's death. Items were initially developed via interviews with a VA sample, followed by expert panel review, and subsequent factor analysis (N=309) revealed six underlying factors, all with $\alpha > 0.70$, and a total α of 0.91. The authors cite the measure's good discriminant validity but did not test convergent validity. Casarett et al. (2010b) later developed a shorter 16-item FATE-S, because the original was too long for routine administration. Testing the FATE-S with a larger sample (N=2827) the authors cite an α of 0.84 and strong discriminant validity, but they acknowledge that item reduction for the shortened form was accomplished via expert consensus rather than evaluation of underlying factor structure. While both the FATE and FATE-S contain important factors related to perceived quality of care, neither addresses perceived suffering or unwanted prolonged dying. Moreover, despite professional consensus that new measures ought to recognize and build upon existing ones, the authors fail to acknowledge or even mention the TIME survey as the current ‘best practice’ QOC measure. As with the TIME measure, the authors present the FATE and FATE-S primarily as quality improvement tools rather than research instruments.

Two recent measures eliciting the caregiver perspective on QOC are specific to caregiver evaluation of physician care at the end of life. The first is the Family Perception of Physician-Family Caregiver Communication (FPPFC), which was developed by Biola et al. (2007) for use in the long-term care setting and which focuses on physician communication at the end of life. The FPPFC elicits caregiver ratings on seven questions: did the caregiver receive information on what to expect while the patient was dying, did the caregiver understand what the physician was saying about what to expect, did the physician always speak to the patient and/or caregiver about the patient’s EOL wishes, did the physician always keep the caregiver informed about the patient’s condition, did the physician always understand what the patient and caregiver were going through, did the physician always listen to what the patient and/or caregiver had to say about EOL treatment, and did the patient or caregiver always have the opportunity to ask questions about the patient’s care? While the authors provide minimal detail regarding development of FPPFC items, they cite the measure’s α of 0.96. Lower FPPFC scores were associated with caregivers not knowing the patient was imminently dying, not having face-to-face interaction with the physician, and not knowing the physician’s name.

The Quality of End-of-Life Care (QEOLC) measure by Engelberg et al. (2010) asks respondents to rate physician skill in delivering various aspects of quality EOL care. The QEOLC authors derived scale items from focus groups with patients, family members and nurses. After dichotomizing all items and entering them into a factor analysis, the authors identified three separate models for patient, family and nurse respondents. The authors report that the 22 items on the family version load meaningfully on a single factor of quality of EOL care, and they group these items into five *ad hoc* domains: patient-centered values, patient-centered systems, affective skills, symptom skills, and communication skills. They tested for convergent validity via associations with physician palliative care knowledge, patient and family satisfaction, nurse ratings of physicians, and patient symptom scores. While one item pertains to physician knowledge about stopping treatments that are no longer helpful, none of the QEOLC family version's 22 items directly addresses perceived suffering or prolonged dying.

Volicer, Hurley, and Blasi (2001) have developed a series of caregiver assessment tools – Satisfaction with Care at the End-of-Life in Dementia (SWC-EOLD), Symptom Management at the End-of-Life in Dementia (SM-EOLD), and Comfort Assessment in Dying with Dementia (CAD-EOLD) – that are specific to perceived quality of care of dementia patients in the final three months of life. The ten items in the SWC-EOLD include questions related to caregiver involvement in decision-making, communication with the care team, reassurances about the type of care received, and preparation for what to expect. Again, none of the measures' items directly address perceived suffering or prolonged dying. The authors cite α values between 0.70 and 0.90, but acknowledge the absence of concurrent validity testing and highlight this as a focus for future study.

Measurement Issues

Methodological challenges. Accompanying the relative proliferation of EOL measurement tools has been a steady stream of papers emphasizing a cautious approach to further instrument development. Tilden et al. (2002) consider several methodological challenges to psychometric measurement at the end of life, including defining the EOL period, controlling for extraneous influences, using proxies as respondents, and minimizing subject burden while maximizing the robustness of scales. The authors cite three main purposes for psychometric measurement of quality of life and quality of care: empirical research to inform practice and policy, clinical assessment of patients and families, and outcome measurement for quality improvement and institutional accountability. They recommend a focus on studies that either lend psychometric evaluation to existing EOL measures or that develop new measures but with rigorous psychometric evaluation. Importantly, the authors highlight the value of caregiver perceptions beyond their function as patient proxies, and make a strong recommendation for future studies focusing specifically on caregiver perceptions of EOL care.

Rudberg et al. (1997) have cited theoretical as well as practical issues regarding the development of EOL measures, pointing to the "unprecedented flux in life experiences, wishes, and needs" (p.528) that characterizes the day-to-day lives of patients and their loved ones nearing the end of life. Even illnesses with relatively predictable trajectories such as advanced cancer may present unanticipated medical complications, worsening physical symptoms and a panoply of psychosocial and spiritual stressors. This inevitable flux makes crafting and implementing measurement tools a challenge, as the target of measurement may shift not only from one patient to the next, but even from one day to the next. The authors encourage systematic rather than haphazard development of new measures, with consideration of the ease with which measures can be incorporated into clinical care, and of clinical meaningfulness in addition to scientific validity. They also advocate for honoring family – "another importance piece in the mosaic of care" – as well as patient perspectives, and developing measures sensitive to the range of care options, care sites, disease types and unique cultures at the end of life.

Donaldson and Field (1998) have parsed out a number of factors that may necessitate a shift in how a new EOL instrument is crafted or used. These include the purpose of measurement (e.g. for research, clinical care or quality improvement), the population of interest, the timing of measurement (i.e. how to identify 'dying' patients or predict critical shifts in the dying period), the role of surrogates, and the care setting. Stewart et al. (1999) have also argued for a thoughtful approach to the development of new EOL measures, with priority placed on those aspects of quality of life that are most likely to be improved with better care, most important to patients, or most modifiable by care teams. The authors emphasize that, in order to serve as quality-of-care indicators, quality-of-life domains must be *improvable*. Many of these issues persist today, as highlighted in a recent review of existing quality of dying and death (QODD) measures that found evidence of minimal or no reporting of validity or reliability testing in two-thirds of the studies examined, an explicit definition of QODD in less than half, and a lack of consensus regarding how the dying phase was defined (Hales et al, 2010).

Quality of care and satisfaction measures. Even though quality of care measures and measures of satisfaction may use different language and have different aims, there is an inescapable overlap between the two and QOC measures fall prey to much of the criticism of satisfaction surveys. George (2002) stresses the historic overreliance on consumer satisfaction scores, which are subjective and can easily be skewed by respondent emotional or existential distress, as well as the chance that ethical care may lead to lower patient and family satisfaction. Teno (1999) delineates several reasons why satisfaction measures have been controversial, including the tendency of respondents to use only the two best categories, so that a response of ‘very good’ rather than ‘excellent’ may signify greater dissatisfaction than is immediately apparent. Teno also cites the worry that respondents are often vulnerable or may not feel empowered to express worries or dissatisfaction for fear that it may impact their care. This issue of vulnerability was partially addressed in a recent study by Kross, Nielsen, Curtis, and Engelberg (2012), in which 62% of bereaved ICU family members reported no or low survey burden. Teno (1999) also cautions that respondents may have low expectations for what is achievable, leading to instances where they may report high satisfaction only because they aren’t aware that there was room for improved care. Even though the concept of satisfaction has fallen into “disrepute”, Teno argues, “this should not lead us to cast aside the patient voice concerning the quality of medical care” (p.169).

Caregiver perspective and retrospective report. The literature is ripe with arguments for and against the use of retrospective caregiver report (Steinhauser, 2005; Teno, 2005). Benefits of retrospective surveys include their role in assessing EOL care for patients who are not prospectively identified as dying; evaluating care that was provided at the time of death, when it is typically inappropriate to intrude upon families at the bedside; and assessing follow-up care provided after the death (Casarett et al., 2010a). Some of the controversy about retrospective surveys lies in the questionable concordance between patient and caregiver assessments of patient care, though findings have varied regarding where concordance is better and worse. Recognizing that memory is a dynamic process that is vulnerable to emotions and subjective perspectives, Addington-Hall & McPherson (2001) encourage researchers to collect data directly from patients whenever possible, rather than retrospectively from caregivers. They recognize, however, that interviewing patients directly is often impossible, and they suggest that imperfect data from surrogates is better than no data at all. Furthermore, the authors recognize that caregiver perceptions are valid in their own right, even when they don't match patient experiences, as these memories determine how caregivers fare in bereavement.

Higginson, Wade, and McCarthy (1990) interviewed terminally ill cancer patients and caregivers and found that caregiver ratings of patient pain, other symptoms and anxiety were significantly worse than patients' own ratings. Notably, family ratings of both hospital services and care by members of the health care team were generally higher than those of patients. The study also found that caregiver anxiety was rated as the most severe problem by patients, and as the second most severe problem by caregivers (second only to symptom control). McPherson, Wilson, Lobchuk, and Brajtman (2008) found a tendency for caregivers of advanced cancer patients to overestimate patients' psychological and physical symptoms. Caregivers were better at accurately reporting symptoms such as nausea, vomiting and constipation, and less accurate with pain, sadness, worry and other less tangible symptoms. Lack of congruence between patient and caregiver report was associated with caregiver emotional state and feeling burdened, being a male caregiver, and with patients feeling like a burden. Hinton (1996) found that cancer patient and caregiver pre-death ratings of patient symptoms matched fairly well, but that caregivers tended to overrate pain and underrate weakness and depression in retrospective report. Caregivers were more accurate in retrospective ratings of patient anxiety, dyspnea, vomiting, immobility, awareness of prognosis and acceptance of dying. A study by Hauksdóttir, Steineck, Fürst, and Valdimarsdóttir (2006) suggests that even the structure of interviews with bereaved families may impact caregiver report. The authors found that cancer widowers reported their wives' psychological morbidity as significantly worse when interview questions about their wives' disease preceded questions about their own psychological wellbeing.

Studies have also looked at concordance between caregiver reports and those of health care providers. Levy et al. (2005) found considerable variation in how medical and nursing staff and family members perceived ICU patient deaths. Attending physicians and family members tended to provide better ratings than nurses or residents, but families did report significantly lower ratings than attendings on whether patients had discussed EOL wishes with doctors. Families reported significantly higher ratings than nurses or medical residents regarding patient autonomy, dignity, time spent with partner, time spent alone, and physical touch from loved ones. Jones et al. (2011) also found that family caregivers and palliative care physicians rated patients' quality of life as significantly worse than did the patients themselves, a trend which decreased only moderately over time.

Finally, nonresponse bias has been another source of controversy with retrospective report. Casarett, Smith, Breslin, and Richardson (2010a) examined this issue and found that while there were several significant differences between respondents and nonrespondents to their retrospective quality-of-care survey – including caregiver age, ethnicity, relationship to patient, site of death, chaplaincy involvement with family, and palliative care involvement – any effect of nonresponse bias on survey results was minimal.

Defining dying. Teno and Coppola (1999) were the first to ask, "Who is in the denominator?" with respect to defining the population of interest in EOL research, though others have echoed their concerns (Fowler et al., 1999; George, 2002). Because there isn't a single, definable state of being terminally ill, Teno and Coppola (1999) have urged researcher precision in qualifying who is dying. They have suggested distinguishing patients living with a life-threatening illness (prognosis ≤ 1-2 years) from those who are actively dying (prognosis of weeks), and have also suggested that defining the denominator retrospectively and asking family members to evaluate quality of EOL care allows researchers to clearly define care received during the final week or month of life.

Impact of EOL Care on Bereaved Caregiver Adjustment

Caregivers at the end of life face unique mental health risks. Hudson et al. (2011) interviewed family caregivers within two weeks of admission to a palliative care program and found that just under half had probable anxiety or depression, 15% met criteria for pre-loss prolonged grief disorder, and 10% had moderate to severe demoralization. Elklit, Reinholt, Hjort, Blum, and Lasgaard (2010) found that 40% of bereaved cancer family members had PTSD symptoms. Gries et al. (2010) interviewed bereaved families of ICU patients and found that 14% met PTSD criteria, 18% met depression criteria, and 11%

met criteria for both. 82% of families who had shared in EOL decision-making in the ICU experienced PTSD symptoms in a study by Azoulay et al. (2005).

Caregiver baseline demographic and psychosocial factors play an important role in how they perceive EOL care and how they fare in bereavement. Kelly et al. (1999) identified baseline psychiatric symptoms as the chief predictor of bereaved cancer caregiver psychiatric distress; other predictors included greater number of adverse life events, caregiver baseline coping responses, history of bereavement or separation, conflictual relationship with the patient, and severity of the patient's illness at time of referral to palliative care. Lower bereaved caregiver satisfaction with EOL care has been associated with patients being younger (Lewis-Newby, Curtis, Martin, & Engelberg, 2011) and caregivers being depressed (Fleming et al., 2006). Decreased PTSD symptoms in bereaved caregivers have been associated with fulltime employment, greater perceived control, secure attachment styles, and less time in the caregiver role (Elklit et al., 2010). Higher levels of PTSD and depression in bereaved caregivers have been associated with caregivers being female, knowing the patient for less time, and having more involved mental health histories (Gries et al., 2010). Increased depression has also been associated with lower sense of optimism, less social support, baseline depression and race (Burton et al., 2008; Kurtz, Kurtz, Given, & Given, 1997). Increased grief symptoms have been associated with caregivers having less time in the caregiving role (Burton et al., 2008), being female, being older, or when decedents are younger (Ringdal, Jordhøy, Ringdal, & Kaasa, 2001). Tomarken et al. (2008) found higher levels of pre-death complicated grief in cancer caregivers who were younger or who had less social support, lower income, baseline depression, pessimistic thinking, or more stressful life events.

While caregivers may present with unique personal risk factors for poor bereavement adjustment, characteristics of the dying experience itself also have clear implications for bereaved caregiver adjustment. Ott et al. (2007) found that caregivers experiencing “chronic bereavement” were more likely to have experienced sudden deaths or perceived deaths as not peaceful. Brazil et al. (2002) found that poorer caregiver mental health in bereavement was associated with patients not dying at home. Azoulay et al. (2005) found moderate to severe PTSD symptoms in one-third of family members whose loved one had been in an ICU, symptoms that increased when patients died in the ICU, when patients died after EOL medical decisions, or when families felt they had incomplete medical information. Buss et al. (2007) identified 19% of cancer caregivers reporting patient delirium at least once a week in the month prior to study, and 3.5% meeting criteria for generalized anxiety disorder (GAD), with those perceiving delirium in their loved one twelve times more likely to have GAD. Given et al. (2005) found a significant, linear relationship between number of patient symptoms and caregiver depression. Wright et al. (2008) found that bereaved cancer caregivers who had opted for aggressive EOL measures were more likely to suffer from subsequent depression and regret, and to report having felt unprepared for the death. A follow-up study by Wright et al. (2010b) identified a higher likelihood of prolonged grief disorder and PTSD in bereaved cancer caregivers whose loved one had died in a hospital or ICU rather than on home hospice. In contrast, Houts, Lipton, Harvey, Simmonds, and Bartholomew (1989) found higher levels of prolonged grief and distress in spousal cancer caregivers whose spouse died at home; prolonged grief was also greater when spouses witnessed patient discomfort during the dying phase, experienced emotional distress prior to the death, or failed to accept the possibility of death. In a small (N=15) qualitative study of bereaved cancer caregivers by Koop and Strang (2003), caregivers attributed their own positive or negative bereavement outcomes to their perceptions of patient suffering, sense of accomplishment and/or meaning related to the caregiver role, and presence of family conflict at the time of decision-making. Tilden et al. (2001) found that family members whose decedent did not have advance directives were more likely to prioritize prolongation of life over quality of life for their hospitalized loved one, and to express post-loss stress around decisions to withdraw life-sustaining treatment.

Complicating the picture for caregiver adjustment is the fact that many do not access mental health support during EOL care or in bereavement. Vanderwerker et al. (2005) found that while 13% of Coping with Cancer caregivers met criteria for a psychiatric disorder, less than half had accessed mental health support since the time of the patient's cancer diagnosis. Importantly, the authors suggest that researchers need to pay attention not only to caregiver utilization of mental health supports, but also *access* to these resources. Cherlin et al. (2007) found that only 30% of all bereaved cancer caregivers, and less than half of those with a diagnosis of major depression, used hospice bereavement supports in the year following a loved ones' death. Caregivers who were younger, the patient's spouse, had a baseline diagnosis of major depression, witnessed highly distressing events at the time of death, or received clearer communication about prognosis were more likely to use bereavement supports. Lichtenthal et al. (2011) found that while 16% of Coping with Cancer caregivers met criteria for prolonged grief disorder (PGD), this did not increase their likelihood of utilizing mental health supports and the majority did not do so.

Coping with Cancer

The Coping with Cancer (CwC) dataset has produced a number of studies, some already described, detailing how cancer patients and caregivers approach EOL care. CwC studies have suggested that greater use of positive religious coping by patients is associated with better overall patient QOL, while the opposite is true for negative religious coping (Tarakeshwar et al., 2006). At the same time, greater use of positive religious coping by patients has also been associated with significantly more ventilator support and life-prolonging care at the EOL (Phelps et al., 2009). Both positive and negative religious coping among caregivers are associated with increased caregiver burden, but negative religious coping is also associated with poorer caregiver QOL, less satisfaction with the caregiving role, and an increased likelihood of depression and anxiety (Pearce, Singer, & Prigerson, 2006). Balboni et al. (2007) found that while most CwC patients felt religion was important, many reported little to no support of their spiritual needs from their religious community or from the medical system. Those receiving more spiritual support had better QOL, although higher religiosity was also associated with wanting life-prolonging measures at the end of life. Patients whose spiritual needs were supported by the medical team were more likely to receive hospice care (Balboni et al., 2010). Minority patients and those with high use of religious coping were more likely to spend time and/or die in an ICU when they received inadequate spiritual support. Furthermore, EOL costs were higher for patients receiving inadequate spiritual support, especially if they were minorities or used high levels of religious coping (Balboni et al., 2011).

Almost 20% of CwC patients were peacefully aware of their prognosis, meaning they were not only aware of their prognosis but also felt a deep sense of inner peace or harmony. These patients experienced less psychological distress, higher rates of advance care planning and the highest overall quality of death, and their bereaved caregivers experienced better physical and mental health (Ray et al., 2006). Patients who acknowledged their terminal illness, or who reported having an EOL discussion with their doctor, were less likely to want life-extending care; those who did want life-extending care were more likely to receive ICU care and less likely to receive hospice (Wright et al., 2010a). Patients who died in an ICU or hospital had more physical and emotional distress and worse QOL at end of life compared to patients who died on home hospice; ICU and hospital deaths were associated with increased caregiver risk for PTSD and prolonged grief disorder, respectively (Wright et al., 2010b). Therapeutic alliance between CwC patients and their oncologists was inversely related to symptom burden, functional status, mental illness, and ICU care at the end of life, and positively associated with emotional acceptance of terminal illness (Mack et al., 2009). CwC patients reporting EOL discussions with their doctor had significantly lower health care costs in the final week of life and a significantly better quality of death (Zhang et al., 2009).

Black CwC patients overall were three times more likely than whites to receive aggressive EOL care, but among patients requesting aggressive care whites were three times more likely than blacks to receive it. White patients who had an EOL discussion with their doctor or who had a DNR order were less likely to receive aggressive care, but the same was not true for blacks, even though the two had similar rates of EOL discussions. Furthermore, even though black patients who discussed EOL care with their doctors were more likely to have a DNR order, there was no significant difference in receipt of life-prolonging care between black patients with and without a DNR order (Loggers et al., 2009; Mack, Paulk, Viswanath, & Prigerson, 2010b). Patients with dependent children were more likely to have panic disorder, to be worried, and to want aggressive EOL care, and less likely to engage in advance care planning. These patients also had worse QOL in the last week of life, and their caregivers were more likely to meet criteria for major depressive disorder and generalized anxiety disorder (Nilsson et al., 2009).

Interventions

Researchers have proposed or tested a number of clinical interventions to help caregivers cope with an expected loss, several of them specific to the role of social work. Cagle and Kovacs (2009) have emphasized the critical role social workers ought to play in educating caregivers at the end of life, including reiterating and clarifying key medical facts, filling information gaps, assessing the emotional impact of EOL communication, pointing out the influence of family dynamics on coping, addressing caregiver cognitive distortions (e.g. “if she’d just eat, she’d get better”), and reframing expectations. Bern-Klug (2004) has used the concept of *ambiguous dying* to describe the experience of patients who have exceeded their life expectancy, or for whom there is no clear disease trajectory, leaving them and their loved ones with ambiguity around whether or when they are dying and how to gauge their remaining time before death. She suggests five roles for social workers in promoting patient self-determination when dying is ambiguous: helping physicians to initiate discussions about medical course even when there is ambiguity, and helping patients and loved ones understand the medical situation;

situating medical information in the context of patients' lives, so that they can prioritize and maintain control over how they spend their time; normalizing feelings associated with the ambiguity of the dying process; incorporating ambiguous dying into advance care planning; and advocating for health care system and public policy change to make room for ambiguity. In this role of 'context interpreter' for the ambiguously dying, Bern-Klug, Gessert, and Forbes (2001) suggest that social workers can help caregivers to avoid unrealistic feelings of control or responsibility over the dying process; identify other, non-physical sources of patient and caregiver pain and suffering; and help providers to understand patient and caregiver hopes, fears and expectations.

Tulsky (2005) has suggested that the three primary communication tasks of physicians working with dying patients and their families are information gathering, information giving, and relationship building. He further suggests that interventions geared toward improving physician EOL communication should generally focus on either improving communication skills directly or facilitating communication between physicians and their patients. In cases where life-sustaining treatments (LST) are to be withdrawn, Curtis (2005) has encouraged health care providers to discuss how LST will be withdrawn, how the team will ensure comfort and continue to care for the patient, patient or family preferences about other aspects of EOL care, and the patient's expected length of survival. Greer (2010) has suggested the use of cognitive behavioral therapy in bereaved caregivers experiencing complicated grief, specifically to address cognitive distortions or 'thinking errors' related to patients' EOL experiences, including unjustified guilt or self-criticism and misdirected anger at the health care team.

Intervention studies have met with varied success. McMillan (2005) distinguishes EOL intervention studies according to their supportive versus educational focus. She cites her own psychoeducational intervention to teach hospice caregivers how to cope with patient symptoms, which resulted in improved caregiver quality of life, decreased burden and less distress related to witnessing patient symptoms. According to McMillan, issues of accrual and attrition have stymied EOL intervention research. Redinbaugh, Baum, Tarbell, and Arnold (2003) found that hospice family caregivers who used ‘reframing coping’ – marked by an acceptance of the patient’s illness, defining illness-related problems in manageable ways, and feeling capable of solving problems associated with EOL care – had less caregiver strain around patient activities of daily living (ADL) needs, psychological distress and poor existential QOL, all of which otherwise increased caregiver strain. McClement et al. (2007) have studied family perspectives on Dignity Therapy – a therapeutic protocol developed by Chochinov (2002) focused on patient generativity and legacy-making, and aimed at reducing patients’ subjective suffering at the same time that it improves their sense of meaning, purpose and dignity – and found that the majority of bereaved families felt this type of therapy helped prepare their loved one for death and helped with family grief. Importantly, 43% of families also felt that Dignity Therapy reduced patient suffering. In their oft-cited study of family-team communication, McDonagh et al. (2004) found that an increased proportion of family-to-team speech in ICU family meetings was associated with greater family satisfaction around physician communication, feeling heard, and understanding their choices and decisions; and with less perceived conflict with the physician leading the family meeting.

Other intervention studies have been less successful. In a small pilot study by Kirchhoff, Palzkill, Kowalkowski, Mork, and Gretarsdottir (2008), families receiving targeted communication regarding what to expect after withdrawal of life support reported significantly higher satisfaction with information received, but the authors found no significant differences in caregiver mood or mental health. O'Hara et al. (2010) likewise found no difference in caregiver burden between intervention and control groups for patients who received an otherwise successful palliative care nurse telephone education intervention.

Chapter III. Methods

Study Design

Data used in the present study comes from Coping with Cancer, a federally funded, longitudinal, multi-site study of advanced cancer patients and their caregivers. CwC sought to examine how various psychosocial factors impact the quality of life and quality of care for cancer patients and their caregivers, as well as caregiver bereavement adjustment.

Sampling

The CwC study recruited patients between September 1, 2002, and February 28, 2008, from eight participating sites: Yale Cancer Center (New Haven, CT), Veterans Affairs Connecticut Healthcare Systems Comprehensive Cancer Clinics (West Haven, CT), Memorial Sloan-Kettering Cancer Center (New York, NY), Parkland Hospital and Simmons Comprehensive Cancer Center (Dallas, TX), Massachusetts General Hospital and Dana-Farber Cancer Institute (Boston, MA), and New Hampshire Oncology-Hematology (Hooksett, NH). Eligible patients were required to have an advanced metastatic cancer diagnosis, disease progression through chemotherapy, estimated prognosis less than six months, age ≥ 20, presence of an informal caregiver, absence of significant cognitive impairment, and English or Spanish proficiency. Trained research staff identified study candidates from weekly clinic rosters and approached identified patients to discuss study participation. After obtaining written informed consent from each patient, research staff confirmed patient eligibility via medical record review and consultation with the patient's physician. Trained interviewers assessed patients and caregivers at baseline (Wave 1), and then interviewed caregivers again following patients' deaths (Wave 2). Patients and caregivers received $25 compensation for completing the interview. Additional information was obtained via chart review and post-mortem interviews with caregivers and/or staff caring for patients at the time of death.

As described in Zhang et al. (2012), of the 1015 eligible patients approached for participation in CwC, 289 (28.5%) declined participation. Nonparticipation reasons included "not interested" (n=120), "caregiver refuses" (n=37), and "too upset" (n=20). Nonparticipants reported significantly more distress than participants, but did not differ significantly from participants in sex, age, or educational level. Latinos were more likely than other ethnic groups to agree to participation. Of the 726 patients who completed the Wave 1 interview, 414 patients died at the time of data analysis and received Post-Mortem assessments. These 414 patients did not differ significantly by cancer type, psychological distress, or presence of psychiatric disorders from participants still living at the time of data analysis, but they did report worse baseline QOL, symptom burden, and performance status. While 414 patients received Post-Mortem assessments, only 315 bereaved caregivers completed Wave 2 interviews. The present study samples these 315 patient/caregiver dyads. There is little consensus on adequate sample size for factor analysis (MacCallum, Widaman, Zhang, & Hong, 1999), but the present study's 15:1 subject-to-item ratio is larger than 70% of the 300 factor analysis studies analyzed by Costello and Osborne (2005).

Measures

Using CwC data for the 315 patient/caregiver dyads with Wave 2 interview data, the present study evaluates findings related to caregiver demographic characteristics, caregiver perception of quality of care at the end of life, and key EOL variables presumed to correlate with or predict perceived quality of care at the end of life.

Demographics

Caregivers answered questions about their own gender, age, race/ethnicity, marital status, income, education, religion, relationship to the patient, and length of time in the caregiving role. Information was also recorded about patient and caregiver recruitment site.

Quality of Care at the End of Life (Hypothesis I)

The CwC dataset contains over 400 Wave 2 interview items, of which the author selected 69 items for consideration of entry into factor analysis. All of these items had either strong face validity as factors related to caregiver-perceived quality of care at the end of life, or strong statistical validity as components of established scales. Item identification was based on existing literature regarding factors important to caregivers at the end of life (Bryce et al., 2004; Curtis et al., 2001; Hanson et al., 1997; Heyland et al., 2006; Steinhauser et al., 2000a) as well as the author's own clinical experience working with dying patients and their caregivers. The author further reduced this initial pool of 69 items to 21 by discarding variables that were redundant, related to patient care prior to the final week of life (to achieve a standardized time reference), or inquired about specific patient symptoms (to achieve greater generalizeability). Of the 21 final items, twelve were adapted for CwC from the TIME instrument (Teno et al., 2001b), one from the Needs Near the End of Life Screening Tool (Emanuel, Alpert, & Emanuel, 2001), and eight originated with the CwC study itself (Table 1).

This process of item selection represents a refinement of the author's initial CEQUEL scale development, in which a smaller pool of seventeen items was retained for factor analysis. The four additional items retained in the present study were TIME questions related to a focus on the patient as an individual. These items asked caregivers about various aspects of patients' personal care needs and respectful treatment. Given the TIME measure's position as the best existing, validated measure of caregiver-perceived quality of EOL care, these four items were included in an attempt to utilize as many TIME items as possible and to maximize the opportunity to develop a comprehensive measure of quality of care at the end of life.

Correlates of Quality of Care at the End of Life (Hypothesis II)

Select Wave 1, Post-Mortem and Wave 2 items were retained for convergent validity analysis based on the hypothesis that all items would be significantly associated with CEQUEL scores (DeCoster, 2005). Taking items used in the author's initial CEQUEL scale development, the present study expands the pool of potential correlates with a measure of patient-doctor therapeutic alliance described below.

Wave 1 patient items. Wave 1 patient items included patient baseline reports of advance care planning and EOL discussions with their physicians. In previous CwC studies, patient-provider discussion of EOL wishes was associated with less aggressive medical care, which was then associated with improved QOL in bereaved caregivers (Wright et al., 2008). Also retained were Wave 1 caregiver responses on the 14-item Brief RCOPE, a validated measure of positive and negative religious coping (Pargament, Koenig, & Perez, 2000). Pargament, Smith, Koenig, and Perez (1998) have distinguished positive religious coping – "an expression of a sense of spirituality, a secure relationship with God, a belief that there is meaning to be found in life, and a sense of spiritual connectedness with others" – from negative religious coping, "an expression of a less secure relationship with God, a tenuous and ominous view of the world, and a religious struggle in the search for significance" (p.712). Negative religious coping has been associated with increased caregiver burden, poor mental health, and decreased QOL and satisfaction (Pargament et al., 1998; Pearce et al., 2006). Finally, patients answered Wave 1 questions about the degree to which they trusted and respected their physician, felt respected and 'seen as a whole person' by their physician, and felt comfortable asking their physician questions about their care. Responses to these five items were summed as a measure of therapeutic alliance, which has been previously identified as important to the QOL of dying patients and their families (Steinhauser et al., 2000b; Zhang et al., 2012).

Post-Mortem items. Post-Mortem items inquired about place of death, hospice enrollment, ICU admission and resuscitation. Prior research suggests that less aggressive medical care, dying on home hospice rather than in an ICU, and longer hospice enrollment are associated with better caregiver satisfaction with care, QOL and mental health (Azoulay et al., 2005; Gries et al., 2008; Kris et al., 2006; Teno et al., 2004; Wright et al., 2010a; Wright et al., 2008; Zhang et al., 2012).

Wave 2 caregiver items. Wave 2 caregiver items included questions related to caregiver regret, which has been inversely associated with perception of peaceful death (Akiyama et al., 2010). Additional Wave 2 items were included to capture psychosocial distress in bereavement as an expected outcome of poor EOL care (Wright et al., 2010b). These include items from the Yale Evaluation of Suicidality (YES) scale (Latham &

Prigerson, 2004; Prigerson et al., 2009), the Stressful Caregiving Adult Response to Experience of Dying (SCARED) scale (Prigerson et al., 2003), the Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974), and the Structured Clinical Interview for DSM-IV (SCID) Axis I modules (First et al., 1995; Williams et al., 1992).

Predictors of Quality of Care at the End of Life (Hypothesis III)

In developing a predictive model of perceived quality of care at the end of life, this study considered a number of patient and caregiver Wave 1 and Post-Mortem items, as well as other CwC items related to structure or process of EOL care, for inclusion in uni- and multivariate regression analyses. Because the items comprising the CEQUEL measure were derived from Wave 2 caregiver interviews, other Wave 2 variables were not considered as potential predictors so that a stronger statement of predictive value might be made. Importantly, as suggested by Garrido and Prigerson (2013) and described in further detail below, the author selected for regression analyses only those factors that were potentially modifiable in the context of clinical interventions with bereaved caregivers. The justification for considering only modifiable factors relates to the author's overarching interest in research as a means of developing targeted clinical interventions with the cancer caregiver population. Factors not immediately modifiable or changeable in the clinical setting – for example, innate or ingrained caregiver characteristics such as optimism – provide an important lens through which to understand caregivers, but may not be realistic targets for immediate clinical intervention. Item selection was also limited by sample size. The author dropped variables from analysis if retaining them would result in > 50% loss of data on other variables when regressing across samples with full data for

Table 1

Initial factor analysis items related to quality of care at the end of life

Toolkit After-Death Bereaved Family Member Interview
Was there ever a problem understanding what any doctor was saying to you about what to expect from treatment? Yes=1 No=2
Did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment? Yes=1 No=2
Did you or your family receive any information about what to expect while (he/she) was dying? Yes=1 No=2
At any time did you or your family receive any information about the medicines that would be used to manage pain, shortness of breath, or other symptoms? Yes=1 No=2
How often were you or other family members kept informed about [PATIENT'S] condition? Always=1 Usually=2 Sometimes=3 Never=4
To the best of your knowledge, did [PATIENT'S] doctor or the medical staff who cared for (him/her) speak to (him/her) or you about (his/her) wishes about medical treatment? Yes=1 No=2
Did (his/her) doctor or the medical staff who cared for (him/her) speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes? Yes=1 No=2
Was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes? Yes=1 No=2 Don't know=3
How often were [PATIENT'S] personal care needs- such as bathing, dressing, changing bedding- taken care of as well as they should have been? Always=1 Usually=2 Sometimes=3 Never=4
How often was (he/she) treated with respect by those who were taking care of (him/her)? Always=1 Usually=2 Sometimes=3 Never=4
How often was [PATIENT] treated with kindness by those who were taking care of (him/her)? Always=1 Usually=2 Sometimes=3 Never=4
Was there enough help with medications and getting dressings changed? Yes=1 No=2
Needs Near the End of Life Screening Tool
On a scale of 1 to 10, how much do you think [PATIENT] suffered from physical symptoms, such as pain, shortness of breath, fatigue, bowel or urination problems? (Not at all=1→A great deal=10)
Items originating in Coping with Cancer

Was the life of [PATIENT] prolonged by medical interventions longer than you would have wished? Yes=1 No=2

Was the life of [PATIENT] prolonged by medical interventions when ___________ was, to the best of your knowledge, dying? Yes=1 No=2

Was the life of [PATIENT] prolonged by medical interventions that resulted in an increase of his/her suffering? Yes=1 No=2

How prepared did you feel for ________'s death?
1 2 3 4 5 6 7
Totally prepared Somewhat prepared Well prepared

How drawn out did the dying process seem to you?
1 2 3 4 5 6 7
Over very quickly Moderate Extremely prolonged

How peaceful or violent did _____'s death seem to you?
1 2 3 4 5 6 7
Peaceful Moderate Violent

To what extent do you think _________ suffered in dying?
1 2 3 4 5 6 7
Minimally Moderately Extremely

How much did __________ suffer compared to what you expected?
1 2 3 4 5 6 7
Much less Same Much more

each variable. Variables included in analysis are presented below, grouped by conceptual category.

Patient Predictors

Quality of life. Caregivers answered questions about their perceptions of patients' quality of life via the McGill Quality of Life questionnaire, a QOL measure that has been validated with terminally ill patients (Cohen, Mount, Strobel, & Bui, 1995). McGill items were grouped by physical, existential, psychological and support subfactors, as well as a sum score comprising all items.

Mental health. Patients completed SCID Axis I modules for Major Depressive Disorder (MDD), Generalized Anxiety Disorder (GAD), Panic Disorder (PD), and Posttraumatic Stress Disorder (PTSD). These have been well validated in the literature and have been used in studies of bereaved family members (First et al., 1995; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008). Due to relatively low prevalence within each diagnosis, SCID diagnoses were summed for each patient to indicate the presence of *any* SCID mental health diagnosis. Patient anxiety has been associated with less trust in physicians, less comfort asking questions about health, and lower likelihood of understanding clinical information received from physicians (Spencer, Nilsson, Wright, Pirl, & Prigerson, 2010). Patients also answered four items about feeling depressed, nervous/worried, sad, or terrified as part of the McGill QOL questionnaire. Patients responded to an item about how often they felt deep inner peace or harmony.

Mental health service use. Patients answered whether or not they had discussed mental health concerns with a healthcare professional since their cancer diagnosis, or accessed any type of mental health intervention to help them adjust to their illness since diagnosis.

Acknowledgment of terminal illness. Patients were asked to describe their health status as terminally ill or not terminally ill. Patients acknowledging their terminal illness are less likely to pursue aggressive EOL care, and caregivers of these patients are less likely to experience bereavement sequelae such as PTSD (Wright et al., 2008; Wright et al., 2010a; Wright et al., 2010b).

Religiosity, spiritual support and religious coping. Patients' summed responses about frequency of attendance at religious services before and after cancer diagnosis, amount of time spent in private religious activities (e.g. prayer, meditation, Bible study) before and after diagnosis, importance of religion, use of religion as a primary coping method, extent to which religious beliefs or activities helped with coping or handling their illness, and extent to which religious views affected recent medical decisions were used as a proxy for patient religiosity. Patients who are more religious are more likely to want life-prolonging measures at the end of life (Balboni et al., 2007). Patient responses regarding support of their religious beliefs by their religious community and by the medical system, receipt of pastoral care services in the hospital or clinic, and visits by or to outside clergy were summed as a measure of patient spiritual support. Higher patient spiritual support has been associated with better patient QOL (Balboni et al.), higher likelihood of hospice enrollment, and lower likelihood of death in an ICU (Balboni et al., 2010; Balboni et al., 2011). Patient positive and negative religious coping was assessed via the Brief RCOPE. Greater use of positive religious coping has been associated with better overall patient QOL (Tarakeshwar et al., 2006), but also with higher likelihood of ventilation and life-prolonging care in the final week of life (Phelps et al., 2009).

Therapeutic alliance. Therapeutic alliance between patients and their oncologists has been associated with greater emotional acceptance of terminal illness by patients and decreased time in intensive care at the end of life (Mack et al., 2009). Patient responses to five items about their relationship with their doctors, described above, were summed as a measure of therapeutic alliance. Two of these items – comfort discussing care with doctors, and feeling seen as a whole person by doctors – were also entered into analysis as individual predictors; the remaining three were not, due to low variability of responses.

Advance care planning. Patients were asked if they had completed a health care proxy and/or living will, if they had discussed their wishes for EOL care with their doctor, and if they had completed a DNR order. Patients are more likely to receive care consistent with their wishes if they have discussed them with their physician (Mack et al., 2010a).

Caregiver Predictors

MOS SF-36. Caregivers completed the Medical Outcomes Study (MOS) Short Form 36 (SF-36) Health Survey, a measure of physical and emotional well-being consisting of eight scaled scores: physical function, role limitation secondary to physical health, role limitation secondary to emotional problems, energy/fatigue, emotional well-being, social function, pain and general health. SF-36 sum scores, scores for each subsection, and a single item asking about health change in the past year were all entered into regression analyses. The author followed SF-36 scoring recommendations outlined by the RAND Corporation (2013).

Health-promoting behavior. Caregivers responded to a series of questions about health-promoting habits in the past month, including concerns about staying in shape, nutrition, and calorie intake; and whether or not they exercised, took daily vitamins or nutritional supplements, had annual health check-ups, and felt they got enough rest. Responses to these items were summed as a composite measure of health-promoting behavior.

Physical health service use. Caregivers were asked about physical health service use in the last three months, including overnight treatment in a hospital, treatment in an emergency room, visit to a medical office or clinic, and dental visits.

Mental health. Caregivers completed SCID Axis I modules for MDD, GAD, PD, and PTSD. As with patient responses, low prevalence of individual caregiver SCID diagnoses necessitated a summary variable capturing the presence of *any* mental health diagnosis.

Mental health service use. Caregivers answered whether or not they had discussed mental health concerns with a healthcare professional since their loved one’s cancer diagnosis, or accessed any type of mental health intervention to help them adjust to their loved one’s illness. Lichtenthal et al. (2011) found that discussing psychiatric concerns with a health care professional was the only significant predictor of caregiver mental health service use.

Religiosity, spiritual support and religious coping. A summary measure of caregiver religiosity was constructed from responses about frequency of attendance at religious services before and after cancer diagnosis, amount of time spent in private religious activities (e.g. prayer, meditation, Bible study) before and after diagnosis, importance of religion, use of religion as a primary coping method, extent to which religious beliefs or activities helped with coping or handling their loved one’s illness, and extent to which religious views affected recent medical decisions. Spiritual support was assessed via questions about visits to or from clergy, and extent to which caregivers felt their religious beliefs were supported by their religious community or by the medical system. Caregiver positive and negative religious coping was assessed via the Brief RCOPE. Positive religious coping by caregivers is associated with greater caregiver burden but also greater satisfaction with caregiving. Negative religious coping has also been associated with greater caregiver burden, poorer QOL, less satisfaction, and an increased likelihood of depression and anxiety (Pearce et al., 2006).

Support system and family relationships. The author analyzed caregivers’ total scores on the Interpersonal Support Evaluation List (ISEL), a validated measure of perceived availability of social support (Cohen, Mermelstein, Kamarck, & Hoberman, 1985). Also analyzed were scores on the four ISEL subscales: Tangible (perceived availability of material help), Appraisal (perceived availability of someone with whom to talk about problems), Self-Esteem (perceived availability of a ‘positive comparison’ when comparing oneself to others), and Belonging (perceived availability of people to do things with). Caregivers also completed the Family Relationship Index (FRI) (Moos & Moos, 1991), and the author analyzed total FRI scores as well as Cohesion, Expression and Conflict subscale scores.

Caregiver burden. The author analyzed caregiver responses on the Caregiver Burden Scale, in which respondents are asked about the amount of time spent on a given task (demand) as well as the difficulty associated with that task (Andren & Elmstahl, 2005). Responses for six different tasks were combined to create composite measures of caregiver demand and difficulty: assistance with feeding, bathing, dressing, or toileting; assistance getting in/out of bed or getting around inside; provision of emotional support; assistance with medications, including injections and bandaging; performing household tasks such as meal preparation, housecleaning, and laundry; and shopping or transportation.

Tobacco and alcohol use. Caregivers responded to questions about the number of cigarettes they currently smoked per day, how often they drank alcohol, and how many alcoholic drinks they had per day.

End-of-Life Care Predictors

Aggressive care in the final week of life. The caregiver or a member of the health care team caring for the patient at the time of death provided information on ventilator use, resuscitation attempts, ICU stays, feeding tubes, chemotherapy, and antibiotics in the week leading up to the patient's death. Low variability among patients for most of these factors necessitated a summary measure of *any* aggressive care received in the final week of life. Aggressive care at the end of life has been associated with worse QOL and greater likelihood of depression, PTSD and prolonged grief disorder for caregivers (Wright et al., 2008; Wright et al., 2010b).

Place of death. Patients' place of death was reported in Post-Mortem interviews. Locations included the ICU, hospital (non-ICU), home, nursing home and an inpatient hospice. Caregivers or team members also reported if patients died where they would have wanted to die. Wright et al. (2010b) found that patients dying in an ICU or hospital suffered greater physical and emotional distress and had worse QOL at the end of life than patients who died on home hospice.

Hospice involvement. Inpatient or outpatient hospice involvement was reported; these were analyzed individually and also combined as a measure of *any* hospice involvement. In addition to hospice enrollment, length of inpatient or outpatient hospice was reported.

Consciousness in final week. Patient level of consciousness in the final week of life was reported.

Statistical Analyses

The present study employs frequency and descriptive statistics, means-difference testing, correlational analyses, and uni- and multivariate regression analyses, all performed using IBM SPSS Statistics, Version 19.0 (SPSS, Inc., 1989-2010), as well as exploratory factor analysis using Mplus, Version 6.12 (Muthén & Muthén, 1998-2011).

Factor analysis

Frequency and descriptive statistics were evaluated for the 21 items to be used in factor analysis. Ten items were yes/no questions, and eleven were Likert scale questions. All items were non-normally distributed and skewed in the direction of perceived better quality of care (e.g. feeling well-prepared or that death was not prolonged), and transformation attempts were unsuccessful in achieving more normal distributions. Due to item non-normality, as well as the goal of achieving an easily summed scale, Likert items were dichotomized. Item dichotomization is common in the development of quality of EOL care measures (Casarett et al., 2008; Teno et al., 2001b). The author dichotomized 4- and 10-point Likert items at midpoint and 7-point items using 4 as the split point (i.e. 1-4=1, 5-7=2). The author also reversed and/or recoded items as necessary to facilitate meaningful item summation, with "1" signifying perceived poorer quality of care and "2" perceived better quality of care. The decision to have higher scores signify better perceived quality of care represented a refinement of the author's initial work, and was based on feedback that higher CEQUEL scores signifying poorer perceived quality of care was likely to feel counterintuitive to CEQUEL's users.

As suggested by Muthén, du Toit, and Spisic (1997) for factor analysis with binary outcomes, a weighted least squares extraction method using tetrachoric correlations was employed via the Weighted Least Squares Mean and Variance Adjusted estimator. Use of Quartimin rotation was based on the assumption that factors would correlate (Browne, 2001; Jennrich & Sampson, 1966). Item and factor retention was based on Muthén (2011) criteria including Eigenvalues > 1 (Fabrigar, Wegener, MacCallum, & Strahan, 1999), scree plot analysis (Cattell, 1966), no negative residual variances, factor loading patterns, and substantive and theoretical interpretability. Model fit statistics obtained via factor analysis were interpreted following Yu's (2002) recommendations: CFI ≥ 0.96, TLI ≥ 0.95, RMSEA ≤ .05, RMSR < .05 and chi-square probability > 0.05. Items with factor loadings < 0.4 were removed in successive factor analyses, a more stringent cut-off value than the 0.32 value typically recommended (Costello & Osborne, 2005), in order to obtain a stronger model.

Consecutive analyses were conducted until a 13-item, 4-factor solution with clear factor loadings and good model fit was achieved. This was based on a final sample size of 275, representing those patient/caregiver dyads with complete data on all thirteen items, and represented a four-subject increase from the author's initial scale development.

Normality tests

The author evaluated the normality of both CEQUEL and subscale score distributions. While full CEQUEL scores fell within an acceptable range of normality, scores for all four subscales were skewed towards perceived better quality of care. Attempts at transformation were unsuccessful in providing sufficient correction.

Reliability and convergent validity analysis

Internal consistency reliability analyses were evaluated using Cronbach's α (Cortina, 1993). Final factor analysis items were summed for each respondent as a total CEQUEL score. Demographic frequency and descriptive statistics were computed, and means-difference tests performed to evaluate demographic differences in scores. The non-normal distribution of CEQUEL subscale scores required the use of nonparametric tests including the Mann-Whitney *U* test for gender differences, Spearman correlations for age and education, and the Kruskall-Wallis test for other demographic variables. Convergent validity was examined via association between CEQUEL (or subscale) scores and related EOL indicators, again using nonparametric tests. While the normal distribution of CEQUEL scores justified the use of parametric tests, the author used nonparametric tests for both CEQUEL and subscale analyses in order to facilitate comparison of convergent validity findings.

Assumptions for multiple linear regression

Prior to regression analyses the author tested CEQUEL scores for the assumptions of linear regression (Polit, 2010, p.245), and found all assumptions adequately met.

Model selection via regression analysis

Because only full CEQUEL scores were to be used as the outcome measure for model selection, parametric testing via multiple linear regression was used for this section of analysis. The author followed a theory-based analytical protocol used by Garrido and Prigerson (2013) to identify the best, most parsimonious model of factors predicting caregiver CEQUEL scores. In their study, Garrido and Prigerson also used CwC data but with the aim of identifying the best set of predictors of bereaved caregivers' mental health. The authors included for analysis only those predictors that were potentially modifiable, in order that their findings might inform the development of viable clinical interventions with bereaved caregivers. The present study similarly considered only those factors that were potentially modifiable in the clinical setting.

Akaike's Information Criterion (AIC)

The protocol for model selection used in this study relies heavily on Akaike's Information Criterion (AIC) criterion, a measure of model fit with a theoretical basis in Kullback-Liebler (K-L) information theory (Burnham & Anderson, 2004). One of the underlying assumptions of information theory is that there is no single true model that reflects full reality, leaving only derived models that best approximate an unknown full reality. As described by Burnham and Anderson, Kullback and Liebler posited that K-L information is the "'distance' between full reality and a model" (p. 7), or the information lost when such a derived model is used to approximate a theoretical 'true' model. The best model is that which loses the least information relative to other approximating models, and the AIC value is an estimate of K-L information. Corrected Akaike's Information Criterion (AICc) values are corrected for small sample size and experts have encouraged their use over traditional AIC values (Hurvich & Tsai, 1989; Bedrick & Tsai, 1994).

As suggested by Garrido and Prigerson (2013), the author followed several steps in this theory-based analysis. First, the author grouped Wave 1 and Post-Mortem items by the conceptual categories described above. The author then constructed a correlation matrix within each category to identify which variables were highly correlated; for the purposes of this analysis, items with correlations below 0.400 were considered not highly correlated. Finally, the author conducted five series of regression analyses as follows:

- Series One: Uni- and multivariate regressions within each category, using individual items as well as combinations of items with low correlations. The author calculated AICc values for each model, with the 'best' model or models having the lowest AICc value. Because AICc comparison between models requires equivalent samples, the author had previously included for analysis only those subjects with full data for all variables within each conceptual category. Models with an AICc value difference of ≤2 are considered equivalent, with differences of 10 or greater indicating model superiority (Burnham & Anderson, 2004).
- Series Two: Multiple linear regressions across categories, using those variables with the lowest AICc values for each category. The author again limited the sample to subjects with full data on all variables and calculated AICc values for each model. Variables with the lowest AICc values across conceptual categories were retained.

- Series Three: Multiple linear regressions using single variables as well as combinations of variables from different categories, again limiting the sample to subjects with full data on all items. This produced a ‘semi-final’ model.
- Series Four: Multiple linear regressions using the semi-final model from Series Three and adding any other variables that had been statistically significant in Series One. Once again, the author conducted these regressions across a new sample with full data on all variables, and compared AICc values for each model.
- Series Five: Multiple linear regressions comparing all models from series 4 with low AICc values, across a new sample with full data on all variables

Following these regression analyses, the author selected as a final unadjusted model the one with the lowest AICc value, *as well as* the fewest number of predictors (i.e. the most parsimonious) if AICc values were within 2 points of one another. Finally, the author adjusted the final model for caregiver gender, age, race, marital status, religion, education, income, relationship to the patient, and length of time as a caregiver, as well as patient/caregiver recruitment site.

Chapter IV: Findings

Sample Demographics

Table 2 provides relevant characteristics for the 275 caregivers used in this report. Seventy-six percent were female, 70% were white, 68% were married, and 39% were Catholic. Caregivers ranged in age from 20 to 83 years (Mean=51.9, Median=53). 53% were the spouse or partner of the patient. Fifty-eight percent of caregivers in the present study were recruited from community-based sites. Mean CEQUEL scores were significantly lower (indicating poorer perceived quality of care) for Catholic than for non-Catholic caregivers (23.2 vs. 23.9, $p=0.015$), as well as for caregivers reporting no religious affiliation compared to those with a religious affiliation (22.1 vs. 23.8, $p=0.021$). Pentecostalists scored highest (Mean=24.5), followed by Baptists (Mean=24.3). CEQUEL scores did not vary significantly by other caregiver characteristics, but they did vary by recruitment site, with mean CEQUEL scores significantly lower for Yale caregivers than for those at both Simmons (22.8 vs. 24.5, $p=0.003$) and Parkland (22.8 vs. 24.1, $p=0.001$). This site difference remained significant at $p<0.05$ after controlling for religion as well as race. Forty dyads with missing data on all 13 CEQUEL items did not differ significantly from those with full data on all examined demographic characteristics other than relationship to the patient (those identifying as “friend” were more likely to have missing information).

Table 2
Demographic Characteristics of Sample Caregivers (N=275*)

Characteristic		Caregivers (N)	Years	Percent
Sex				
	Male	64		24
	Female	201		76
Age				
	Mean		51.9	
	SD		13.6	
Race/ethnicity				
	White	185		70
	Black	37		14
	Asian-American, Pacific Islander, Indian	5		2
	Hispanic	33		12.5
	Other	4		1.5
Marital status				
	Married	172		68
Income				
	< $31,000	62		25
	≥ $31,000	123		50
	Don't know	45		18
	Declined	14		6
Education				
	Mean		13.5	
	SD		3.6	
Religion				
	Catholic	102		39
	Protestant	47		18
	Baptist	36		14
	Pentecostal	11		4
	Jewish	13		5
	Other	37		14
	None	18		7
Relationship to patient				
	Spouse/partner	120		53
	Son/daughter	57		25
	Sibling	15		7
	Other relative	17		7
	Friend	6		2
	Parent	11		5
	Other	2		1
Recruitment site				

Yale University Cancer Center	65	24
Veterans' Affairs Connecticut Comprehensive Cancer Clinics	13	5
Memorial Sloan-Kettering Cancer Center	18	6.5
Simmons Comprehensive Cancer Center	21	7.5
Parkland Hospital	89	33
Dana-Farber Cancer Institute	8	3
Massachusetts General Hospital	1	0.5
New Hampshire Oncology Hematology	56	20.5

[*] Available Ns for each characteristic (due to missing data) were as follows:
Sex, Age: N=265; Race/ethnicity, Education, Religion: N=264; Marital status: N=253; Income: N=244; Relationship to patient: N=228; Recruitment site: N=271

Factor Analysis

Eigenvalue, scree-plot and parallel analyses all favored a 4-factor structure. Eight items with factor loadings < 0.4 or with negative residual variances were dropped from successive models. Importantly, four of these were TIME items related to individual-focused care (e.g. patient being treated with respect and kindness). One item ("Was there any medical procedure or treatment that happened to patient that was inconsistent with his/her previously stated wishes?") with a 0.39 factor loading was retained because its removal created model instability and because retention made substantive sense. Figure 1 shows the scree plot suggesting four factors for the final model, each with an Eigenvalue greater than 1. Twelve of thirteen items loaded significantly on one of four identified factors (see Table 3): Prolongation of Death ("Prolongation"), Perceived Suffering ("Suffering"), "Shared Decision-Making" and Preparation for the Death ("Preparation"). TIME items all loaded on Shared Decision-Making or Preparation, whereas items created for CwC all loaded on Prolongation or Suffering. Small, positive, significant correlations between most factors indicated that they represent four distinct aspects of a single construct. Fit statistics indicated strong model fit.

Confirmation of Hypothesis I

Hypothesis I for the present study proposed that variables related to caregiver-perceived quality of care in the final week of life would load significantly and uniquely on a set of distinct factors that include perceived suffering and prolongation of death. The results of this factor analysis, in which the thirteen proposed items loaded significantly and uniquely on a set of distinct factors related to perceived quality of EOL care

(Prolongation, Suffering, Shared Decision-Making, and Preparation) allow the author to accept this hypothesis.

CEQUEL Distributions

CEQUEL scores ranged from 16 to 26 out of a possible 26 points (M=23.6, SD=2.2, Median=24), with higher scores signifying better perceived quality of care. Twenty-five percent of caregivers had CEQUEL scores ≤ 22, indicating four or more identified problems with quality of care. Almost 25% had CEQUEL scores of 26, indicating no perceived problems with quality of care.

Despite a positive experience with perceived quality of care for the majority of caregivers, a closer look at individual CEQUEL items reveals some important concerns. The most significant perceived problems were those related to perceived suffering. Twenty-four percent of caregivers felt their loved one’s death was more violent than peaceful, 35% felt their loved one suffered in dying, and over 50% felt that this suffering was greater than they had expected. Caregivers identified fewer concerns with prolongation of death, but problems still remained. Thirteen percent of caregivers felt that their loved one’s life was prolonged by medical interventions longer than the caregiver would have wished, and 15% felt that their loved one’s life was prolonged even though s/he appeared to be dying, or in a way that resulted in increased patient suffering.

Caregiver scores on Shared Decision-Making and Preparation items were more variable. Six percent of caregivers felt medical staff hadn’t spoken to the patient or caregiver about wishes for medical treatment, and 7% felt their loved one had received a medical procedure or treatment that was inconsistent with his/her wishes. Twelve percent felt that doctors hadn’t listened to their concerns about treatment, however, and 18% had

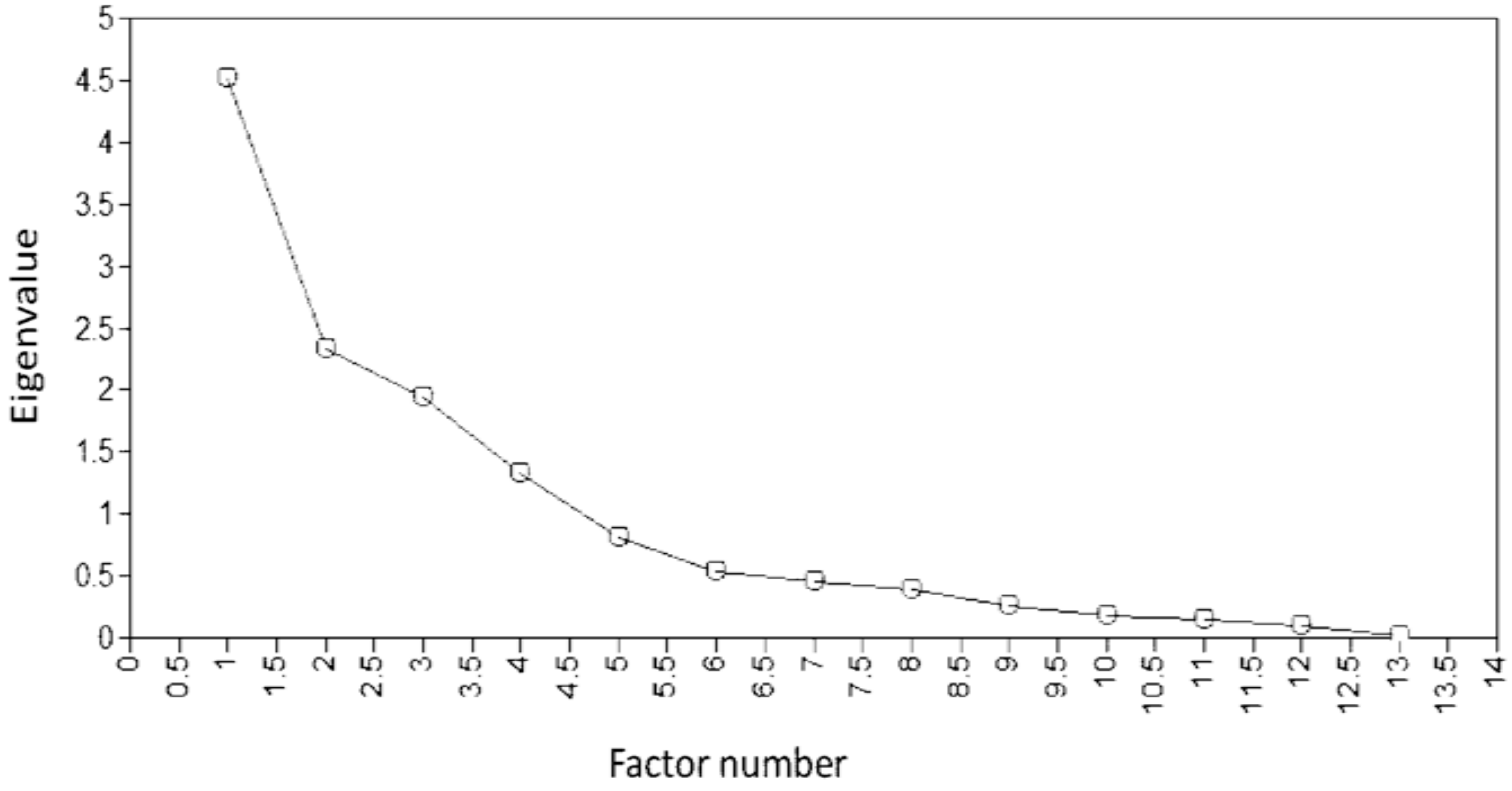

Figure 2. *Scree plot of final four-factor, thirteen-item model.*

Table 3

Factor Loading Scores and Fit Statistics for Final EFA Model

	Prolongation of Death	Perceived Suffering	Shared Decision-Making	Preparation for the Death
1. Was the life of [PATIENT] prolonged by medical interventions longer than you would have wished?	0.848*			
2. Was the life of [PATIENT] prolonged by medical interventions when ___________ was, to the best of your knowledge, dying?	0.990*			
3. Was the life of [PATIENT] prolonged by medical interventions that resulted in an increase of his/her suffering?	0.843*			
4. How peaceful or violent did _____'s death seem to you?		0.708*		
5. To what extent do you think _________ suffered in dying?		0.953*		
6. How much did __________ suffer compared to what you expected?		0.846*		
7. Was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?‡			0.698*	
8. Did you feel that the doctors you talked to listened to your concerns about [PATIENT'S] medical treatment?‡			0.881*	
9. Was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her) previously stated wishes?‡			0.390	

10. To the best of your knowledge, did [PATIENT'S] doctor or the medical staff who cared for (him/her) speak to (him/her) or you about (his/her) wishes about medical treatment?[‡]	0.548*	
11. How often were you or other family members kept informed about [PATIENT'S] condition?[‡]	(0.486)	0.562*
12. Did you or your family receive any information about what to expect while (he/she) was dying?[‡]		0.668*
13. At any time did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?[‡]		0.799*

	CFI	TLI	RMSEA	RMSR	X^2
EFA fit statistics	1.000	1.016	0.000	0.042	26.227 (p=0.75)

*p≤.05

[‡] Toolkit of Instruments to Measure End-of-Life Care (TIME) After-Death Bereaved Family Member Interview

Table 4

Patterns of Association between CEQUEL, Prolongation and Suffering Scores and Key End-of-Life Outcomes (N=275)

	CEQUEL			Prolongation			Suffering		
	ρ	χ^2	z	ρ	χ^2	z	ρ	χ^2	z
Wave 1 patient items									
Do you have a signed Living Will/Health Care Proxy/Durable Power of Attorney for health care/all or none?[1]			-.095			-.609			-.746
Have you completed a Do Not Resuscitate (DNR) order?[2]			-1.82			-1.17			-1.96***
Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?[1]			-.103			-.92			-.92
Therapeutic alliance	.129***			.094			.114		
Wave 1 caregiver items									
Positive RCope[3]	.105			-.017			.016		
Negative Rcope[3]	-.117			-.126***			-.155***		
Post-mortem items									
Where did the patient's death take place?[4]		9.67			6.76			6.09	
Was inpatient hospice involved in the care of (PATIENT), so that (he/she) stayed in a hospice facility?[5]			-1.27			-1.44			-1.19

For about how long did (PATIENT) get inpatient hospice care before (his/her) death?[6]		11.80**			5.53			10.45**	
Was outpatient hospice involved in the care of (PATIENT), so that a hospice worker cared for (him/her) in the home?[7]			-2.09***			-1.52			-.05
For about how long did (PATIENT) get outpatient hospice care before (his/her) death?[8]		4.61			4.64			4.95	
Was the patient in the Intensive Care Unit in the week leading up to his/her death?[7]			-1.18			-1.01			-.22
Was the patient resuscitated in the week leading up to the death?[7]			-.54			-.58			-.13
Wave 2 bereaved caregiver items									
On a scale of 1 to 5, how would you rate your regrets about how (PATIENT) died?[9]	-.359*			-.211*			-.340*		
On a scale of 1 to 5, how would you rate your regrets about the care provided by clinicians to (PATIENT) just prior to his/her death?[10]	-.434*			-.178**			-.357*		
On a scale of 1 to 5, how would you rate your regrets about the care you were able to provide to (PATIENT) just prior to his/her death?[11]	-.214*			-.148***			-.154**		

In light of current circumstances, how strong would you say your wish to die has been?[10]	-.029		-.025		-.033	
In light of your current circumstances, have you ever had thoughts of killing yourself?[12]	-.113		-.082		-.070	
Felt __________ had had enough[13]	-.176**		-.182**		-.076	
How fearful related to this?[14]	-.185**		-.134***		-.210*	
How helpless related to this?[3]	-.096		-.069		-.124	
Beck Hopelessness Scale[15]	-.085		-.183		-.074	
Bereavement Challenges Scale[16]	-.032		-.034		.031	
MDD[4]		-1.30		-1.10		-.10
PTSD[7]		-2.06***		-3.90*		-.36
GAD[17]		-.14		-.72		-.85
PD[4]		-1.30		-.02		-.57

Asymptotic significance levels: *p≤.001, **p≤.01, *** p≤.05

Statistical tests: ρ: Spearman's rho correlation coefficient, χ^2: Kruskall-Wallis test, z: Mann-Whitney U test

Missing data: 1: N=250, 2: N=248, 3: N=237, 4: N=261, 5: N=259, 6: N=49, 7: N=260, 8: N=176, 9: N=274, 10: N=273, 11: N=272, 12: N=270, 13: N=256, 14: N=238, 15: N=93, 16: N=179, 17: N=257 a problem understanding what doctors were saying about what to expect from treatment. Similarly, while 9% of caregivers felt they hadn't received information about medicines that would be used for pain and symptom management and 10% felt poorly informed about their loved one's condition, almost 22% felt they hadn't received information about what to expect while their loved one was dying.

Reliability

CEQUEL demonstrated an acceptable Cronbach's α of 0.69 (ITC=0.32) Prolongation and Suffering had acceptable α's of 0.78 (ITC=0.62) and 0.73 (ITC=0.55), while Shared Decision-Making and Preparation had moderate α's of 0.52 (ITC=0.32) and 0.54 (ITC=0.36).

Convergent Validity

The author evaluated patterns of association between CEQUEL and subscale scores and related EOL outcomes. Data for CEQUEL and its Prolongation and Suffering subscales are presented in Table 4. In interpreting these associations, it is important to recall that higher CEQUEL and subscale scores reflect perceived better quality of care. Higher Prolongation and Suffering scores actually reflect *lower levels* of perceived prolongation and suffering (hence better quality of care within these domains).

Wave 1 patient items

Higher Suffering scores (indicating less perceived suffering) were positively associated with baseline completion of a DNR order ($p \leq .05$). There were no other significant differences in CEQUEL or subscale scores based on baseline advance care planning. Higher CEQUEL scores were significantly positively associated with therapeutic alliance ($p \leq .05$), consistent with previous research demonstrating that therapeutic alliance results in less aggressive, burdensome EOL care and improved patient mental health (Mack et al., 2009; Zhang et al., 2012).

Wave 1 caregiver items

Higher Preparation scores were significantly associated with higher levels of positive religious coping ($p \leq .05$) and higher Prolongation and Suffering scores (i.e. less perceived prolongation and suffering) were associated with lower levels of negative religious coping ($p \leq .05$). This finding is significant in light of the association between negative religious coping and caregiver mental health and QOL outcomes (Pargament et al., 2000).

Post-Mortem items

Higher CEQUEL and Suffering scores were positively associated ($p \leq .01$) with length of inpatient hospice enrollment, consistent with previous findings that shorter hospice lengths of stay are associated with worse caregiver mental health (Bradley, Prigerson, Carlson, Cherlin, Johnson-Hurzeler, & Kasl, 2004; Kris et al., 2006). Higher CEQUEL ($p \leq .05$), Shared Decision-Making ($p \leq .05$) and Preparation ($p \leq .01$) scores were also positively associated with receipt of home hospice care, but not length of enrollment. There were no significant differences in CEQUEL or subscale scores based on location of death, ICU admission, resuscitation or receipt of inpatient hospice care.

Wave 2 bereaved caregiver items

Higher scores on CEQUEL ($p \leq .001$) as well as all four subscales ($p \leq .001$–$p \leq .05$) were negatively associated with bereaved caregiver regrets about how the patient died, the care provided to the patient by the team, and the care provided by the caregiver him/herself. This is consistent with Akiyama et al.'s (2010) findings that perceived peacefulness of death is associated with decreased caregiver regret. Higher CEQUEL and Prolongation scores were also negatively associated with feeling that the patient had had enough ($p \leq .01$) and related fear. Finally, higher CEQUEL ($p \leq .05$) and Prolongation ($p \leq .001$) scores were negatively associated with meeting Post Traumatic Stress Disorder criteria, and higher Shared Decision-Making scores were negatively associated with meeting criteria for Major Depressive Disorder ($p \leq .01$).

Confirmation of Hypothesis II

Hypothesis II for the present study proposed that the refined CEQUEL scale, as well as its Suffering and Prolongation subscales, would demonstrate acceptable reliability (via Cronbach's alpha and mean item-total correlation) and convergent validity (via significant associations and correlations with key EOL variables). The results described above suggest that both the refined CEQUEL scale, as well as its Suffering and Prolongation subscales, demonstrate acceptable reliability and convergent validity, thereby allowing the author to accept this second hypothesis

Regression Analysis and Model Selection

Unadjusted analyses

Table 5 provides univariate frequencies for patient, caregiver, and end-of-life care variables, as well as the unadjusted relationships between these variables and caregiver CEQUEL scores. Results for select unadjusted uni- and multivariate regression analyses by conceptual category, including AICc values, are presented in Table 6. Models with AICc values within 2 points of the lowest value were considered equivalent in terms of "best" models. Potentially important variables including caregiver history of suicide and Covinsky Family Impact Scale (CFIS) scores were dropped from analysis due to inadequate sample size. Variables with low variability (i.e. fewer than 5 counts in a response category) were either dropped from analysis or recoded to ensure adequate distribution across response categories. As previously noted, only modifiable factors were included for analysis.

Table 7 presents results from the second series of regressions, this time comparing variables across categories (N=106). Seven CEQUEL-predicting models were identified with AICc values within 2 points of the lowest value. These included: patients feeling that their physicians saw them as a whole person; caregivers' physical health service use in the last three months; caregivers' use of mental health intervention since the patient's diagnosis; patients dying in a hospital; patients being on inpatient hospice for less than a week prior to death; patients dying where they wanted to die; and one model that included both patients' receipt of any hospice care prior to death and being on inpatient hospice for less than a week prior to death.

The author analyzed the seven models with the lowest AICc values, both individually and in combination with one another (N=202) (Table 8). Only select models with the lowest AICc values are shown due to the high number of permutations analyzed. Eleven models fell within 2 AICc points of the lowest value, including one model with only three variables: patients feeling that their physicians saw them as a whole person, dying in a hospital, and being on inpatient hospice for less than a week prior to death. These were also the only statistically significant items in any of the selected models. Based on this and the author's goal of selecting the most parsimonious model, a "semi-final" model containing only these factors was retained for the next step of analysis.

For the next series of regressions, the author identified twenty variables that were statistically significant in univariate regressions but which were dropped from subsequent models due to higher AICc values (N=148) (Table 9). Five of these variables, when combined with the semi-final model, had equivalent AICc values: frequency of caregivers' alcohol consumption, patients' sense of inner peace, caregivers' religiosity, and both patients' and caregivers' spiritual support. Importantly, all five of these models had lower AICc values than the semi-final model alone.

Table 10 details the final series of regression analyses, using a sample with full data for the eight remaining variables (three from the semi-final model, plus the five from the previous regression series) (N=187). Combining the five new variables with the semi-final model both singly and in all possible permutations, seven models emerged with equivalent AICc values. The author selected a final model comprised of patients feeling that their physicians saw them as a whole person (B=1.00, SE=0.48, p=0.039), dying in a hospital (B=-0.89, SE=0.36, p=0.014), inpatient hospice length of stay (LOS) <1 week (B=-2.07, SE=0.58, p=0.000), and caregiver religiosity (B=0.06, SE=0.02, p=0.008). Selection of this final model was based on it having the lowest number of predictors, all of which were consistent with the research literature and clinical practice. This was also the only model in which all predictors were statistically significant (Table 11).

Adjusted analyses

Adjusting the final model for patient recruitment site and for caregiver characteristics including race, gender, age, religious affiliation, marital status, income, education, length of time in the caregiving role, and relationship to patient, only two predictors remained statistically significant: dying in a hospital (B=-1.65, SE=0.42, p=0.000) and inpatient hospice LOS <1 week (B=-1.87, SE=-.69, p=0.008) (Table 12).

Confirmation of Hypothesis III

Hypothesis III for the present study proposed that caregiver-perceived quality of care at the end of life could be significantly predicted by a unique and parsimonious set of EOL factors. The results of the preceding multiple regression analyses suggest that a parsimonious model of factors including in-hospital death and inpatient hospice length of stay <1 week can predict caregiver CEQUEL scores. These results enable the author to accept Hypothesis III.

Table 5

Univariate frequencies of patient, caregiver, and end-of-life care variables and unadjusted relationships between covariates and CEQUEL scores

Variable	N(%) or Mean(SD)	β	p
Patient variables			
Quality of life (caregiver as proxy) (N=224)			
McGill Physical subscale	9.14(4.43)	0.08	0.260
McGill Existential subscale	43.18(11.39)	0.07	0.276
McGill Psychological subscale	22.96(10.90)	0.12	0.067
McGill Support subscale	16.81(3.63)	0.13	0.061
McGill sum score	96.93(25.27)	0.13	0.045
Mental health (N=239)			
Any mental health diagnosis	26(10.9)	-0.10	0.116
Feels depressed	7.33(2.93)	0.03	0.697
Feels nervous or worried	6.65(3.31)	0.10	0.136
Feels sad	7.05(3.10)	-0.03	0.607
Feels terrified	7.03(3.12)	0.12	0.055
Inner peacefulness	167(69.9)	0.14	0.033
Mental health access (N=253)			
Discussed mental health concerns with healthcare professional since diagnosis	104(41.1)	-0.07	0.286
Accessed mental health intervention since diagnosis	86(34.0)	-0.12	0.066
Terminal illness acceptance (N=248)			
Acknowledges being terminally ill	98(39.5)	-0.01	0.883
Religion and spirituality (N=219)			
Positive religious coping	10.5(6.27)	0.11	0.120
Negative religious coping	1.84(3.17)	-0.06	0.389
Religiosity	22.23(7.03)	0.15	0.023
Spiritual support	9.66(3.38)	0.15	0.023
Therapeutic alliance (N=246)			
Pt feels physician sees him/her as a whole	222(90.2)	0.20	0.002

person			
Pt feels comfortable discussing care with physician	192(78.0)	0.10	0.102
Therapeutic alliance	4.65(.63)	0.19	0.003
Advance care planning (N=225)			
Patient has health care proxy	179(79.6)	0.01	0.903
Patient has living will	170(75.6)	0.04	0.512
Pt has both health care proxy and living will	158(70.2)	0.05	0.466
Patient and physician discussed EOL wishes	89(39.6)	0.04	0.556
DNR order	98(43.6)	0.13	0.047
If patient could choose, would s/he prefer treatment that focused on extending life as much as possible, even if it meant more pain and discomfort, or care that focused on relieving pain and discomfort as much as possible, even if it meant not living as long	164(72.9)	0.04	0.577
Caregiver variables			
Medical Outcomes Study (MOS) Short Form 36 (SF-36) (N=264)			
Physical function	86.65(21.02)	-0.05	0.389
Role limitation 2/2 physical health	80.94(35.03)	-0.03	0.609
Role limitation 2/2 emotional problems	67.93(40.88)	0.07	0.253
Energy/fatigue	55.74(22.71)	-0.004	0.945
Emotional well-being	66.39(21.10)	0.14	0.020
Social function	74.76(27.76)	0.08	0.197
Pain	80.00(22.91)	-0.01	0.895
General health	70.06(22.85)	0.07	0.232
Health change from last year	49.72(17.91)	0.09	0.144
TOTAL MOS-36	632.18(159.47)	0.06	0.366
Health-promoting behavior (N=240)			
Health-promoting behavior sum	4.53(1.62)	0.09	0.153
Physical health service use (N=145)			
Any hospital, ER, clinic, any other med contact	125(86.2)	0.24	0.004
Overnight treatment in hospital	11(7.6)	-0.006	0.948
Treatment in ER	17(11.7)	-0.08	0.350

Office/clinic visit	111(76.6)	0.07	0.395
Dental care	60(41.4)	0.02	0.779
Mental health (N=249)			
Any mental health diagnosis	31(12.4)	-0.03	0.619
Mental health access (N=255)			
Discussed mental health concerns with professional since patient diagnosis	78(30.6)	-0.04	0.567
Accessed mental health intervention since patient diagnosis	58(22.7)	-0.02	0.768
Religion and spirituality (N=217)			
Positive religious coping	8.21(6.12)	0.10	0.134
Negative religious coping	1.63(3.04)	-0.08	0.218
Religiosity	19.29(6.67)	0.21	0.002
Spiritual support	5.24(2.68)	0.13	0.054
Social supports and relationships (N=237)			
Interpersonal Support Evaluation List (ISEL) Self-esteem subscale	12.87(2.46)	0.14	0.032
ISEL Belonging subscale	14.03(2.38)	0.26	0.000
ISEL Appraisal subscale	12.03(1.46)	0.20	0.002
ISEL Tangible subscale	14.11(2.41)	0.17	0.010
ISEL total score	55.34(7.38)	0.24	0.000
Family Relationship Index (FRI) Cohesion subscale	7.46(.87)	0.11	0.101
FRI Expression subscale	6.78(1.12)	0.01	0.906
FRI Conflict subscale	4.95(1.14)	-0.08	0.240
FRI total score	21.29(2.29)	0.08	0.206
Caregiver burden (N=160)			
Caregiver Burden Scale (CBS): Demand	15.15(4.18)	0.01	0.925
Caregiver Burden Scale (CBS): Difficulty	8.63(3.36)	-0.06	0.467
Tobacco and alcohol use (N=101)			
Number of cigarettes per day	6.44(10.96)	-0.01	0.964
Frequency of alcohol consumption	39(38.6)	-0.20	0.048

Number of alcoholic drinks per day	1.85(1.32)	-0.10	0.308
End-of-life care variables			
Aggressive care in final week of life (N=253)			
Any aggressive care	78(30.8)	-0.116	0.066
Place of death (N=253)			
ICU	15(5.9)	-0.01	0.918
Hospital, non-ICU	52(20.6)	-0.19	0.003
Home	141(55.7)	0.18	0.005
Nursing home	8(3.2)	0.03	0.649
Inpatient hospice	37(14.6)	-0.04	0.497
Did patient die where they would have wanted	182(71.9)	0.21	0.001
Hospice use (N=248)			
Any hospice	184(74.2)	0.09	0.165
Inpatient hospice involvement	46(18.5)	-0.06	0.366
Outpatient hospice involvement	167(67.3)	0.14	0.029
Inpatient hospice length of stay (LOS) = 0	202(81.5)	0.07	0.292
Inpatient hospice LOS < 1 week	17(6.9)	-0.25	0.000
Inpatient hospice LOS ≥ 1 week	29(11.7)	0.12	0.068
Home hospice length of stay (LOS) = 0	79(31.9)	-0.15	0.015
Home hospice LOS < 1 week	26(10.5)	0.10	0.105
Home hospice LOS ≥ 1 week	143(57.7)	0.08	0.203
Patient consciousness (N=261)			
Consciousness in final week of life (1=awake, interactive)	41(15.7)	0.18	0.003

Table 6

Regression Series 1: AICc values for individual covariates and select combinations of variables within categories

Variable	N	AICc
Patient variables		
Quality of life (caregiver as proxy)		
McGill Physical subscale	224	355.87
McGill Existential subscale		355.96
McGill Psychological subscale		353.76
McGill Support subscale		353.60
McGill sum score*		353.08
Physical, Existential		357.34
Physical, Support		354.87
Psychological, Support		353.93
Mental health		
Any mental health diagnosis	239	363.42
Feels depressed		365.76
Feels nervous or worried		363.67
Feels sad		365.65
Feels terrified		362.20
Inner peacefulness**		361.31
Mental health diagnosis, Inner peace*		360.42
Nervous/worried, Inner peace		361.99
Terrified, Inner peace		361.45
Mental health diagnosis, Depressed, Inner peace*		362.25
Mental health diagnosis, Nervous/worried, Inner peace*		362.04
Mental health diagnosis*, Sad, Inner peace*		360.87
Mental health diagnosis, Terrified, Inner peace		361.31
Mental health access		
Discussed mental health concerns with healthcare professional since diagnosis	253	398.48
Accessed mental health intervention since diagnosis		396.21

Terminal illness acceptance		
Acknowledges being terminally ill	248	385.90
Religion and spirituality (N=219)		
Positive religious coping	219	344.65
Negative religious coping		346.35
Religiosity*		341.91
Spiritual support**		341.87
Positive religious coping, Negative religious coping		344.85
Negative religious coping, Religiosity*		343.11
Negative religious coping, Spiritual support*		342.93
Therapeutic alliance		
Pt feels physician sees him/her as a whole person[a]	246	382.30
Pt feels comfortable discussing care with physician		389.53
Therapeutic alliance**		383.54
Whole person[a], Comfortable discussing care		382.94
Advance care planning		
Patient has health care proxy	225	363.46
Patient has living will		363.04
Pt has both health care proxy and living will		362.93
Patient and physician discussed EOL wishes		363.12
DNR order*		359.49
Patient preference for focus on extending life as much as possible, versus relieving pain and discomfort as much as possible		363.16
Health care proxy and living will, DNR		361.43
HCP, DNR*		361.47
Living will, DNR		361.50
Discussed EOL wishes, DNR		361.53
Caregiver variables		
Medical Outcomes Study (MOS) Short Form 36 (SF-36)		
Physical function	264	412.65
Role limitation 2/2 physical health		413.14

Role limitation 2/2 emotional problems		412.08
Energy/fatigue		413.39
Emotional well-being*		407.96
Social function		411.72
Pain		413.38
General health		411.96
Health change from last year		411.24
TOTAL MOS-36		412.57
Physical function, Emotional well-being**, Health change		406.72
Physical function, Emotional well-being**		407.07
Role limitation due to physical health, Emotional well-being*, Health change		408.30
Health-promoting behavior		
Health-promoting behavior sum	240	372.75
Physical health service use		
Any hospital, ER, clinic, or other medical contact*	145	204.32
Overnight treatment in hospital		212.82
Treatment in ER		211.94
Office/clinic visit		212.09
Dental care		212.75
Overnight treatment, Treatment in ER		213.97
Treatment in ER, Office/clinic visit		213.10
Treatment in ER, Dental visit		213.99
Mental health		
Any mental health diagnosis	249	391.54
Mental health access		
Discussed mental health concerns with professional since patient diagnosis	255	397.93
Accessed mental health intervention since patient diagnosis		398.17
Religion and spirituality		
Positive religious coping	217	339.86

Negative religious coping		340.59
Religiosity**		332.37
Spiritual support*		338.36
Positive religious coping*, Negative religious coping		338.67
Negative religious coping, Religiosity**		333.06
Negative religious coping, Spiritual support*		338.76
Social supports and relationships		
Interpersonal Support Evaluation List (ISEL) Self-esteem subscale*	237	369.19
ISEL Belonging subscale***		357.72
ISEL Appraisal subscale**		364.34
ISEL Tangible subscale**		367.24
ISEL total score***		360.04
Family Relationship Index (FRI) Cohesion subscale		371.15
FRI Expression subscale		373.85
FRI Conflict subscale		372.47
FRI total score		372.25
Belonging**, Appraisal		356.87
Belonging**, Appraisal, Expression		358.27
Belonging**, Appraisal, FRI total		358.71
Caregiver burden		
Caregiver Burden Scale (CBS): Demand	160	240.07
Caregiver Burden Scale (CBS): Difficulty		239.54
Tobacco and alcohol use (N=101)		
Number of cigarettes per day	101	170.62
Frequency of alcohol consumption*		166.60
Number of alcoholic drinks per day		169.56
Frequency alcohol consumption, Number alcoholic drinks per day		168.44
Number cigarettes, Frequency alcohol*		168.63
Number cigarettes, Frequency alcohol, Number alcoholic drinks		170.53

End-of-life care variables		
Aggressive care in final week of life		
Any aggressive care	253	388.97
Place of death		
ICU	253	393.86
Hospital, non-ICU**		384.95
Home**		386.01
Nursing home		393.66
Inpatient hospice		393.41
Did patient die where they would have wanted***		382.00
ICU, Patient died where wanted***		383.61
Hospital*, Patient died where wanted**		380.11
Nursing home, Patient died where wanted***		382.24
Hospice use		
Any hospice	248	386.45
Inpatient hospice involvement		387.57
Home hospice involvement*		383.60
No inpatient hospice		387.27
Inpatient hospice LOS < 1 week***		372.29
Inpatient hospice LOS ≥ 1 week		385.04
No home hospice*		382.44
Home hospice LOS < 1 week		385.74
Home hospice LOS ≥ 1 week		386.75
Any hospice*, Inpatient hospice < 1 week***		369.81
Any hospice, Inpatient hospice ≥ 1 week		385.92
Any hospice, Home hospice < 1 week		386.59
Patient consciousness		
Consciousness in final week of life (1=awake, interactive)**	261	400.69

*: p≤.05, **: p≤.01, ***: p≤.001

Table 7

Regression Series 2: Submodels from each conceptual category with lowest AICc values (N=106)

Variable	AICc
Patient variables	
Quality of life (caregiver as proxy)	
McGill Psychological subscale	162.78
McGill Support subscale	162.49
McGill sum score	163.00
Mental health	
Any mental health diagnosis	162.76
Feels terrified	161.94
Inner peacefulness	162.19
Inner peacefulness, Terrified	163.54
Any mental health diagnosis, Inner peacefulness	164.06
Any mental health diagnosis, Inner peacefulness, Terrified	165.43
Mental health access	
Discussed mental health concerns with healthcare professional since diagnosis	162.29
Accessed mental health intervention since diagnosis	163.01
Terminal illness acceptance	
Acknowledges being terminally ill	162.83
Religion and spirituality	
Religiosity	161.80
Spiritual support	161.71
Therapeutic alliance	
Pt feels physician sees him/her as a whole person*	159.08
Therapeutic alliance	162.02
Advance care planning	

DNR order	162.23
Caregiver variables	
Medical Outcomes Study (MOS) Short Form 36 (SF-36)	
Physical function	162.60
Emotional well-being	162.26
Health change from last year	162.01
Physical function, Emotional well-being	162.98
Physical function, Emotional well-being, Health change	164.00
Health-promoting behavior	
Health-promoting behavior sum	163.02
Physical health service use	
Any hospital, ER, clinic, or other medical contact	159.64
Mental health	
Any mental health diagnosis	163.01
Mental health access	
Discussed mental health concerns with professional since patient diagnosis	161.45
Accessed mental health intervention since patient diagnosis	159.76
Religion and spirituality	
Religiosity	162.77
Social supports and relationships	
ISEL Belonging subscale	162.47
ISEL Appraisal subscale	161.13
Belonging, Appraisal	163.24
Caregiver burden	
Caregiver Burden Scale (CBS): Demand	162.52
Caregiver Burden Scale (CBS): Difficulty	162.56
Tobacco and alcohol use	

Frequency of alcohol consumption	162.72
End-of-life care variables	
Aggressive care in final week of life	
Any aggressive care	162.91
Place of death	
Hospital, non-ICU	159.89
Did patient die where they would have wanted	160.77
Hospital, Patient died where they wanted	161.39
Hospice use	
Any hospice	162.12
Inpatient hospice LOS < 1 week	159.95
Any hospice, Inpatient hospice LOS < 1 week	160.56
Patient consciousness	
Consciousness in final week of life (1=awake, interactive)	161.33

*: p≤.05

Table 8

Regression Series 3: Submodels from each conceptual category with lowest AICc values (N=202)

Variable	AICc
Pt feels physician sees him/her as a whole person*	303.36
Caregiver had any hospital, ER, clinic, any other med contact	307.01
Caregiver accessed mental health intervention since patient diagnosis	307.06
Hospital (non-ICU) death**	299.14
Inpatient hospice LOS < 1 week***	297.50
Any hospice	304.68
Did patient die where s/he would have wanted**	298.53
Whole person*, Any medical contact, Hospital death*, Inpatient hospice < 1 week***, Any hospice	286.39
Whole person*, Any medical contact, Hospital death*, Inpatient hospice < 1 week	286.91
Whole person*, Hospital death*, Inpatient hospice < 1 week***, Any hospice	287.17
Whole person*, Any medical contact, Hospital death*, Inpatient hospice < 1 week**, Patient died where s/he wanted	287.37
Whole person*, Any medical contact, Hospital death*, Inpatient hospice < 1 week**, Any hospice, Patient died where s/he wanted	287.60
Whole person*, Hospital death***, Inpatient hospice < 1 week***	287.51
Whole person, Hospital death*, Inpatient hospice < 1 week**, Patient died where s/he wanted	287.73
Whole person*, Caregiver accessed mental health, Hospital death*, Inpatient hospice < 1 week***, Any hospice	287.94
Whole person*, Caregiver accessed mental health, Hospital death***, Inpatient hospice < 1 week***	288.02
Whole person*, Hospital death, Inpatient hospice < 1 week**, Any hospice, Patient died where s/he wanted	288.15

Whole person, Caregiver accessed mental health, Hospital death*, Inpatient hospice < 1 week**, Patient died where s/he wanted	288.38

*: p≤.05, **: p≤.01, ***: p≤.001

Table 9

Regression Series 4: Semi-final model with additional significant variables from Series 1 (N=148)

Variable	AICc	Significant variables
Semi-final model (SFM): Pt feels physician sees him/her as a whole person, Hospital (non-ICU) death, Inpatient hospice LOS < 1 week SFM plus:	218.90	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Patient McGill sum score	220.65	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Patient inner peacefulness	215.37	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week**, Inner peacefulness*
Patient religiosity	217.78	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Patient spiritual support	217.29	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Patient DNR order	220.79	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver MOS SF-36 Emotional well-being subscale	219.49	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week***
Caregiver religiosity	216.22	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week**, Caregiver religiosity*
Caregiver spiritual support	217.34	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver ISEL total score	219.06	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver ISEL Self-esteem subscale	220.59	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**

Caregiver ISEL Belonging subscale	218.14	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver ISEL Appraisal subscale	218.56	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver ISEL Tangible subscale	220.25	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver frequency of alcohol consumption	215.31	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week***, Frequency alcohol consumption*
Home hospice involvement	217.80	Pt feels physician sees him/her as a whole person*, Inpatient hospice LOS < 1 week**
Patient level of consciousness in final week of life	217.59	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week**
Any hospital, ER, clinic, any other med contact	218.12	Pt feels physician sees him/her as a whole person*, Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**
Caregiver accessed mental health intervention since patient diagnosis	219.32	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week***
Any hospice	218.32	Pt feels physician sees him/her as a whole person*, Inpatient hospice LOS < 1 week***
Did patient die where they would have wanted	219.18	Inpatient hospice LOS < 1 week**
Hospital (non-ICU) death, Inpatient hospice LOS < 1 week	220.48	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week**

*: p≤.05, **: p≤.01, ***: p≤.001

Table 10

Regression Series 5: Submodels with lowest AICc values after combining semi-final model with additional significant variables from Series 1 (N=187)

Variable	AICc	Significant variables
Semi-final model: Pt feels physician sees him/her as a whole person, Hospital (non-ICU) death, Inpatient hospice LOS < 1 week	276.85	Pt feels physician sees him/her as a whole person*, Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***
Semi-final model plus:		
Caregiver frequency of alcohol consumption	274.75	Pt feels physician sees him/her as a whole person*, Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***, Alcohol consumption*
Patient inner peacefulness	273.34	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week***, Inner peacefulness*
Patient spiritual support	276.01	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***
Caregiver religiosity	272.27	Pt feels physician sees him/her as a whole person*, Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***, Caregiver religiosity*
Caregiver spiritual support	277.48	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week***
Patient inner peacefulness, Caregiver religiosity	271.16	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***
Caregiver frequency of alcohol consumption, Patient inner peacefulness, Caregiver religiosity	271.31	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***, Patient inner peacefulness*
Caregiver frequency of alcohol consumption, Caregiver religiosity	271.76	Pt feels physician sees him/her as a whole person*, Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***, Caregiver religiosity*
Caregiver frequency of alcohol consumption, Patient inner peacefulness	272.59	Hospital (non-ICU) death**, Inpatient hospice LOS < 1 week***, Patient inner peacefulness*
Patient inner peacefulness, Caregiver religiosity, Patient spiritual support	273.14	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***

Caregiver frequency of alcohol consumption, Patient inner peacefulness, Caregiver religiosity, Caregiver spiritual support	273.18	Hospital (non-ICU) death*, Inpatient hospice LOS < 1 week***

*: p≤.05, **: p≤.01, ***: p≤.001

Table 11

Final unadjusted model (N=193)

Variable	B	SE B	β	p
Constant	21.946	0.618		0.000
Pt feels physician sees him/her as a whole person	0.998	0.479	0.141	0.039
Hospital (non-ICU) death	-0.893	0.359	-0.170	0.014
Inpatient hospice LOS < 1 week	-2.069	0.583	-0.241	0.000
Caregiver religiosity	0.060	0.022	0.182	0.008

Adjusted $R^2 = 0.12$

Table 12

Final adjusted model including caregiver demographic and other characteristics (N=135)

Variable	B	SE B	β	p
Constant	21.429	1.550		0.000
Pt feels physician sees him/her as a whole person	0.946	0.665	0.121	0.158
Hospital (non-ICU) death	-1.650	0.418	-0.320	0.000
Inpatient hospice LOS < 1 week	-1.872	0.688	-0.218	0.008
Caregiver religiosity	0.051	0.032	0.149	0.120
Northeast recruitment site	-0.537	0.506	-0.125	0.291
Male	0.843	0.415	0.169	0.045
Income	0.633	0.423	0.143	0.137

Married	0.427	0.447	0.092	0.341
Patient has healthcare insurance	-0.128	0.544	-0.028	0.815
Race (reference=White)				
Black	-0.500	0.573	-0.083	0.384
Asian or other	-1.690	1.196	-0.116	0.160
Hispanic	-0.908	0.675	-0.137	0.182
Religious affiliation (reference=Catholic)				
Protestant	0.714	0.545	0.116	0.193
Jewish	-0.541	1.991	-0.022	0.786
Other religion	0.493	0.576	0.078	0.394
No religion	-1.668	0.763	-0.213	0.031
Pentecostal	1.656	0.913	0.159	0.072
Baptist	0.750	0.609	0.129	0.220
Length of time as primary caregiver	0.001	0.003	0.031	0.706
Relationship to patient: Spouse (1=spouse, 0=all others)	-0.245	0.456	-0.057	0.592
Relationship to patient: Child (1=child, 0=all others)	-0.677	0.547	-0.136	0.219
Age	0.002	0.016	0.015	0.883
Education	-0.005	0.061	-.007	0.941

Adjusted $R^2 = 0.25$

Chapter V: Discussion

Introduction

The catalyst for the present study was the author's ten years of clinical social work practice with patients and caregiver facing advanced cancer and other life-limiting illnesses. In the course of providing psychosocial support and guidance to these families – in many cases to caregivers alone, with patients too ill to participate – the author has been struck by the grace and bravery, but also the heartbreak and struggle, with which caregivers face the final days and weeks of life. At a time when caregivers are attempting to make peace with their impending loss and to say their final goodbyes, they are all too often caught off guard by the unpredictable course of the dying process. As if the preceding weeks, months and perhaps years were not trying enough, many caregivers face a new set of trials as they wait for a loved one to die. Caregivers invariably find moments of meaning and beauty amidst the chaos – for some, these moments even come to outshine the anguish and the uncertainty – but even with the best care they are likely to face difficult and perhaps unanswerable questions. *Is my mother suffering? Why can't they do something to put her at peace? Nobody told us it would take this long. We treat dogs better than we treat people, why can't we put her out of her misery? She never would have wanted to linger like this.* These are the questions, heard time and again by the author, that have informed the present study of how caregivers perceive the quality of care provided to their dying loved ones. They are also the questions that have driven the author to corroborate his clinical bedside experience with 'hard data' and statistics, so that researchers and clinicians alike might be prompted to recognize more fully the importance of caregivers and the indelible impact of perceived suffering and prolonged dying on how caregivers move forward from their loss.

CEQUEL as a Reliable and Valid Quality-of-Care Measure

This study's findings support CEQUEL's reliability and validity as a measure of quality of care at the end of life from the perspective of cancer caregivers. The thirteen items comprising CEQUEL represent four distinct but related factors that are consistent with the EOL research literature as well as the author's own clinical experience: prolonged dying, suffering, shared decision-making, and preparation for death. Higher CEQUEL scores were positively associated with factors known to improve EOL outcomes (e.g. patient-physician therapeutic alliance, hospice enrollment) and negatively associated with poor bereavement outcomes such as PTSD and regret, suggesting that the measure has strong convergent validity.

The Unique Role of Perceived Suffering and Prolonged Dying

A unique contribution of the CEQUEL measure is its inclusion of suffering and prolonged dying as key indicators of caregiver-perceived quality of care. Existing caregiver-perceived quality-of-care measures have not included these factors. While perceived suffering and prolonged dying are often discussed as abstract concepts with assumed detrimental impact on caregiver wellbeing, the present study demonstrates their quite real implications for perceived quality of care as well as bereaved caregiver adjustment. Both factors were both positively associated with caregiver use of negative religious coping, as well as bereaved caregiver fear and regret. Perceived suffering was also positively associated with absence of a DNR order and with shorter inpatient hospice length of stay, and perceived prolongation of death was positively associated with bereaved caregiver PTSD symptoms. These findings highlight the important role these two factors play in the final week of life, and the need for social workers and others to assess caregivers for distress related to both. Perceived suffering emerged as particularly important to caregiver wellbeing, representing the three most frequently identified problem areas for perceived quality of care.

Factors Predicting Poorer Perceived Quality of Care

When the author accounted for patient/caregiver recruitment site and caregiver demographics, place of death (including dying in a hospital and short inpatient hospice length of stay) was the sole predictor of caregiver CEQUEL scores. Without adjusting for recruitment site or caregiver demographics, caregiver religiosity and patients feeling seen as a whole person by their physician also predicted higher CEQUEL scores. Despite their exclusion from the final adjusted model, these two factors provide important avenues for clinical intervention and merit further exploration. Indeed, CEQUEL's significance as a quality-of-care measure is bolstered by the appearance of these same three key factors in both Hypothesis II and III analyses. These three aspects of care are important because each is potentially modifiable, but also because each presents an opportunity to modify the caregiver's experience at a different starting point in this study's conceptual model: the patient (therapeutic alliance), the caregiver (religiosity and religious coping), and structure and process of care (place of death).

Implications for Research

CEQUEL as a Research Measure

This study advances EOL research on caregiver-perceived quality of care in several important ways. By analyzing a broad range of quality-of-care variables that clinicians consistently witness at the bedside, but that researchers have not always adequately explored, CEQUEL lends statistical credibility to what many already ‘know’ to be true and promotes evidence-based practice, a core element of palliative care as cited by the National Consensus Project for Quality Palliative Care’s (2013) *Clinical Practice Guidelines for Quality Palliative Care*. In particular, this study brings prolonged death and suffering from the abstract realm into which they have drifted in the professional literature, and into reality by providing statistical evidence of their impact on caregiver evaluation of quality of care and subsequent bereavement adjustment. In doing so, this study not only gives suffering and prolonged dying their ‘statistical due’ but also solidifies them as key aspects of caregiver-perceived quality of care.

As previously described, researchers including Hudson et al. (2010) and Williams & McCorckle (2011) have advised a cautious approach to further instrument development, suggesting that expanding upon an existing measure is preferable to designing a completely new one. The present study accomplishes this task by building upon the established TIME interview, combining two key of its key components (shared decision-making and preparation) with two new factors with known clinical implications but little in the way of statistical evidence (prolonged dying and suffering). In so doing, the author addresses a gap in the research literature by introducing a new, carefully constructed instrument that more fully captures quality of care in the final week of life. The present analyses also build upon the existing research literature by underscoring previous research findings related to caregiver outcomes at the end of life and in bereavement, while at the same introducing new findings related to perceived suffering and prolonged dying.

CEQUEL further improves upon the existing body of quality-of-EOL-care measures in that it has been designed as both a research tool and as a clinical assessment tool. Authors of similar measures have emphasized the primary utility of their instruments in the quality improvement realm (Casarett et al., 2008; Teno et al., 2001). Still others have developed their measures with a specific focus on caregiver evaluation of physician skill at the end of life (Biola et al., 2007; Engelberg et al., 2010). These measures are an important contribution to the literature as well as to the toolbox of available instruments, but with increasing appreciation of the truly interdisciplinary nature of oncology, palliative care and hospice it is limiting to have an instrument that speaks only to the physician's role. The majority of CEQUEL's items are relevant to the broader, interdisciplinary provision of care at the end of life, and CEQUEL is equally adaptable as a tool for quality improvement, clinical assessment or knowledge building.

Study Limitations and Implications for Further Research

The present study suggests several directions for further research, some related to this study's findings and others to the limitations of the CwC dataset. While research and clinical evidence highlight the universal challenges faced by dying patients and their loved ones, CEQUEL's reliability and validity need to be confirmed in non-cancer patient and caregiver samples that may interpret quality of EOL care differently than those dying from cancer. The very language used over the course of the cancer trajectory – e.g., "She's a fighter, she's going to win this battle against cancer!" – may hold important implications for the way in which cancer caregivers make decisions, develop emotional responses, and perceive care at the end of life, that may not hold true for caregivers facing other life-limiting illnesses like dementia or heart failure. While the proportion of black CwC participants exceeds that of the U.S. population, the present study's generalizability to black and other minority populations (Hispanic and Asian subjects are both slightly under-represented in the CwC study) may also be limited by the relative preponderance of white subjects.

This study's finding that Catholic caregivers and those with no religious affiliation scored worse than other groups on CEQUEL merits further examination of potential reasons for this discrepancy. One clue may lie in caregiver use of religious coping. Predictably, caregivers with no religious affiliation were significantly less likely to use positive religious coping than any other group. Catholic caregivers, however, also used significantly less positive religious coping than Baptists, Pentecostalists or those selecting "Other" as their faith affiliation (including Muslim but excluding Protestant or Jewish). Caregivers with no religious affiliation may be at a disadvantage relative to those who can rely on an extra layer of support via their religious community, or a religious framework that lends broader meaning to times of crisis and loss. Explanations other than purely hypothetical are beyond the scope of this study, but future research should explore why religious affiliation, or lack thereof, may influence caregiver perceptions of quality of care at the end of life.

While CwC included a Veterans Affairs hospital and two community-based sites (Parkland Hospital and New Hampshire Oncology-Hematology (NHOH)) in its recruitment sites (accounting for 58% of the total present sample), the study also included several academic medical centers that may have more inclination or resources to pursue aggressive interventions with advanced cancer patients, including trial participation. Interestingly, there was no clear relationship between community-based vs. academic care setting and CEQUEL scores in the present sample, with mean CEQUEL scores as follows (out of a possible 26 points): Simmons Comprehensive Cancer Center, 24.5; Parkland, 24.1; Dana-Farber Cancer Institute, 24.1; Memorial Sloan-Kettering Cancer Center, 23.9; Veterans Affairs Connecticut Healthcare Systems Comprehensive Cancer Clinics, 23.4; NHOH, 23.4; and Yale Cancer Center, 22.8. Hospice enrollment at time of death was higher among CwC participants (63%) than for total US deaths (45%) in 2011 (National Hospice and Palliative Care Organization, 2012), but the proportion of hospice patients dying at home was similar between CwC (70%) and the US (66%), as were deaths on inpatient hospice units (CwC: 19%, US: 26%). Taken together, these data suggest CwC data provided a fairly representative sampling of patients. Still, because all of the medical systems sampled by CwC were in the Northeast or Texas, generalizability of the present study's findings may also be limited by regional culture variations between one part of the United States and the next. It also bears considering that CwC data comes from patients and caregivers active in the medical system, and may miss factors unique to those who choose to forego or are otherwise unable to access traditional medical care.

Another point of caution with the present study is CwC's use of retrospective caregiver report for Wave 2 and Post-Mortem data. Some researchers have questioned the reliability of data collected via post-death interviews rather than during the dying process (Fowler et al., 1999; Hinton, 1996). While this debate is an important one, it is the present author's stance that assessing caregiver perceptions of EOL care in 'real time' while patients are actively dying may not only be impractical (i.e. it is difficult to know when patients are dying, and to make concurrent caregiver assessments), but also introduces important questions about ethics and compassion. One could argue that pulling a vulnerable caregiver away from the bedside of a dying loved one in order to administer a research instrument lacks compassion and introduces an unnecessary distraction at a time when the caregiver's focus should be on the patient. Future research will need to compare the reliability of caregiver reports taken in the first few months of bereavement compared to six months post-loss.

The present study's use of secondary CwC data to develop and validate the CEQUEL scale is a potential limitation in interpretation of findings. The author's use of existing CwC items, rather than items constructed specifically for CEQUEL scale development, requires some extrapolation in terms of how caregivers interpreted those items. Ultimately, these items must serve as proxies – albeit carefully considered proxies – for factors of interest to the author. Finally, while the adjusted predictive model explains almost a quarter of the variance in caregiver CEQUEL scores, a large proportion of variance remains unexplained; future studies will need to explore additional EOL factors not included in the present analysis that may help to predict caregiver perception of quality of care at the end of life.

Implications for Interdisciplinary Clinical Practice

The data derived from this study has a number of implications for clinical social workers and other providers working with dying patients and their families. By pulling prolonged dying, suffering and other aspects of perceived quality of EOL care out of the abstract and demonstrating their substantive impact on caregivers at end of life and in bereavement, this study highlights a number of opportunities for clinical intervention. The study also lends statistical credibility to phenomena that clinicians see every day in their work at the bedside, arming them with evidence-based means by which to assess and intervene with caregiver distress. Understanding the association between low CEQUEL scores and bereaved caregiver regret and trauma, for example, reinforces for clinicians that regret may not merely be a matter of caregivers blaming the team, but may entail significant self-directed blame as well. Caregivers feeling traumatized by the dying process may not simply be upset, they may be experiencing actual symptoms of PTSD. Hence CEQUEL helps to highlight the real clinical implications of how caregivers experience care at the end of life. This study is also important because it provides clinical social workers and others with *modifiable targets* for clinical intervention around aspects of care that caregivers perceive to be problematic. As previously discussed, the term *modifiable* as used in the present study refers to patient, caregiver, or care structure/process characteristics that are not fixed, but that clinical social workers or caregivers themselves may have some control in changing to improve EOL outcomes.

CEQUEL as an Assessment Tool

One of CEQUEL's strengths lies in its design as both a research and a clinical assessment tool. The items used in factor analysis were selected specifically on the basis of their clinical applicability and support in the professional literature. CEQUEL's brevity as well as its dichotomous-response design further facilitate its use by clinicians and caregivers. The thirteen items comprising CEQUEL, because they were crafted for retrospective report, are most immediately useful for post-death evaluation of caregivers. At the same time, because these care components all pertain to care provided in the final week of life, CEQUEL is easily adapted for prospective use prior to patient death, either as a formal assessment tool or as a more informal conversation guide or checklist. The logistics of administering a formal measure while patients are actively dying are difficult for reasons previously described. Regardless of how CEQUEL is used, this study's findings related to perceived quality of care as well as its correlates and predictors can inform clinical interventions at the bedside as well as in bereavement.

Used as a checklist or conversation guide prior to a patient's death, problems identified in any of CEQUEL's domains may prompt a family-team meeting in which caregiver expectations about preventing a prolonged death or mitigating perceived suffering are weighed against what is achievable, and redirection of care or reframing of caregiver interpretations are pursued as necessary. This last point is important: in certain situations, the key outcome of pre-loss assessment of perceived quality of care may not be identification of caregiver distress, but rather identification of real problems in the patient's plan of care. The caregiver plays a key role in providing the context of a patient's life outside of his/her illness, and in helping the healthcare team to interpret the patient's experience. Caregiver perception of patient suffering or other problems may prompt the team to reevaluate what they themselves are seeing and to change the plan of care accordingly (e.g. change a medication regimen so that suffering is lessened). Another benefit of pre-loss assessment of CEQUEL domains is that clinicians in day-to-day practice are likely to overlook some of the key questions addressed in the instrument, resulting in situations where caregivers either act out or suffer silently without the team understanding why. CEQUEL helps to identify these underlying causes of distress and, to the extent that these issues are effectively addressed, may mitigate caregiver-team conflict or poor bereavement outcomes.

Administered after a patient's death, CEQUEL may facilitate bereavement adjustment by helping clinicians to identify, reframe or process bereaved caregivers' underlying sources of regret, trauma or other distress. Each CEQUEL factor represents a component of care that may leave caregivers feeling like the team should have done something differently, or that caregivers themselves have failed their loved ones. Associations between CEQUEL scores and caregiver regret, including regrets about their own role in the final week of life, highlight this potential. Data on caregiver bereavement regret suggests that regret resolution leads to improved bereavement outcomes (Torges, Stewart, & Nolen-Hoeksema, 2008). Minimizing caregiver regret is one way to reduce suffering in bereaved caregivers, and CEQUEL provides social workers and other clinicians with a way to identify caregivers at risk for post-loss regret and other bereavement sequelae.

Modifiable Targets for Intervention

The three modifiable targets that have emerged most clearly from the present analyses are place of death (including site of death and inpatient hospice length of stay), therapeutic alliance and caregiver religiosity. Each of these factors may be viewed as a *stabilizer* in the experience of dying patients and their caregivers. Ideally, each provides caregivers with a context and a structure for what is happening as patients come closer to death, lending some predictability and reassurance amidst the chaos. The metaphor of patients and their loved ones being set adrift upon the tumultuous seas of advanced illness may appear trite and is arguably overused, but the premise behind the metaphor holds true. Caregivers *do* feel set adrift, left to navigate uncharted waters that may make or break their loved one's 'good death' at the same time that their own hearts are breaking. In this context they *do* need something to grasp hold of, something solid and grounded. That rock amidst the storm may come from the reassurance that the health care team sees their loved one as a whole person, or it may come from religious community. It may come from having a solid EOL plan established, or from having a social worker who understands the context of their grief, trauma and regret. Regardless of the specific means, the important point is that there are numerous fronts on which clinical social workers and other providers can intervene.

Dying in the hospital. The present study's finding of hospital death as a predictor of poor caregiver evaluation of quality of care (which, in turn, is associated with poor bereavement outcomes) is consistent with the existing literature. With few exceptions, including a small study by Ringdal et al. (2001) suggesting that place of death had no impact on caregivers' subsequent grief reactions, research has pointed towards better caregiver outcomes when patients die at home. Much of the current literature has compared caregiver outcomes when patients are enrolled on home hospice versus in-hospital at the time of death. Teno et al. (2004) found that caregivers of patients who died in a hospital, compared to those who died on home hospice, were more likely to report unaddressed pain and emotional support needs, insufficient contact with physicians, not always being treated with respect, and insufficient information about what to expect while the patient was dying.

Studies directly examining the impact of hospital death on caregiver outcomes have also been largely consistent in reporting poor caregiver outcomes. Wright et al. (2010b) found an increased risk of patient physical and emotional distress as well as poorer patient QOL (both per caregiver report) when patients died in a hospital rather than on home hospice. Bereaved caregivers of patients who died in a hospital were also at greater risk for prolonged grief disorder. Wright et al. (2008) had previously reported that more aggressive care at the end of life was associated with worse patient QOL and greater risk of major depressive disorder in bereaved caregivers. A number of studies have also examined the detrimental impact of EOL decision-making in the hospital on caregiver mental health (Norton et al., 2003; Gries et al., 2008; Radwany et al., 2009; Tilden et al., 1999). A recent review of 40 studies by Wendler & Rid (2011) highlights the significant negative emotional burden faced by caregivers following EOL decision-making, including stress, guilt, and doubt about the decisions made.

Despite this clear consensus on the additional burdens faced by caregivers facing an in-hospital death, there is less consensus regarding how much patients and caregivers are concerned with place of death. Research suggests that while many patients wish to die at home, many die elsewhere. Karlsen & Addington-Hall (1998) interviewed bereaved cancer caregivers in London and found that of the 38% of decedents expressing a preference for place of death, three-quarters wished to die at home but only about half did so. In a similar, smaller study also conducted in the United Kingdom, Townsend et al. (1990) found that 69% of patients who died in a hospital had expressed a wish to die elsewhere. In their study of seriously ill patients, however, Steinhauser et al. (2000b) found that only 35% agreed it was important to die at home, with more than half neither agreeing nor disagreeing. These findings indicate that while place of death is not important for a large number of patients, those for whom it is important often wish to die at home, a wish that is many times unfulfilled.

The knowledge that dying in a hospital is likely to impact bereavement outcomes as well as perceived quality of care for many cancer caregivers presents clinicians with a mandate to think proactively about the best plan of care for dying patients and their caregivers. Is dying in the hospital necessary? If it isn't, have all the necessary discussions taken place to clarify the patient and caregiver's understanding of prognosis and goals of care, giving them the opportunity to shift away from aggressive, life-sustaining interventions and towards a comfort-focus approach? Do the patient and caregivers know what to expect as death comes closer, and do they have a realistic sense of how long the dying process might take? Sometimes a complicated EOL case boils down to a single unresolved problem. A family may tell the team, "You promised me she'd be comfortable and wouldn't suffer, but look at her gasping for breath!" or, "You told us it would only take a day or two for her to die once they removed the ventilator, but it's been a week!" Cases like this remind clinicians of the critical need for clarity with patients and caregivers regarding what is and is not achievable, including the real risk that things may happen differently than expected, and how the team will anticipate that and what the back-up plan will be. If leaving the hospital isn't feasible for logistic or psychosocial reasons (e.g. patients on high-flow oxygen that is increasing their comfort and cannot be provided outside of the hospital, or patients whose loved ones can't be with them at home 24 hours a day), are there steps the team can take to make in-hospital care feel less sterile or frightening and more peaceful and dignified?

Early hospice enrollment. This study's findings related to length of hospice stay and caregiver evaluation of quality of care are also consistent with the existing literature. Research has shown that shorter lengths of stay (LOS) in hospice are associated with worse bereaved caregiver outcomes (Bradley et al., 2004; Kris et al., 2006), although Teno et al. (2007) suggest that these negative outcomes are related less to actual hospice LOS than to caregivers' *perception* that hospice enrollment was too late (Teno et al., 2007). Teno et al. (2012) have also highlighted the impossibility of earlier hospice referrals in many cases, including those where patients initially refuse enrollment or have an unexpected, acute life-limiting illness. These authors emphasize the need for high-quality hospice care even when patients are only enrolled for a short time. Wright et al. (2008) found that longer hospice length of stay was associated with better patient QOL which, in turn, was associated with better caregiver QOL. In a qualitative study by Waldrop (2006) of cancer caregivers experiencing short (< 2 weeks) hospice lengths of stay, a number of bereaved caregivers knew about their loved ones' diagnosis in advance but delayed hospice enrollment due to ongoing curative treatment or feeling that they could manage the care on their own. Many cited wanting to retain control and normalcy for as long as possible, until reaching a 'point of no return' where hospice was the only choice. In a subsequent study, Waldrop and Rinfrette (2009) interviewed bereaved cancer caregivers and found that these 'late-stage' hospice admissions felt chaotic, emotional, and like a crisis for many caregivers.

At the same time that clinical social workers and other team members explore options for patients dying out of the hospital, they should also be thinking critically about early hospice enrollment for seriously ill patients. If home hospice is not a realistic option – and this is increasingly the case, as family members live further away from one another, work fulltime, or have other responsibilities that limit their availability – but inpatient hospice may be, team members might ask themselves what the barriers are to enrolling patients on inpatient hospice sooner rather than later. While the present study was not designed to explore the underlying reasons why short inpatient hospice length of stay might result in lower caregiver evaluation of quality of care, other researchers have examined the problem of late hospice referral. In addition to acute illness and initial patient refusal that preclude earlier hospice enrollment in a number of cases, Teno et al., (2012) have highlighted problems with physician communication and prognostication that can delay hospice referral. Other reasons for late referral might include the oncology team continuing to offer cancer-directed therapies late into the disease trajectory; acute onset of pain or other symptoms at advanced stages of illness; or, for patients who have been ill for some time, simply an end to the understandable weeks or months of 'foot-dragging' that often results as patients, caregivers and physicians alike process the emotional ramifications of hospice enrollment. Any of these situations are ripe for high caregiver distress and anxiety around their loved one's symptoms or around the emotional aspects of coming to terms with impending loss. Without the inpatient hospice team having adequate time to develop a rapport with patients and their caregivers, to adequately assess their psychosocial and spiritual needs, or to adequately address patients' pain and symptom needs – in short, without the hospice team having adequate time to lend a sense of *control* to a situation that otherwise feels very much out of control to patients and their caregivers – it is no wonder that caregivers will recall their loved one's final days with anger, sorrow or regret.

Caregiver religiosity and religious coping. Alcorn et al. (2010) have found that religion and spirituality are important to most advanced cancer patients, and religion was a recurrent theme in the present study's findings. Caregiver religious affiliation emerged as one of the only significant caregiver characteristics associated with differences in CEQUEL scores, use of negative religious coping was associated with an increase in perceived suffering and prolonged dying, and a summed measure of religiosity was one of four predictors of CEQUEL scores in the unadjusted final regression model.

It is easy to imagine the ways in which caregiver religiosity – defined in the present study as frequency of attendance at religious services, time spent in private religious activities, importance of religion, use of religion as a primary coping method, extent to which religious beliefs or activities helped with coping or handling their illness, and extent to which religious views affected recent medical decisions – may impact the evaluation of care provided to a dying loved one by the health care team. One of religion's key functions may be to provide caregivers with a moral and theological framework from which to approach and make meaning of life stressors such as the death of a loved one. Religions provide a "unique framework for coming to grips with the limits of personal knowledge, control, and resources in coping" (Pargament, 1990, p.818). In so doing, they help to "ensure that these problems of bafflement, suffering, and injustice are not ultimately incomprehensible" (Pargament et al., 1997, p.49).

> To what may seem like the most senseless accident, the most unbearable pain, or the most unjust outcome, religions have their own responses. Most suggest a different way of thinking about hardship, about people, or about the sacred…. In this process of reframing, suffering may become something explainable, bearable, and even valuable. Reframing is designed….to soften the blows of crisis, to reaffirm that life has meaning in spite of its pain, to protect the sacred…. (Pargament et al., 1997, p.222)

Another key function of religion may be to provide caregivers with a sense of belonging to a religious community, and with critical emotional and spiritual support from both God as well as fellow church members. Of religious people, Pargament (1997) has written: “When events threaten to upset their equilibrium, they often reach out beyond themselves for balance, or they may find that a helping hand is extended to them without asking for it. In either case, the function of the support is the same: to uphold and sustain the person through hard times” (p.209). Given the literature around the role of social support in coping with illness and other stressors (Brazil et al., 2002; Kurtz et al., 1997; Tomarken et al., 2008) it would not be surprising for caregivers who felt part of an overtly supportive religious community, or who felt a greater connection to the Divine via solitary prayer, to also have better resources to cope with the stressors of the final week of life.

This study’s finding that low CEQUEL scores were associated with higher use of negative religious coping makes clinical sense. Pargament et al. (1990) found that belief in a just and loving God, viewing God as a supportive partner in the coping process, involvement in religious rituals, and a search for spiritual or personal support through religion – all components of positive religious coping – were predictive of positive psychological, religious and health-related outcomes. In contrast, negative religious coping typically includes an insecure relationship with God, an ominous view of the world, and a struggle to find significance in the face of adversity. Subsequent studies (Pargament et al., 2000; Pargament et al., 2001) have been consistent in finding that people tend to make more use of positive than negative religious coping, and that positive religious coping is associated with better mental health outcomes while negative religious coping is associated with greater depression, poorer QOL, and more psychological symptoms. Several CwC studies have similarly suggested a positive relationship between patients' positive religious coping and improved QOL (Tarakeshwar et al., 2006), while the opposite is true for negative religious coping. Pearce et al (2006) found that negative religious coping by caregivers was associated with a decrease in their own QOL and satisfaction with caregiving, and an increase in depression and anxiety. Demonstrating the complex nature of the construct, however, use of positive religious coping by patients has also been associated with more use of life-prolonging care at the end of life (Phelps et al., 2009). Balboni et al. (2007) found that higher patient religiosity was associated with wanting life-prolonging measures at the end of life. However, patients with high use of religious coping who also received spiritual support from the team were more likely to receive hospice care (Balboni et al., 2010). Some of the components of negative religious coping are not atypical at the end of life – for example, patients and caregivers often question the kind of God that would allow cancer to happen – but one can imagine that caregivers who engage more fully and consistently in this of coping may also see more problems with EOL care.

The health care field's increasing awareness of the importance of culture and religion in how patients and caregivers face medical illness, as well as growing interdisciplinary respect for hospital- and community-based chaplains, have equipped clinical social workers and other providers with a better understanding of the religious context in which caregivers live. Pargament (1997) argues that those in the psychological disciplines should work collaboratively with those in the theological disciplines to help people manage life stressors, rather than approaching religion as completely distinct from coping. Both disciplines, he argues have something to contribute:

The psychological world says that we are not as powerless as we imagine

> ourselves to be; we have resources within ourselves that can be tapped more fully. The religious world says that in fact we are powerless in important ways and that we must look past ourselves alone for answers to important questions….[T]he psychological world helps people extend their personal control, while the religious world helps people face their personal limitations and go beyond themselves for solutions. (p.8)

The critical role of religion and spirituality in coping for many caregivers at the end of life mandates not only that clinical social workers collaborate with their chaplain colleagues, but also that they enhance their own ability to conduct a religious/spiritual assessment with caregivers. Social workers and other team members must have an appreciation of the core components of caregiver religion or spirituality, and an ability to provide clinical guidance and support around related aspects of coping and meaning making, but also a level of interdisciplinary respect and self-awareness to know when to refer caregivers to the 'theological experts'. Key questions for caregivers might include: How are they making meaning of a loved one's death? What role do they feel God (or other Higher Power) is playing in their loved one's illness and death? Do they feel they are being punished or tested? Does their faith inform the way in which they perceive suffering or prolonged dying as negative-versus-redemptive? What is their relationship with the Divine, and is their loved one's death challenging that relationship? What role does their faith community play in helping or hindering their coping?

At the same time that social workers and other team members explore the ways in which religion or spirituality helps caregivers to process or make meaning of their loss, they might also encourage caregivers to maintain those practices and rituals that have helped them to cope in the past. In cases where caregivers cannot access their own religious community or engage in their typical religious practices – as well as in cases where they can – utilizing hospital or home-based chaplains can help to identify and strengthen those aspects of religious practice that are likely to bolster caregivers' ability to cope. Given the stance that some religions may take on care at the end of life (e.g. life is precious, is in God's hands, and should be preserved at all costs) calling upon a caregiver's outside church members or clergy may not be helpful to the team in transitioning a patient to a comfort-oriented approach. Similarly, bolstering a caregiver's religious supports runs the risk of also bolstering religious coping mechanisms that may work counter to the team's own aims at avoiding a prolonged dying process or prolonged suffering. Despite these risks, the data suggest that supporting caregiver religiosity is critical in fostering positive evaluation of care provided to dying patients.

Therapeutic alliance. The positive association between caregiver CEQUEL scores and patient-physician therapeutic alliance – defined in the present study as the degree to which patients trusted and respected their physicians, felt respected and seen as a whole person by their physicians, and felt comfortable asking their physicians questions – highlight its critical role for caregivers as well as patients. This is further bolstered by the inclusion of patients feeling seen as a whole person in the final unadjusted model. Most primary caregivers will have been present for clinical visits, hospitalizations and treatment discussions over the course of a loved one's cancer trajectory. Caregiver observations of the patient-physician dynamic during these key moments, as well as the way in which physicians relate to caregivers themselves, will likely influence and be influenced by patient perceptions of these same aspects of care.

This study's findings are consistent with the broader literature on the patient-physician relationship. A review by Auerbach (2009) highlights the impact of patient-physician relationship on patient QOL, patient-physician communication and enhanced patient participation in decision-making. Back et al. (2008) propose that therapeutic alliance is key to setting the stage for a successful patient-physician relationship throughout the cancer trajectory. Using CwC data, Mack et al. (2009) found that patients reached greater emotional acceptance of their terminal illness and spent less time in intensive care at the end of life when they had a stronger therapeutic alliance with their oncologist. Another CwC study by Zhang et al. (2012) found therapeutic alliance to be among the most important predictors of QOL at the end of life.

The particular role of 'whole-person care' in patient-physician therapeutic alliance has also been well documented in the literature. Steinhauser et al. (2000b) include affirmation of the whole person as one of six key components of a good death. Being viewed by physicians as a whole person has been included as a critical aspect of quality of death (Munn et al., 2007) as well as an indicator of quality of care (Engelberg et al., 2010). Feeling like a whole person – being able to laugh, be touched, find meaning, and maintain dignity – has been cited as a key domain of quality of dying and death (Patrick et al., 2001; Downey et al., 2010). In his model of Dignity-Conserving Care for dying patients, Chochinov (2002) writes, "Dignity-conserving strategies should attempt to reinforce the patient' s sense of self-worth by adopting a therapeutic stance that conveys steadfast respect for the patient as a whole person with feelings, accomplishments, and passions independent of the illness experience" (p.2257). McClement et al.'s (2007) finding that almost half of the caregivers for patients receiving

Dignity Therapy felt that it reduced their loved ones' suffering further bolsters the value of whole-person care.

Clearly, patient-physician therapeutic alliance falls largely under the control of physicians themselves. The patient-physician relationship is one that begins with the first office visit, and which is shaped and cemented with each subsequent visit or conversation. Recent initiatives including a Serious Illness Communication Checklist by Block (2012) have attempted to facilitate early patient-physician communication about EOL wishes, and it is likely that these types of interventions will also have a positive impact on how patients feel about their physicians, but ultimately it is the physician's responsibility to foster therapeutic alliance with his/her patients.

At the same time, as team experts on communication and interpersonal dynamics, clinical social workers have an important role to play in identifying opportunities for improved relations between physicians, patients and caregivers. Proactively identifying patient- or caregiver-perceived deficits in physician trust, respect or whole-person care, social workers may be able to coach patients and caregivers in communicating their needs to physicians. Social workers may also find opportunities to mentor physicians in developing improved relations with their patients, or to model for physicians what whole-person care looks like. Furthermore, while CwC examined therapeutic alliance between patients and physicians, it is important for all members of the interdisciplinary team to instill in patients and their caregivers a sense of trust and confidence in the care being provided at the end of life. Assuming that a health care team is providing truly interdisciplinary care, then therapeutic alliance between any member of the health care team and a patient or caregiver should promote positive alliance for the team as a whole, including physicians.

The Role of Clinical Social Work

This study's findings are relevant to the work accomplished by all members of the health care team, but they present a unique opportunity for teams to capitalize on the training and skill sets of their clinical social workers, and for social workers to assert their expertise as key members of teams providing effective EOL care (Higgins, 2012b). For their part, physicians need to be held accountable for aspects of care including early, proactive communication with patients and caregivers; continuity over time and between care sites; honesty; and good therapeutic alliance. Many of the problems identified by CEQUEL and related analyses lay in one of two areas: inadequate communication between the medical team and the caregiver, and the caregiver's potentially inaccurate perception of what is happening. Whether the medical team or the caregiver is the social worker's target for intervention, the social work skill set is well suited to both improving caregiver-team communication and clarifying and reframing perceptions of care. Social work interventions around caregiver-perceived quality of care can be broken into four domains: assessment, communication, education and counseling.

Assessment. Social workers play a key role in helping the care team to accurately assess the patient and caregiver context as well as caregiver coping at the end of life. As experts in family dynamics and coping, social workers have the time and skill set to develop an in-depth understanding of the way in which both may be informing how a caregiver responds to the care being provided. Social workers' biopsychosocial-spiritual approach can also help to identify additional aspects of family history, strains or stressors

– some immediately related to patient care, others with less direct but equally important ramifications – that impact the caregiver's experience in the final week of life.

Communication. Social workers have an important role in facilitating communication around problems related to each of CEQUEL's four domains. Physicians and other primary medical providers need to take the lead in keeping caregivers informed about what the team is seeing clinically, what they are doing to maintain patient comfort, and what to expect as patients come closer to death. Such preparation needs to be initiated early on, and needs to be reinforced over time. Social workers, however, can and should also play an integral role in reinforcing this information. As non-medical clinicians who have a different, more therapeutically- (rather than medically-) oriented focus with caregivers, social workers may see or be told things that medical providers are not. Indeed, much of a social worker's 'work' may entail processing with caregivers what they have been told once the medical team has left the room. This role provides social workers with an ideal vantage point from which to help caregivers prepare for what is to come. Medical providers again have a key role to play in clarifying patients' treatment wishes, listening to caregiver concerns about treatments, and helping caregivers understand what to expect from treatments. Many related aspects of care, however, fall well within the social work skill set, including clarifying patient and caregiver values and goals of care, recognizing potential shifts in those values and goals over time, and helping the medical team to recognize when there is a need to revisit goals of care with the caregiver so that patient wishes are respected and caregivers feel heard.

With regard to prolonged dying and suffering, physicians and other medical providers need to be aware of whether death is being prolonged in a way that doesn't meet patients' wishes, at a time when death feels close at hand, or in a way that increases perceived patient suffering. They must also maintain active awareness of whether the dying process is one that appears peaceful or violent to caregivers, and how any potential suffering jibes with caregiver expectations. Clinical social workers, however, have an equally vital role to play in monitoring caregiver perceptions of patient suffering and prolonged dying. In many instances social workers are the primary keepers of caregiver emotional distress, including their hopes and fears about EOL care and their concerns about maintaining the patient's personhood and dignity, and this again provides them with a unique vantage point on how caregivers may be evaluating suffering and prolonged dying. Social workers can help caregivers and team members alike to discern whether there is something that can realistically be changed to reduce suffering or limit prolonged death, or whether the change needs to take place internally with how caregivers or providers are interpreting what they are seeing.

Education. The social worker's task of education is closely related to that of communication. Cagle and Kovacs (2009) posit that while education is an interdisciplinary responsibility, it is often filled by social workers given their expertise as well as the time they may be able to justify towards this task compared to other providers. Social workers may need to identify incongruence between what caregivers understand about medical condition and prognosis and what the team has told them (or, in some cases, what the team needs to tell them more clearly), and to provide re-education regarding what the team expects to happen. Social work education around key theoretical frameworks such as the Circumplex model (Olson & Gorall, 2003) or Bronfenbrenner's Ecological Systems Theory (Jacques, 2003) can help the rest of the team as well as caregivers themselves to better understand how family dynamics may be contributing to caregiver perceptions of care. In their role as context interpreters, social workers can help caregivers to place the patient's medical condition within their unique family context so that they can make decisions or align expectations in a way that best serves their family (Bern-Klug, 2004; Bern-Klug et al., 2001). Part of the context interpreter role is also to educate other members of the health care team about the caregiver's family context, so that all involved can better understand the background for caregiver hopes, fears and expectations.

Counseling. Finally, clinical social workers play a primary role in providing caregivers with supportive counseling as they face a loved one's final week of life. Supportive counseling includes active listening, normalizing, reassuring, and meaning-making, and these clinical tools may be particularly relevant in situations where the team is doing everything they can to address caregiver concerns, yet patients are still facing a prolonged dying process that makes caregivers feel they are suffering. Greer (2010) has suggested using cognitive behavioral therapy (CBT) techniques with bereaved caregivers to help reframe cognitive distortions, address unjustified guilt and self-criticism, and counteract all-or-nothing thinking or inappropriate anger at the health care team. Social workers can be expected to have a working knowledge of such techniques, and should be encouraged to develop further expertise in order to be better equipped to help bereaved caregivers to process their experiences of care at the end of life.

Implications for Health Care Policy

The present study suggests that caregivers whose loved ones die in the hospital, have delayed hospice enrollment, or have poor patient-physician therapeutic alliance are more likely to perceive shortcomings in the quality of EOL care and to suffer negative bereavement outcomes. This data has implications not only for research and clinical practice, but for health care policy perspective as well, both at the state or national legislative level and that of individual health care institutions.

State and national policy

Recent national data on Medicare expenditures and health care utilization at the end of life make this study's findings particularly relevant to current state and national health care policy. Two recent studies suggest that physicians, rather than patients, drive much of the disproportionately high Medicare expenditures at the end of life. Riley and Lubitz (2010) have noted a non-significant decrease in the percentage of Medicare payments going toward care in the final year of life between 1978 (28.3%) and 2006 (25.1%). The authors attribute some of this inertia to ongoing Medicare incentives for physicians to provide more treatments and interventions, rather than less. According to a recent study by Cutler, Skinner, Stern, and Wennberg (2013), the primary predictor of regional Medicare expenditures at the end of life is not patient care preference, but physician preferences related to their beliefs about the effectiveness of treatment options. The authors estimate that Medicare spending at the end of life would decrease by 36% if physicians followed professional guidelines about EOL care.

A recent Dartmouth Atlas Project report highlights several national trends related to hospital death, ICU care in the final month of life, and hospice enrollment for terminally ill cancer patients (Goodman et al., 2013). Comparing Medicare data from 2003-2007 and 2010, the Dartmouth report notes a decrease in the percentage of cancer patients dying in a hospital (28.8% to 24.7%) and an increase in patients enrolled in hospice in the last month of life (54.6% to 61.3%). The percentage of patients admitted to an ICU in the final month of life, however, also increased (23.7% to 28.8%), as did the percentage of patients admitted to hospice during the last three days of life (8.3% to 10.9%). Continuity of care suffered, as well, marked by a significant increase in the percentage of patients seeing ten or more different physicians in the last six months of life (46.2% to 58.5%). These findings neatly mirror those of a recent study by Teno et al. (2013), which compared Medicare deaths in 2000, 2005 and 2009. Teno and colleagues found a decrease in acute care hospital deaths and an increase in hospice enrollment at the time of death, but also an increase in ICU care in the last month of life. Health care transitions in the last three days of life increased, as well, with almost one-third involving 'late-stage' transitions from acute hospital care to General Inpatient (GIP) hospice (a level of hospice care provided to patients requiring inpatient admission for intensive symptom management or EOL care).

It is likely that these national trends in hospice enrollment are a reflection of both individual physician stances on hospice care and current Medicare hospice benefit policy. The data suggest that while physicians and other health care providers may be hearing part of the message about hospice's positive impact on patient quality of life and perhaps even survival time (Temel et al., 2010), they may not understand that these benefits are predicated on hospice teams having adequate time to establish trust, improve physical symptoms, and address psychosocial issues including family coping and expectations. While some hospices have developed 'open-access' policies that allow for enrollment of patients with less clear prognoses, or who are receiving active chemotherapy or other costly and/or potentially life-prolonging treatments, most continue to follow traditional

Medicare guidelines. It is likely that these limitations are contributing to late-stage hospice enrollment, as physicians may be wary of predicting a six-month prognosis or (together with patients and caregivers) may not be willing to forego certain treatments. In response to this, hospice advocates have promoted national legislative reform of the Medicare hospice benefit, specifically those policies (including some introduced by the Affordable Care Act of 2010) that restrict many patients from receiving the EOL care they need or punish physicians for inaccurate prognostication (Hospice Association of America, 2013).

Recent reforms in Medicare legislation as well as private payer policies also hold important fiscal implications with regard to readmissions and length of stay for hospitals and other health care institutions. The advent of Accountable Care Organizations and a shift away from fee-for-service models are likely to shift institutional incentives for avoiding unnecessary hospitalizations and limiting hospital length of stay. This may, in turn, encourage earlier utilization of home hospice as a means of discharging patients and reducing readmissions; it is less clear whether hospitals will have similar incentives to promote earlier inpatient hospice enrollment in the acute care setting.

In August 2013, United States Senators Mark Warner (D-VA) and Johnny Isakson (R-GA) introduced the Care Planning Act (CPA). A key component of this legislation would reimburse physicians for having EOL discussions with their patients, a component of the Affordable Care Act that was dropped due to allegations that these constituted ‘death panels’ or care rationing. By creating a billing code for EOL planning, the CPA would allow physicians to bill Medicare for conversations that are typically too lengthy and involved for physicians to have without the ability to be reimbursed (Vox, 2013). It is this very type of legislation that might address many of the significant findings in the current study. Encouraging physicians to spend more time with their patients would allow for greater clarity around patients' EOL wishes, which might in turn help to avoid unwanted care at the end of life, including dying in a hospital or having a delayed hospice admission. Equally as important, legislation such as the CPA would encourage physicians to develop a stronger therapeutic alliance with patients and caregivers.

Health care institution policy

The positive news of fewer cancer patients dying in the hospital is quickly tempered by the fact that more are spending time in the ICU in their final month of life. One can assume from this data that of the cancer patients who are dying in the hospital, an increasing number may be dying in intensive care or at least spending time there. This is cause for concern, given that ICU care typically entails the most aggressive and costly medical interventions including prolonged life-sustaining treatments – care that has been shown to have a negative impact on caregivers at the end of life and in bereavement (Wright et al., 2008). In light of this data, hospitals and other health care institutions ought to be developing policies to prevent hospital deaths where possible, and where desired by patients and their loved ones. Such practice standards might include automatic team-family meetings within the first few days of ICU or hospital admission for patients with life-limiting illness, with regular follow-up meetings thereafter. Another standard might entail the development of 'trigger criteria' for palliative care consultation for seriously ill patients in community, acute inpatient or Emergency Department settings, to promote timely clarification of goals of care and avoid unwanted medical treatments at the end of life (Bernacki et al., 2012; Bookbinder et al., 2011; O'Mahony et al., 2008). As noted by Cutler et al. (2013), hospitals should also be encouraging their physicians and other providers to follow professional guidelines on EOL care as a means of ensuring that patient values and goals are superseding those of the health care team. Policies encouraging proactive consultation of clinical social workers and chaplains – in particular those with specialized training in palliative care, oncology, intensive care, and other seriously ill patient populations – would also help to ensure that patients and caregivers have ample opportunity to voice their hopes, fears and goals related to EOL care, including preference for place of death.

Acknowledging that timely hospice enrollment is a multifactorial problem, hospitals and other health care institutions should be developing practice standards that encourage hospice referral, either at home or inpatient, as soon as it is clinically indicated. Understanding that earlier hospice enrollment may not always be clinically appropriate or desired by patients or their loved ones, hospitals should also be developing standards that encourage early discussion of hospice, so that families are better equipped and prepared when the time is right. Such standards would require hospitals to educate their physicians, nurses, social workers, and other team members about hospice policies and benefits, as well as how to have the ‘hospice conversation’, to ensure that patients and caregivers receive the most accurate and sensitively-delivered information. Some dying patients will not be able to leave the hospital and may not be candidates for inpatient hospice; for these and other patients, hospitals should be developing policies to promote more effective EOL care and patient comfort in the acute care setting, including policies on ventilator withdrawal and palliative sedation.

There has been a recent trend toward promoting generalist palliative care competencies for all physicians, with Quill and Abernethy (2013) and other authors citing the lack of available physician palliative care specialists to meet the growing population of patients in need. This conversation is an important one, but it should also include discussion of how advanced practice nurses and clinical social workers can help health care institutions meet the increasing demand for palliative care. Hospitals and other institutions should be promoting generalist palliative care skills training for all members of the health care team, not just physicians. Providing clinical social workers with training specific to palliative and EOL care – including family dynamics at the end of life, complex medical decision-making, helping families to understand palliative as well as disease-focused interventions, and how to lead a goals-of-care discussion – would capitalize on their existing Masters-level education and training. Standardizing social work bereavement follow-up after in-hospital deaths – including skills training around grief and bereavement – would be another important step for hospitals to help address caregiver distress related to their experiences in the final week of life.

Conclusion

The results of this study suggest that CEQUEL is a reliable and valid tool for assessing caregiver perception of the quality of care provided to dying cancer patients. Significant associations between CEQUEL and other factors with established positive or negative ramifications for EOL care and bereavement – including hospice enrollment, therapeutic alliance, and post-loss trauma and regret – support the measure's strong convergent validity. By including novel dimensions of suffering and prolongation of death, CEQUEL represents a clinical assessment tool that more fully captures perceived deficiencies in EOL care. CEQUEL may help to identify important targets for clinical intervention with bereaved cancer caregivers, as well as for caregivers and health care teams still anticipating a patient's death. The best predictive models identified in this study suggest that place of death – including not dying in a hospital and early inpatient hospice enrollment – as well as whole-person physician care and caregiver religiosity are key, modifiable targets to improve the caregiver's experience of care at the end of life. These findings are important for all members of the health care team, but there are particularly rich opportunities for clinical social workers to enhance the caregiver's experience prior to patient death and in the bereavement period that follows.

At the same time that this study's findings can help clinicians to assess and intervene with caregivers at the end of life, it is also important to recall that caregiver assessments of EOL care may not always be accurate, given the inevitable influence of high emotions and unrealistic expectations at this time of life. Even when they are accurate, perceived shortcomings in care may not always be changeable. Field & Cassel (1997) capture this idea well when they write that "the concept of a dignified death may unwittingly romanticize death, and its incautious use may produce distress or anger by creating expectations that professional and other caregivers cannot always fulfill for all patients, given the nature of their disease" (p.25).

In the end, however, if a caregiver's perception of care is what impacts his or her emotional adjustment at the bedside and in bereavement, clinical social workers might draw upon a fundamental tenet of social work practice and 'start where the client is'. Rather than disregard or grow defensive about what may feel like a caregiver's inaccurate perception of care, the health care team will serve caregivers better by addressing their worries, perceptions and memories directly. This is not to suggest that every perceived failing is justified, or that the health care team's job is to eliminate each one in turn. Indeed, the task for clinical social workers and other members of the health care team is to balance clinical objectivity with emotional investment in patients and caregivers, and professional integrity with an openness to caregiver and self-critique. Emotional upset, regret and anger may not be an inevitable part of death and dying, but they are more common than not. Recognizing this, perhaps the best approach for social workers and other providers is that of harm reduction, striving to reduce caregiver distress rather than cure it completely. This is not to relieve the health care team of their obligation to strive for the best possible care for patients and their loved ones. Quite the opposite, it should spur cancer clinicians to redouble their efforts at addressing caregiver distress both before and after a patient's death, and to recall that there is almost always an opportunity to improve the experience of caregivers at the end of life.

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