

4-5-2016

Investigating the Mutual Effects of Depression and Spiritual Well-being on Quality of Life in Hospice Patients with Cancer and Family Caregivers Using the Actor-Partner Interdependence Model

Li-Ting Huang

Follow this and additional works at: <https://digitalcommons.usf.edu/etd>



Part of the [Nursing Commons](#)

Scholar Commons Citation

Huang, Li-Ting, "Investigating the Mutual Effects of Depression and Spiritual Well-being on Quality of Life in Hospice Patients with Cancer and Family Caregivers Using the Actor-Partner Interdependence Model" (2016). *USF Tampa Graduate Theses and Dissertations*.
<https://digitalcommons.usf.edu/etd/6097>

This Dissertation is brought to you for free and open access by the USF Graduate Theses and Dissertations at Digital Commons @ University of South Florida. It has been accepted for inclusion in USF Tampa Graduate Theses and Dissertations by an authorized administrator of Digital Commons @ University of South Florida. For more information, please contact digitalcommons@usf.edu.

Investigating the Mutual Effects of Depression and Spiritual Well-being on Quality of Life in
Hospice Patients with Cancer and Family Caregivers Using the Actor-Partner Interdependence
Model

by

Li-Ting Huang

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
College of Nursing
University of South Florida

Major Professor: Susan C. McMillan, Ph.D., ARNP
Cindy S. Toftagen, Ph.D., ARNP
Cathy D. Meade, Ph.D., RN
Brent J. Small, Ph.D.

Date of Approval:
March 25, 2016

Keywords: Palliative Care, Dyads, Spirituality, Structural Equation Modeling, LISREL

Copyright © 2016, Li-Ting Huang

DEDICATION

I dedicate this work to all the cancer patients and their supportive family caregivers I have encountered in my life as they have inspired me to pursue my nurse scientist career in the United States.

ACKNOWLEDGMENTS

I am so grateful to have had such wonderful mentors and friends accompanying me since I began my journey as a nurse scientist in the United States. Without their endless support and encouragement, this journey would not have been joyful and fulfilled. Indeed, none of this could have occurred without God's blessings.

First of all, I would like to express my deepest appreciation to Dr. Susan C. McMillan for her full support and constant guidance. I have learned so much from her as she has been the greatest role model demonstrating her enthusiasm in research, and especially teaching. Specifically the trust she had in me gave me the possibility of having substantial experience by being involved in multiple research projects. In addition, my sincere gratitude goes to my committee members for their guidance, Dr. Brent Small, Dr. Cathy Meade, and Dr. Cindy Tofthagen. Because of their expertise in statistics and cancer research, this dissertation would not have been possible without their support.

A special thanks to Dr. Jason Beckstead for believing in my potential to become a doctoral student, which allowed me to enjoy my journey here at the University of South Florida. Last but not least, I would like to thank my best friends Benson, Chun-Yi, Mulubrhan, Melissa Shelton, Shannon Morse, and Winta Araya for their constant support, kindness, and true friendship.

TABLE OF CONTENTS

List of Tables.....	iii
List of Figures	iv
List of Abbreviations.....	v
Abstract.....	vi
Chapter One: Introduction	1
Specific Aims and Hypothesis	4
Definition of Terms	5
Significance to Nursing.....	5
Chapter Two: Review of Literature	7
Conceptual Framework	7
Quality of Life in Hospice Patients with Cancer	8
Quality of Life in Family Caregivers.....	10
Depression in Hospice Patients with Cancer	12
Depression in Family Caregivers of Cancer Patients	14
Spirituality in Cancer Patients	15
Vague Definition of Spirituality.....	15
Insufficient Spiritual Care in Cancer Patients.....	15
Spirituality in Family Caregivers.....	17
Summary	18
Chapter Three : Methods	20
Research Design.....	20
Setting and Subjects.....	20
Instruments for Both Patients and Caregivers.	21
Center for Epidemiological Study-Depression Scale	21
Spiritual Needs Inventory	21
Patient Instruments.....	22
Hospice Quality of Life Index-14.....	22
Family Caregivers Instruments	23
The Short-Form 12 Health Survey.....	23
Demographic data	23
Procedures.....	23
Statistical Analysis Plan.....	24

Chapter Four: Results	26
Data Preparation.....	26
Description of the Sample.....	30
Assessment of the Measurement Model of Depression.....	32
Assessment of the Structural Model of Depression.....	34
Post-Hoc Analysis of Depression in Spousal Dyads.....	35
Assessment of the Measurement Model of Spirituality.....	36
Assessment of the Structural Model of Spirituality.....	37
Chapter Five: Discussion	44
Mutuality in Hospice Dyads	44
Limitations	49
Implications for Nursing.....	49
Future Directions	51
References.....	52
Appendices.....	63
Appendix A: The Approved Letter for Human Subject Research from the Institutional Review Board of the University of South Florida.....	63
Appendix B: Table A1 The Correlation Matrix of the Indicators	65
Appendix C: Table A2 Key to the Corresponding Variable Names	75
Appendix D: Hospice Quality of Life Index-14.....	77
Appendix E: Center for Epidemiological Studies–Depression Short Form.....	79
Appendix F: Spiritual Needs Inventory.....	80

LIST OF TABLES

Table 1:	Descriptive Statistics for the Indicator Variables.....	28
Table 2:	Frequency and Percent of Patients and Caregivers by Gender, Marital Status, Ethnicity, and Religious Affiliation.....	31
Table 3:	Spiritual Needs within Dyads	32
Table 4:	Summary of Model Fit Statistics	38
Table 5:	Factor Loadings for the Structural Model of Depression in Dyads (Model 3)	39
Table 6:	Factor Loadings for the Structural Model of Spiritual Needs in Dyads (Model 9)	40
Table 7:	Standardized Structural Coefficients between Depression and QOL in the Overall Dyads	42
Table 8:	Standardized structural coefficients between Spiritual Needs and QOL in the Overall Dyads	42
Table A1:	The Correlation Matrix of the Indicators	65
Table A2:	Key to the Corresponding Variable Names	75

LIST OF FIGURES

Figure 1: Conceptual Framework.....	8
Figure 2: The Structural Model of Depression and Quality of Life in the Spousal Pairs.....	43

LIST OF ABBREVIATIONS

AGFI	Adjusted Goodness of Fit
CESD	Center for Epidemiological Study-Depression Scale
CFI	Comparative Fit Index
Dep	Depression
Fc	Family caregivers
GFI	Goodness of fit index
HQLI	Hospice Quality of Life Index
IRB	Institutional Review Board
Pt	Patients with Cancer
QOL	Quality of Life
RMSEA	Root Mean Square Error of Approximation
SNI	Spiritual Needs Inventory
SRMR	Standardized Root Mean Square Residual
SF	Short-Form 12 Health Survey
WHO	World of Health Organization

ABSTRACT

The World Health Organization and the leading hospice organizations have emphasized the inclusion of family caregivers of hospice patients with cancer into end-of-life care, as these two dyad members may spiritually and emotionally influence each other. Given that depression and spiritual needs, which are prominent in these pairs, may impair quality of life (QOL) of hospice dyads, examining mutuality within dyads is imperative to develop a more accurate model that includes family caregivers. Therefore, the purpose of the study was to elucidate the importance of mutual effects within hospice dyads by examining the contribution of depression and unmet spiritual needs on their personal and their counterparts' QOL. Structural equation modeling was used to integrate the feature of actor and partner effects in the Actor-Partner Interdependence Model. After eliminating outliers, the final sample was comprised of 660 hospice dyads in which the majority of hospice patients were white (97%) and male (56.6%) with a mean age of 73 years. Most of the family caregivers were white (95.9%) and female (73.5%) with a mean age of 65 years. On average, hospice patients reported a depression score of 4.00 ($SD = 1.53$), and their family caregivers had a significantly lower mean depression score of 3.65 ($SD = 1.48$). With respect to their spiritual needs, 25.5% of hospice patients indicated going to religious services was an unmet need, and about 13% of family caregivers also reported that going to religious services was an unmet spiritual need, followed by being with friends, laughing, thinking happy thoughts, and being around children. The results of structural equation modeling revealed that depression and spiritual needs in cancer patients and family caregivers

exhibited significant actor effects on the individual's QOL after controlling for the partner effects. Among the spousal pairs, depression in family caregivers exhibited a positive partner effect on hospice patients' functional well-being ($\beta = .15, p < .05$), implying that as depressive symptoms increase, hospice patients' functional well-being increases. This study supported the need for considering both as one unit and the mutuality inherent in dyads. The findings of the study suggest the importance of consistent assessment in emotional and spiritual well-being for hospice patients as well as family caregivers, as their concerns may be transmitted to each other due to mutuality existing within the dyads.

CHAPTER ONE:

INTRODUCTION

Hospice patients and their informal family caregivers confront situational challenges together in their cancer trajectory, from the time when they are informed of the cancer diagnosis through a series of transitional stages. While living with uncertainties, such as fear of suffering from treatment effects, recurrence, or impending death, dyads' perceived interpersonal resources may be reduced, leading to difficulties coping with the illness (Song et al., 2012). Due to the limited assistance from professionals regarding provision of resources during these transitions, dyads' physical, psychological, social, and spiritual well-being may deteriorate, resulting in impaired quality of life (QOL)(Applebaum et al., 2014). Furthermore, family caregivers may undergo a life-changing transition as their overall end-of-life experiences in caregiving may further influence their coping strategies and perceptions of their own death (Carlander, Sahlberg-Blom, Hellstrom, & Ternestedt, 2011). As emphasized by the World Health Organization (WHO) (2002), it is imperative to incorporate psychological and spiritual care for dyads as two primary dimensions in QOL following a cancer diagnosis. Hospice healthcare providers, therefore, attempt to bolster both hospice patients and family caregivers by providing holistic interdisciplinary care to maintain their optimal QOL (National Hospice and Palliative Care Organization, 2014). However, the American Cancer Society (2015) indicated that at least one out of four cancer patients may suffer from depression, and yet this this serious problem may be overlooked. Higginson and Costantini (2008) revealed that 3-77% of advanced cancer patients

experience depressive symptoms at some time during their cancer trajectory. Such depression also occurs in 18-67% of family caregivers (Nik Jaafar et al., 2014; Rhee et al., 2008; Tang et al., 2013). These findings imply that clinicians may still underdiagnose depression and overlook the necessities of assessing psychological well-being for dyads, especially in older adults with chronic disease or life-threatening illness (Centers for Disease Control and Prevention, 2015).

Correspondingly, depression can be provoked by taking care of demanding hospice patients, in particular when family caregivers disregard their own needs (Osse, Vernooij-Dassen, Schade, & Grol, 2006). While facing 200 potential caregiving problems including the fear of loss as well as symptom management, family caregivers may not vent their overwhelming feelings, resulting in negative influences on their social, emotional, financial, and health status (Haley, 2003; Stenberg, Ruland, & Miaskowski, 2010). Nonetheless, the attachment within the dyads may gradually increase the intensity of the bond, as the primary caregivers play a significant role in symptom management and accompany the loved one during the patients' final stage of life (Lau, Downing, Lesperance, Shaw, & Kuziemy, 2006; Mikulincer, Florian, & Hirschberger, 2003). As a result, such intertwined relationships within dyads may compromise each individual's QOL as both not only witness their partners struggles with cancer, but also experience comparable depressive symptoms themselves (Kim et al., 2015).

Depending upon the status of spiritual well-being in either member of the dyad, satisfied spiritual needs may facilitate dyads to become more resilient and adapt to their current stressful situations. It is believed that spiritual needs may increase during the last few months of life as dyads seek to find purpose and meaning in life; simultaneously, family caregivers are facing the challenges that occur after the cancer diagnosis (Paiva, Carvalho, Lucchetti, Barroso, & Paiva, 2015). Hospice patients, specifically elderly people, can reduce their prospective

uncertainty about death by utilizing their inner resources when they perceive no conflict between their internalized religious worldview and reduced engagement in religious activities due to serious illness (Ardelt & Koenig, 2006). However, at least 50% of advanced cancer patients reported that their spiritual needs were not fulfilled by either the medical systems or religious communities (Balboni et al., 2007); specifically, lack of attending religious services, being with friends and families, and laughing were identified as the unmet spiritual needs among hospice patients (Hampton, Hollis, Lloyd, Taylor, & McMillan, 2007). Cancer patients, therefore, may turn to their family caregivers for assistance, resulting in patients and family caregivers struggling with similar spiritual needs (Murray, Kendall, Boyd, Worth, & Benton, 2004; Taylor, 2003, 2006). Buck and McMillan (2008) found that family caregivers of hospice patients with cancer also reported lack of being with friends, families and laughing as unmet spiritual needs. Thus, when dying people are in the process of interpreting an impending death through their spiritual resources, those that surround them, especially family caregivers, may be affected by either positive or negative feedback from their loved ones due to their intimate relationships (Ohnsorge, Gudat, & Rehmann-Sutter, 2014). In contrast, when spiritual needs are not fulfilled and no longer serving as protective resources to alleviate diverse suffering, depressive symptoms may emerge and degrade the dyad's QOL.

Failing to adequately address potential risks of depression and unmet spiritual needs for dyads may exaggerate the effects of emotional and spiritual challenges and thereby deteriorate their own QOL due to their intensive and frequent interactions. To date, in spite of knowing the interdependent relationships within dyads, most studies still investigate either cancer patients or family caregivers with little consideration to taking both as one unit and mutual effects within dyads. Hence, the purpose of the study is to elucidate the importance of

mutual effects within hospice dyads by examining the contribution of depression and unmet spiritual needs on their individual and their counterparts' QOL using the Actor-Partner Interdependence Model.

Specific Aims and Hypothesis

The primary aim of this study is to evaluate the actor-partner interdependence model applied to dyads of hospice patients with cancer and family caregivers.

Hypothesis 1: Depression in hospice patients with cancer has a statistically adverse impact on their QOL.

Hypothesis 2: Depression in family caregivers has a statistically adverse impact on their QOL while providing assistance for hospice patients with cancer.

Hypothesis 3: Depression in hospice patients with cancer has a statistically adverse effect on their family caregivers' QOL.

Hypothesis 4: Depression in family caregivers has a statistically adverse effect on hospice patients with cancer' QOL.

Hypothesis 5: Spiritual needs in hospice patients with cancer have a statistically adverse impact on their QOL.

Hypothesis 6: Spiritual needs in family caregivers have a statistically adverse impact on their QOL while providing assistance for hospice patients with cancer

Hypothesis 7: Spiritual needs in hospice patients with cancer have a statistically adverse effect on their family caregivers' QOL.

Hypothesis 8: Spiritual needs in family caregivers have a statistically adverse effect on hospice patients with cancer' QOL.

Definition of Terms

Family Caregivers: Caregivers providing at least 4 hours of care each day may be spouses, adult children, grandchildren, other family members, partners, or friends, who have been identified by the patients as their primary caregivers (McMillan, Small, & Haley, 2011).

Interdependence: One member of the dyad whose thoughts or feelings affect the other member of the dyad results in both thoughts or feelings similar to each other (Cook & Kenny, 2005).

Quality of Life: The overall status of hospice patients in terms of their psychophysiological well-being, functional well-being, and social/spiritual well-being (McMillan & Weitzner, 1998).

Spiritual Needs: The needs that emerge when hospice cancer dyads find meaning and purpose through life experiences that impact their inherent quality of human connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Hermann, 2006; Puchalski et al., 2009).

Depression: Mood change due to a perceived stressful event, resulting in the occurrence of symptoms, such as sadness and loss of interest (National Alliance on Mental Illness, 2015).

Significance to Nursing

Over the past four decades, stages of grief proposed by Dr. Elisabeth Kübler-Ross (1969) specified that patients may experience the following five stages of grief as they near the end of their lives: denial, anger, bargaining, depression, and acceptance. These stages could emerge and have similar impact on caregivers as they anticipate the death. As interpersonal relationships between the dyads of hospice patients with cancer and caregivers become more intimate, the

focus of end-of-life care should shift from patient-centered care to family-centered care. In particular, the strength of the relationships between the dyads should be taken into consideration as healthcare providers attempt to provide comprehensive care to the whole family. However, the hospice interdisciplinary team has been providing care for both patients and their family caregivers as part of their mission while other cancer health providers may focus exclusively on patients. Therefore, the Actor-Partner Interdependence Model adopted from relationship research is a promising approach to configure more accurate mutual effects among patients and caregivers so that researchers can develop and test supportive interventions and nurses and other health providers may be able to proactively sustain psychological and spiritual well-being by delivering adequate interventions for dyads. By applying the Actor-Partner Interdependence model, such interventions may substantially decrease avoidable emotional and spiritual suffering among cancer patients and their supportive family caregivers. Most importantly, dyads may face their impending death peacefully; and their family caregivers would recover from the loss of a loved one more easily.

CHAPTER TWO:

LITERATURE REVIEW

This chapter primarily scrutinizes research articles published within the last fifteen years with respect to depressive and spiritual issues contributing to the unfulfilled QOL among hospice cancer patients and family caregivers. First, the conceptual framework is presented. The sections that follow in the literature review include hospice patient QOL, family caregiver QOL, depression in hospice patients with cancer, depression in family caregivers, spirituality in patients, spirituality in family caregivers, and a summary.

Conceptual Framework

Due to the dynamic interaction in end-of-life care between dyads, it has been suggested that hospice care should focus on the dyads as a unit rather than on separate individuals while implementing care. It is imperative, therefore, to consider the characteristics of the interdependence between dyads when investigating mutual effects. The Actor-Partner Interdependence Model, a conceptual and analytic framework concerning two components of an actor effect and partner effect (Cook & Kenny, 2005), is applied to this study. An actor effect as illustrated in Figure 1 denotes the effects of depression and unmet spiritual needs as independent variables on the dependent variable, QOL (Path B: patients only and Path E: family caregivers only). In addition, a partner effect represents the effects of the individuals' own depression and unmet spiritual needs on their partners' QOL (Path C: patients impacting family caregivers; Path

D: family caregivers impacting patients). Features of the actor-partner interdependence model may reflect the philosophy of end-of-life care by considering the individual and dyadic factors.

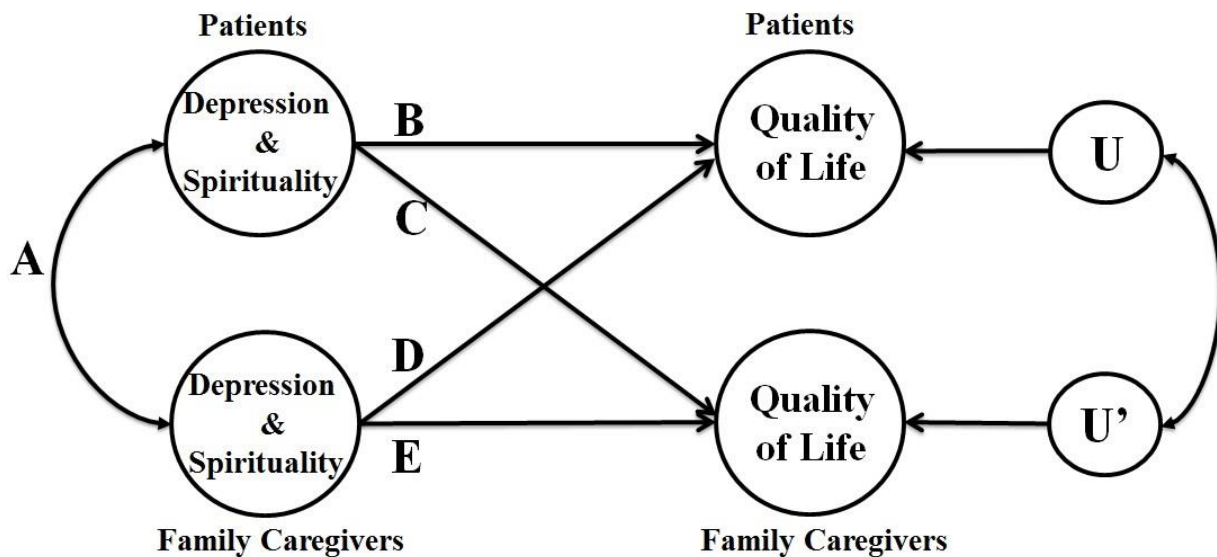


Figure 1. Conceptual framework. U = unexplained portion of quality of life in hospice patients with cancer; U' = unexplained portion of quality of life in family caregivers.

Quality of Life in Hospice Patients with Cancer

The World Health Organization mandates that clinicians should make provisions to maintain optimal QOL for cancer patients and families due to its multidimensional construct in line with the function of recognizing the effectiveness of treatments (WHO, 2015). In an attempt to prevent any aspect of QOL from declining, diverse interventions regarding the mitigation of cancer-related symptoms and distress have been developed for advanced cancer patients (Bakitas et al., 2009; Campbell & Campbell, 2012). Despite the fact that symptom management-based interventions are imperative to relieve psychophysiological symptoms, these types of interventions seemed to have less direct improvement on QOL of hospice patients with cancer, as it has been shown that patients in control groups or experimental groups had similar increased rates of QOL (McMillan & Small, 2007; McMillan et al., 2011). Consistently, a meta-analysis

revealed only small to medium effects of psycho-oncologic interventions on QOL in cancer patients, and the duration of implementation may determine the effectiveness of interventions (Faller et al., 2013). Moreover, QOL may be compromised as a consequence when distress associated with the most prevalent symptoms, fatigue, pain, and constipation, for instance, may intervene in hospice patients with cancer (Hermann & Looney, 2011; McMillan & Small, 2002). In the randomized trial conducted by McMillan and Small (2007), after knowing the limited intervention effect on QOL, they further recognized the experimental group reported significantly lower scores of symptom distress along with the increased QOL after nine days of the intervention. Currently, the National Comprehensive Cancer Network (2015) advocates the necessity for distress screening in cancer patients as distress may increase the risk of developing subsequent symptoms, such as depression, anxiety, and spiritual crisis. These results all imply that clinicians are required not only to minimize symptoms that are present but also to prevent any psychosocial ripple effects occurring due to the interrelationships among physical, functional, psychological, social, and spiritual aspects in QOL.

On the other hand, cancer patients may iteratively change their responses to the disease after they refine the values of QOL as to what consists of acceptable QOL during the course of their cancer trajectory (Sprangers & Schwartz, 1999; Tierney, Facione, Padilla, & Dodd, 2007). As cancer patients are triggered to cognitively respond to a subjective QOL index, they may undergo a response shift as a result of changing their standards, values, and constructs of QOL (Tierney et al., 2007). Although the theoretical model of response shift still needs further investigation, Traa et al. (2015) revealed that colorectal cancer patients recalibrated their values over time in terms of physical health, such as the ability to concentrate after treatments. It should be noted that Erikson's Psychosocial Stages of Psychosocial Development about older

adults (Haber, 2006), Kübler-Ross' stages of grief (1969) as well as response shift all addressed a similar cognitive process that older adults may change their responses to their life crises, such as impending death. Therefore, considering that hospice patients may experience accumulated symptoms due to their disease prognosis at the end-of-life, they may tolerate those unpleasant symptoms with less emotional suffering and thereby maintain QOL (McMillan & Small, 2007), which may be due to their adjustment related to their internal response shift. On the contrary, the occurrence of depressive symptoms and spiritual needs may link to less accommodation and acceptance of death (Price et al., 2012). While the current practice and interventions are more capable of addressing physical symptoms, such as pain and constipation, it is equivalently essential to attenuate to the consequences of negative adjustment for cancer patients.

Quality of Life in Family Caregivers

Family caregivers who are not diagnosed with cancer are physically, psychologically, socially, financially, and spiritually affected by cancer because of the additional responsibilities of caretaking for their loved ones (National Cancer Institute, 2013). According to the National Alliance for Caregiving (2015), family caregivers on average spend 24.4 hours a week engaging in nursing tasks and making medical decisions for patients after the initial diagnosis (Stenberg et al., 2010). However such chronic caregiving stress was identified as a significant predictor of the decrease in the psychological health, physical health, and psychological distress of family caregivers (Kim, Spillers, & Hall, 2012). Specifically, family caregivers reported that they are in need of assistance to relieve their own symptoms, such as insomnia, fatigue, and depression (Skalla, Smith, Li, & Gates, 2013). In addition, a significant decrease in social relationships was found to account for the deteriorated QOL as well (Traa et al., 2015), which may subsequently increase the risk of developing depression (Haley, LaMonde, Han, Burton, & Schonwetter,

2003). In particular, younger, female spouses (Haley et al., 2003; Kim & Spillers, 2010; Kim et al., 2012), and the sandwich generation, who are simultaneously taking care of children and elderly cancer patients (Buck, 2013), are recognized as being at risk for impaired QOL. The aftereffects of being family caregivers may manifest in higher mortality when family caregivers do not benefit during the caregiving process (Schulz & Beach, 1999). However, with regard to research interventions provided for family caregivers during the past three decades, a meta-analysis found that most randomized trials were implemented in the context of symptom management with little attention to family caregivers' self-care (Northouse, Katapodi, Song, Zhang, & Mood, 2010). The insufficiency of care for family is also reflected in the current hospice practices based on the services addressed by the National Hospice and Palliative Care Organization (2014), which may signify that enhancing family caregivers' QOL has not been emphasized as comparable to hospice patients with cancer.

Cancer patients who have family as caregivers have demonstrated better health-related outcomes when compared to those without assistance from family (Devik, Enmarker, Wiik, & Hellzen, 2013). In addition, caregiving may gradually become family caregivers' obligations to meet the expectations of society, and they, most often women, are required to modify themselves in order to satisfy the social norm of ideal caregivers by shielding their feelings of inadequacy (Carlander et al., 2011; Kim, Carver, & Cannady, 2015; Sjolander, Hedberg, & Ahlstrom, 2011). However, depending upon how they appraise their hardships during the demanding caregiving process, the caregiving experience may either help them grow positively by boosting caregivers' self-esteem and acceptance of difficult circumstances (Carlander et al., 2011; Kim, Baker, & Spillers, 2007; Wong, Ussher, & Perz, 2009) or render them vulnerable to stress, resulting in opposite outcomes in QOL (Kim et al., 2007). In

particular, psychological and spiritual issues, such as difficulties in accepting the patients' disease and fear of the future are the most common difficulties requiring professional support (Osse et al., 2006). Apparently, when family caregivers are not equipped with adequate coping mechanisms toward taxing caregiving, they may in turn have worse psychological well-being as well as QOL.

Depression in Hospice Patients with Cancer

Without thoughtful preparation for impending death, diverse emotions, such as fear, anger, guilt, regret, depression, or grief all could emerge when cancer patients experience the transitional period at the end-of-life (American Cancer Society, 2014a). Expressing sadness and other emotions has been recognized as the normal adjustment process, engendering the challenges of differentiating depression from grief, specifically in dying patients with physical symptoms (Rabkin, McElhiney, Moran, Acree, & Folkman, 2009; Rhondali, Chirac, Laurent, Terra, & Filbet, 2015). Due to the partnerships with clinicians, family caregivers may be counted on to monitor the presence of depressive symptoms occurring in patients; however, Fasse, Flahault, Bredart, Dolbeault, and Sultan (2015) identified that family caregivers only accurately perceived 69% of psychological difficulties that cancer patients encountered. In addition, some family caregivers may consider that asking health care providers to manage depression is relatively less important when compared to other physical symptoms, such as pain (Rhondali et al., 2015). As a result, interdisciplinary members may under-recognize the severity of depression in hospice patients even though they recognize the impact of depression on patients and co-sufferers—family caregivers (Irwin et al., 2008). Correspondingly, McMillan et al. (2011) verified that cancer patients' depressive symptoms can be improved once a systematic assessment of depression was administered to patients in the current hospice practice,

demonstrating that depression should receive more attentive assessment by clinicians rather than by family caregivers who are emotionally involved.

Open communication within dyads is particularly influential during the end-of-life as it may serve as a mechanism to share emotions and concerns and may consequently alleviate the impact of depressive symptoms in dyads (American Cancer Society, 2014b). Given that mutual self-disclosure about cancer-related concerns can increase the intimacy within dyads (Hagedoorn et al., 2011), open communicative behaviors should be initiated by cancer patients so that they can determine the depth and breadth of discussion with family caregivers (Venetis, Magsamen-Conrad, Checton, & Greene, 2014). However, effective communication skills may be hindered in dyadic interactions when both are facing uncertain events, such as pending death (Song et al., 2012). In particular, topic avoidance communication is often utilized by dyads as protective buffering specifically related to topics such as prognosis, fear of death, and funeral arrangement (Badr & Taylor, 2006); such ineffective communication may not only worsen spousal relationships (Badr & Taylor, 2006) but also increase the distress and depression severity in dyads (Haun et al., 2014). Hagedoorn et al. (2011) identified that emotions such as guilt and anxiety may be exacerbated in cancer patients who tend to withdraw when family caregivers initiated so-called supportive communication. As a result, with the presence of depressive symptoms among cancer patients, such as drowsiness, hopelessness, low self-esteem, and feelings of being a burden to family may prompt hospice patients to express negative idealization, seen as a wish to die (Ohnsorge et al., 2014). Therefore, clinicians should intervene in the communication process within dyads to prompt withdrawn cancer patients to discuss their emotions; simultaneously, less burden may be perceived by family caregivers by understanding how to initiate cancer-related topics with their loved one (Venetis et al., 2014). However,

clinicians tend to be in a passive position assuming that patients may lead the conversations by asking about end-of-life issues (Roscoe, Tullis, Reich, & McCaffrey, 2013).

Depression in Family Caregivers of Cancer Patients

Family caregivers are susceptible to mood changes appearing in cancer patients, as dyads have a deep attachment to each other at the end-of-life. The desperate idealization, such as “I should have noticed the change earlier and encouraged him to seek help” (Kübler-Ross, 1969, p. 142) occurred frequently among spousal family caregivers who responded to a life-threatening illness happening to a loved one (Kübler-Ross, 1969). While the dyads’ relationship may grow deeper during the caregiving process (National Cancer Institute, 2013), family caregivers’ moods may vary in accordance with cancer patients’ circumstances. Specifically, their depressive symptoms may reach the level of clinical depression when their loved ones’ death become visible (Tang et al., 2013). Lack of social support was found to be associated with their depressive symptoms as well (Kim, Carver, Rocha-Lima, & Shaffer, 2013; Tang et al., 2013). However, McMillan et al. (2006) indicated that a family caregivers’ perceived caregiving burden did not significantly change despite the emotional supports that was provided by clinicians. Negative social interactions with significant others was specifically identified as one of the predictors of depression among family caregivers (Haley et al., 2003). Therefore, to diminish the severity of depression, these results may suggest family caregivers should maintain their positive social relationships with others and simultaneously obtain adequate training, such as problem-solving skills to ameliorate perceived burden with caretaking (McMillan et al., 2006). However, while juggling ongoing care demands with limited assistance, family caregivers’ desire to maintain their social networks may be beyond their control as they could not switch their focus of caretaking with their loved one (Paiva et al., 2015). As a result, such suffocating effects of

caretaking with the presence of depressive symptoms may persist after the death of the patients for at least one month (Ling et al., 2013).

Spirituality in Cancer Patients

Vague Definition of Spirituality. Spirituality and religion have functioned as guidance for how to react and find meaning for stressful life events. These two terms have been utilized interchangeably due to their complementary roles to each other in research, resulting in the confusion and inability to distinguish their difference as well as operationalize relevant care in clinical settings (Gijsberts et al., 2011; Hill & Pargament, 2003). However, disagreement regarding their definitions has yet to be resolved even though multiple questionnaires have been developed to distinguish the constructs of spirituality and religion over the years (Gijsberts et al., 2011; Hill & Pargament, 2003). The Consensus Conference, therefore, was held not only to demonstrate the awareness of spirituality as one of the dimensions in palliative care but also to finalize the definition of spirituality in order to diminish the disagreement (Puchalski et al., 2009). In addition, the National Cancer Institute (2015) also differentiated spirituality and religion with respective characteristics where religion includes a specific set of practices within an organized group to express spirituality. In accordance with the definition of spirituality provided by the Consensus Conference, the group of content experts defined it in the context of palliative care and suggested practical recommendations for health professionals. Thus, the current study utilized the definition of spirituality as suggested because of its completeness embracing spiritual well-being, spiritual-cognitive behaviors, and spiritual coping (Gijsberts et al., 2011).

Insufficient Spiritual Care in Cancer Patients. The integrity of spiritual beliefs held by individuals can help search for meaning and purpose in life as it represents individuals'

inner resources and belief systems (Villagomez, 2005). The needs for spirituality are particularly evoked when patients are facing advanced illness at the time of the initial diagnosis and end-of-life (Murray et al., 2004), and such an inherent quality of connectedness with nature and others may boost their happiness (Ando, Morita, Okamoto, & Ninosaka, 2008) and personal growth as beneficial resources in response to stressful events (National Cancer Institute, 2013). After re-evaluating their spiritual beliefs during crises, having adequate spiritual behaviors via the life review (Ando et al., 2008), for example, may strengthen dying people to reflect on the meaning of life and their connection to transcendence while pursuing a good death with dignity, and therefore facilitates patients' coping strategies (Koenig, George, Titus, & Meador, 2004). However, health professionals often fail to respond to the collapse of connection when terminally ill patients undergo such a process (Abbas & Dein, 2011), exposing patients to the suffering of psychological problems. In particular, spiritual needs are manifested when the number of attendances at religious services was significantly decreased after cancer diagnosis; private religious activities, such as prayer as an alternative, was significantly increased in order to fill the gap (Balboni et al., 2007). Although such change signifies the needs for support of patients' spirituality, meeting spiritual needs is less addressed by clinicians because they are simultaneously concerned with an average of 14 physical and psychological symptoms that cancer patients experience (Roscoe et al., 2013; Stark, Tofthagen, Visovsky, & McMillan, 2012). Given that oncology physicians and nurses endorsed the importance of providing spiritual care for cancer patients, the majority of advanced cancer patients still did not receive spiritual care (Phelps et al., 2012). Lack of training for clinicians, limited time, and professional role conflicts were the potential factors that led to such important needs being neglected in clinical settings (Balboni et al., 2013; Rodin et al., 2015). In addition, chaplains who have been expected to

provide spiritual support in hospices were found to provide less contribution in standard interdisciplinary team meetings when family caregivers were not involved (Wittenberg-Lyles et al., 2013), whereas 47% of advanced cancer patients did not receive support by their religious communities either which left their unmet spiritual needs to their family caregivers (Balboni et al., 2007).

Spirituality in Family Caregivers

The long-term responsibilities of caretaking imposed on family caregivers often constrain them from having regular lives that they used to have. As articulated above, spirituality refers to the connections with others and transcendence involving practicing religious rituals or not (Edwards, Pang, Shiu, & Chan, 2010; Hermann, 2006); specifically, spouses may experience the disconnection with their withdrawn loved ones (Badr & Taylor, 2006). They may, therefore, require additional support from their social network to supplement their missing attachment with their partners (Sjolander & Ahlstrom, 2012; Taylor, 2003). Obtaining emotional and spiritual support from church, for example, can help family caregivers to accept the fact of the impending loss and foster the hope of a reunion with their loved one in the afterlife (Sjolander & Ahlstrom, 2012). Other coping strategies identified by family caregivers, such as living in the moment with friends, can distract the attention from the lurking difficulties (Kanter, D'Agostino, Daniels, Stone, & Edelstein, 2014). However, decreased social activities resulting from long-term caretaking hinder family caregivers from nurturing their internal resources through church (Paiva et al., 2015). In the meantime, they may shoulder all the burden alone by not disclosing the prognosis to their relatives (e.g., children and parents) (Sjolander et al., 2011). Consequently, the sense of isolation and lack of perceived support from friends and family may further decrease their spiritual well-being specifically in finding meaning and peace during

caretaking (Adams, Mosher, Cannady, Lucette, & Kim, 2014). In addition, reciprocal suffering may also emerge when they are trying to fulfill their loved-one's spiritual needs (Buck & McMillan, 2008). Alternately praying to God with great intensity was endorsed by family caregivers to replace the spiritual activities at church (Paiva et al., 2015) even if some family caregivers demonstrated conflicts with God involving anger, disappointment, and positive emotions (Exline, Prince-Paul, Root, & Peereboom, 2013). Taken together, family caregivers of cancer patients are in a desperate situation with the attempt to balance their connections among others, transcendence, and themselves; indeed, as a caretaker, they often make compromises to satisfy their loved ones.

Summary

The dyads of hospice cancer patient and family caregiver are a unique and vulnerable population. Although maintaining their QOL has been emphasized by leading organizations, the presence of depression and unfulfilled spiritual needs among dyads elucidates the needs to examine the current clinical limitations. The integrity of spirituality should be fulfilled serving as a coping mechanism for the coming death, and family members and professionals are required to be involved in order to improve cancer patients' spiritual well-being. However ambiguous definitions of spirituality, insufficient depression screening for dyads, and ineffective communication between clinicians and dyads all could increase the risk to deterioration of QOL. In addition, family caregivers are often not equipped to provide such assistance for their loved ones, and their responsibilities of caregiving may lead them to become co-sufferers due to the fact that they often disregard their own needs, resulting in providing less effective caregiving for patients. Therefore, it is essential for care providers to be aware of the mutual and reciprocal effects regarding depression and unmet spiritual well-being between dyads in order to fulfill the

philosophy of hospice care. Despite knowing the potential mutual effects between dyads and the concept of family-centered care for end-of-life research, there are limited studies considering dyads as one unit while implementing interventions or applying adequate methodologies for investigating the mutual effects of dyads among hospice patients with cancer.

CHAPTER THREE:

METHODS

This chapter delineates how the proposed conceptual model will be verified as well as the implementation procedures, including research design, setting, subject, utilized instruments, and the analysis plan for applying the Actor-Partner Interdependence Model among hospice dyads with cancer.

Research Design

This cross-sectional design is a secondary analysis of data collected from the parent study, a National Institutes of Health R01 funded clinical trial investigating the effectiveness of a systematic assessment of the cancer patient and caregiver dyads in hospice home care settings.

Setting and Subjects

The parent study was conducted at two large private, not-for-profit hospices, Hernando-Pasco Hospice and Tidewell Hospice located in west-central Florida. Each of these facilities provides comprehensive interdisciplinary services from nurses, social workers, counselors, physicians, certified nursing assistants, volunteers, and clergy to patient and family caregiver dyads. Overall, 716 hospice dyads were enrolled in the parent study. According to MacCallum, Widaman, Zhang, and Hong (1999), the sample size estimates for this study should be based on the level of communality, and the current sample size is larger than the recommended sample size of 500 under the worst conditions of low communality. Therefore, the total participants included in this study were feasible and adequate for utilizing a structural

equation modeling approach. Inclusion criteria for patients included (1) be 18 years or older; (2) be diagnosed with cancer; (3) have a primary caregiver who assisted the patient at least 4 hours each day; (4) be able to read and understand English; and (5) be able to pass a mental status screening test. Eligible family caregivers must be 18 years or older without receiving active treatment due to a cancer diagnosis. Patients who were confused, comatose, excessively debilitated or actively dying were excluded.

Instruments for Both Hospice Patients and Caregivers

Center for Epidemiological Study-Depression Scale. The short-form version of the Center for Epidemiological Study-Depression Scale (CES-D), a 10-item self-report instrument, was developed to measure depressive symptomatology in order to improve on the effectiveness of administration in clinical settings and decrease the response burden for elderly and ill patients. The total scores of the instrument ranges from zero to ten using a dichotomy to represent whether the item is present or absent, with the higher scores indicating an increase in depressive symptoms. Cronbach's coefficient alpha of .92 and the correlation coefficient of .88 between original CES-D and the short form of the CES-D suggested that the short-form version of CES-D is both valid and reliable (Irwin, Artin, & Oxman, 1999).

Spiritual Needs Inventory. The Spiritual Needs Inventory (SNI), a 17-item self-report instrument, was designed based on Maslow's theory of motivation to determine the frequency of perceived spiritual needs and whether or not such spiritual needs are met. The initial underlying construct of the SNI contains five subscales, outlook, inspiration, spiritual activities, religion, and community; these were identified using factor analysis in a sample of hospice patients. The total scores of perceived spiritual needs range from 17 to 85 using a Likert-type scale from 1 (never) to 5 (always), and a higher score indicates an increased number

of spiritual neediness. With respect to measuring their unmet spiritual needs, respondents are required to respond to each spiritual needs as met or unmet spiritual needs by answering yes or no. Cronbach's coefficient alpha for the SNI was .85 (Hermann, 2006). Buck and McMillan (2012) utilized this instrument for measuring spiritual needs among family caregivers of hospice patients with cancer, and the results indicated that the underlying factors of the SNI were slightly different from the original population. About 55% of variability could be explained by three factors with the factor alphas ranging from .68 to .89, suggesting that this instrument can be further extended for measuring caregivers' spiritual well-being (Buck & McMillan, 2012).

Patient Instruments

Hospice Quality of Life Index-14. The Hospice Quality of Life Index-14 (HQLI-14) is the short version of the Hospice Quality of Life Index (HQLI) to assess QOL among hospice patients with cancer. The underlying construct of the original 28 items of the HQLI includes psychophysiological (13 items), functional (7 items), and social/spiritual well-being (8 items) (McMillan & Weitzner, 1998). The construct validity was revealed via a weak correlation between the HQLI and the Eastern Cooperative Oncology Group Performance Status Rating ($r = .26, p < .01$) as hypothesized, and the HQLI was able to discriminate between healthy adults and hospice cancer patients with $\lambda = .34, p < .01$. The Cronbach's coefficient alpha estimated for the total scale was .88 and the three subscales ranging from .82 to .83 (Garrison, Overcash, & McMillan, 2011; McMillan & Small, 2002). For the purpose of clinical repeated measurement, the total items of the HQLI was reduced from 28 items to 14 items (McMillan et al., 2011). The HQLI-14 still encompasses three subscales of psychophysiological well-being (six items), functional well-being (four items), and social/spiritual well-being (four items) using an 11-point summated rating scale with the total scores ranging from 0 (worst QOL) to 140 (highest QOL).

The construct validity of the HQLI-14 revealed from the parent study that the relationship between the subscales of the HQLI and the HQLI-14 were significantly correlated as follows: psychophysiological well-being ($r = .90, p < .01$), functional well-being ($r = .96, p < .01$), and social/ spiritual well-being ($r = .89, p < .01$). Cronbach's coefficient alpha for the total tool and subscales of psychophysiological well-being, functional well-being, and social/spiritual well-being were .77, .68, .72, and .82, respectively (Garrison et al., 2011).

Family Caregivers Instruments

The Short-Form 12 Health Survey. The Short-Form 12 Health Survey (SF-12) is the short version of the SF-36 Health Survey containing 36 items to measure physical and mental health on eight dimensions including physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. The SF-12 self-report generic instrument was utilized in the study to measure caregivers' perspectives about their own physical health (six items) and mental health (six items) as a proxy measure for QOL. The Cronbach's coefficient alpha for the subscales of the SF-36 for physical functioning and general health perception were .93 and .81, respectively (SF-36.org, n.d.).

Demographic data

The demographic data from dyads includes age, gender, ethnicity, race, marital status, religious affiliation, education, and the relationship between dyads. Additional data from patients include their primary diagnosis.

Procedures

After obtaining approval for the parent study from both the hospices and university institutional review board (IRB), potential participant and caregiver dyads were identified and approached by the research assistants within 24 hours of admission to hospice. Once dyads

agreed to participate in the parent study and consented, the dyads were screened by research assistants using the short portable mental status questionnaire for ruling out cognitive impairment of dyads. Eligible dyads who met the inclusion criteria were randomly assigned to either experimental or control conditions. In order to understand the effectiveness of the intervention, all dyads were required to complete the baseline questionnaires, and post-intervention data was collected after the intervention was completed.

Only the baseline data were analyzed in the current study after the approval for this secondary data analysis by the IRB of the University of South Florida. Once IRB approval was granted, the principle investigator 1) had meetings with team members of the parent study to understand the detailed recruitment process, findings, and difficulties while conducting the parent study; 2) scrutinized the completeness of the data from the parent study, such as missing data and violations that might influence the data analysis.

Statistical Analysis Plan

Descriptive statistics including frequencies, percentages, means and standard deviations were calculated to describe the sample and also utilized to screen for univariate and multivariate normality and outliers using IBM SPSS Statistics 22. To verify the proposed hypotheses through Hypothesis one to Hypothesis eight, structural equation modeling were performed by using LISREL 9.1, a statistical package for structural equation modeling (Jöreskog & Sörbom, 1996) after the preliminary analysis regarding missing values and outliers was complete.

In terms of model evaluation as recommended by Jackson, Gillaspay, and Purc-Stephenson (2009), the quality of structural models should be assessed via multiple fit indices and different types of fit statistics. Kline (2010) categorized these fit indices into the following: absolute, incremental, residual-based, and population-based; therefore, the following fit statistics

were selected accordingly, as each fit index reflected different measurement properties: the χ^2 minimum fit function as well as practical fit indices, such as the goodness of fit index (GFI; range from zero to one, values of .9 are desired), the adjusted goodness of fit (AGFI; range from zero to one, values of .9 are desired) (Jöreskog & Sörbom, 1996), the comparative fit index (CFI; range from 0 to 1, values of .9 are desired) (Bentler, 1990), the standardized root mean square residual (SRMR; range from 0 to 1, values of .08 or less are desired) (Hu & Bentler, 1999), and the root mean square error of approximation (RMSEA; range from 0 to 1, values of .08 or lower are desired) (Browne & Cudeck, 1993).

CHAPTER FOUR:

RESULTS

This chapter presents the analysis procedures and results when performing structural equation modeling, including data preparation, description of the sample, assessment of measurement model, and assessment of the structural model. To verify the hypotheses proposed in this study, the two primary independent latent variables, depression and spirituality, are described separately.

Data Preparation

Data were initially screened by calculating univariate descriptive statistics including means, standard deviations, and frequencies to inspect missing data, out-of-range values, and univariate outliers for accuracy of data input. The original sample consisted of 716 dyads, and 117 (16.3%) dyads were found to have missing values on the indicators of depression, spiritual needs, and QOL. Dyads were eliminated if either member of the dyads did not respond completely to either the measures of depression, spiritual needs, or QOL; therefore, 40 (5.6%) dyads were dropped, leaving 677 dyads along with less than one percent of the missing values on the indicators of the latent variables. In addition, 17 (2.5%) dyads were removed as these were identified as multivariate outliers based on the Mahalanobis distance with the critical value of $\chi^2(66) = 107.26, \alpha < .001$. Multiple imputation was then employed to estimate missing values through the method of Markov chain Monte Carlo to generate 20 complete imputed datasets. Furthermore, ten dichotomous indicators of the CES-D were rescaled into two continuous

indicators by randomly selecting five out of ten items and summing the respective items for each indicator. By means of making two parcels for each member of the dyads as described above, the new indicators of the CES-D were closely normally distributed, and the degree of skewness and kurtosis met the criterion of ± 1 . With regard to indicators with a high degree of kurtosis, Benson and Fleishman (1994) found that maximal likelihood estimation was still considered robust when all of the indicators were moderate departures from normality. Although an alternative method to estimating non-normality data was available, such as asymptotically distribution-free estimation, this estimation would perform poorly when the sample size was less than 2500 (Ullman, 2007). Taken together, no specific data preparation for the non-normality was implemented, as about half of the indicators were closely normally distributed with less than one absolute value in skewness and kurtosis and none of the indicators reached a problematic and severe kurtosis of 10 (Kline, 2010). Descriptive statistics, including means, standard deviations, skewness, and kurtosis of the indicator variables after the imputation, are shown in Table 1.

Table 1

Descriptive Statistics for the Indicator Variables

Latent Variables/Corresponding Indicators	<i>M</i>	<i>SD</i>	Skewness	Kurtosis	α
Pt_Dep1	1.44	1.23	0.60	-0.53	.60
Pt_Dep2	1.49	1.28	0.48	-0.81	
Fc_Dep1†	1.33	1.22	0.71	-0.27	
Fc_Dep2†	1.54	1.20	0.45	-0.56	
Functional Well-Being					
HQLI_3	5.51	3.37	-0.13	-1.19	.59
HQLI_7	7.08	2.71	-0.68	-0.39	
HQLI_8	5.31	3.09	-0.14	-0.97	
HQLI_9	6.09	3.39	-0.41	-1.08	
Social/Spiritual Well-Being					.53
HQLI_10†	9.46	1.18	-2.64	7.33	
HQLI_11†	9.23	1.43	-2.28	5.84	
HQLI_12†	8.70	2.09	-1.91	3.68	
HQLI_13†	9.06	1.56	-2.14	5.27	
Psycho-Physiological Well-Being					.80
HQLI_1	6.72	2.65	-0.47	-0.52	
HQLI_2	6.82	2.90	-0.58	-0.65	
HQLI_4	7.05	3.36	-0.75	-0.79	
HQLI_5†	7.45	2.79	-0.87	-0.20	
HQLI_6	5.68	3.34	-0.30	-1.06	.70
HQLI_14†	8.36	2.14	-1.42	1.78	
Physical Health					
SF1†	3.39	1.06	-0.22	-0.57	
SF2†	1.59	0.67	-1.35	0.49	
SF3†	1.36	0.81	-0.74	-1.08	.90
SF4†	0.67	0.47	-0.73	-1.46	
SF5	0.70	0.46	-0.85	-1.28	
SF8†	3.10	1.20	-1.16	0.27	
Mental Health					
SF6	0.55	0.50	-0.20	-1.97	.90
SF7	0.77	0.42	-1.30	-0.30	
SF9†	2.69	1.38	-0.29	-0.85	
SF10†	2.78	1.38	-0.28	-0.80	
SF11†	3.18	1.33	-0.63	-0.14	
SF12†	2.57	1.48	-0.50	-1.20	.90
Religious Needs					
SNI_P1†	2.53	1.44	0.35	-1.24	
SPI_P3†	2.21	1.49	0.81	-0.84	
SNI_P6†	2.46	1.47	0.49	-1.18	
SNI_P8†	2.30	1.45	0.66	-1.00	
SNI_P9†	2.07	1.40	0.99	-0.45	

Table 1

Descriptive Statistics for the Indicator Variables (Continued)

Latent Variables/Corresponding Indicators	<i>M</i>	<i>SD</i>	Skewness	Kurtosis	α
SNI_P11†	2.67	1.55	0.24	-1.47	
SNI_P12†	3.57	1.56	-0.64	-1.15	
SNI_P13†	2.52	1.65	0.43	-1.50	
SNI_P17†	2.20	1.49	0.26	-1.17	
Outlook Needs					.74
SNI_P2	3.93	1.04	-0.84	0.31	
SNI_P5†	3.71	1.21	-0.75	-0.22	
SNI_P14†	4.12	0.98	-1.22	1.46	
SNI_P15†	3.83	1.22	-0.93	-0.05	
SNI_P16	4.11	1.12	-1.35	1.23	
Community Needs					
SNI_P4	4.35	0.89	-1.39	1.73	
SNI_P7†	3.85	1.21	-1.03	0.30	
SNI_P10	3.06	1.53	-0.09	-1.44	
Religious Needs					
SNI_C1	2.81	1.37	-0.94	0.83	
SNI_C3	2.50	1.47	-1.13	0.86	
SNI_C6†	2.63	1.38	0.30	-1.11	
SNI_C8†	2.66	1.43	0.27	-1.24	
SNI_C9	2.63	1.52	0.31	-1.36	
SNI_C11	2.79	1.48	0.15	-1.36	
SNI_C12†	3.93	1.39	-1.07	-0.23	
SNI_C13	2.74	1.61	0.23	-1.53	
SNI_C17	2.52	1.53	0.48	-1.27	
Outlook Needs					
SNI_C2	4.09	0.91	0.49	-1.16	
SNI_C5	3.74	1.09	-0.66	-0.09	
SNI_C14†	4.20	0.94	-1.21	1.41	
SNI_C15†	4.05	1.04	-1.07	0.77	
SNI_C16†	4.29	0.91	-1.39	1.97	
Community Needs					
SNI_C4	4.15	1.00	-0.66	-0.09	
SNI_C7†	4.08	1.07	-1.15	0.79	
SNI_C10	3.54	1.32	-0.49	-0.86	
Unmet Spiritual Needs					
Pt_unmet†	1.09	1.68	2.33	7.19	
Fc_unmet†	1.23	1.96	2.27	6.17	

Note. N = 660. †Variable's mean, standard deviation, skewness, and kurtosis were calculated based on 20 imputed datasets. Pt_Dep = Depression in hospice patients. Fc_Dep = Depression in family caregivers. HQLI = Hospice Quality of Life Index. SPI_P = Spiritual Needs Inventory in hospice patients. SNI_C = Spiritual Needs Inventory in family caregivers.

Description of the Sample

A total of 660 distinguishable hospice dyads were included for the analysis in which most dyads were spousal pairs (56.8%) followed by mother-daughter pairs (10.6%). The majority of the hospice patients were white (97%) and male (56.6%) with a primary diagnosis of lung cancer (34%), and 95.9% of family caregivers were white (95.9%) and female (73.5%). Hospice patients and family caregivers had a mean age of 72.67 ($SD = 12.19$, range = 21–95 years) and 65.49 years ($SD = 13.81$, range = 19–97 years), respectively. On average, hospice patients had been diagnosed with cancer for 2.21 years ($SD = 3.89$) at the time of recruitment, and the average patient depression score on the CES-D was 4.00 ($SD = 1.53$). In contrast, their family caregivers had a significantly lower mean depression score of 3.65 ($SD = 1.48$) on the CES-D ($t(658) = 4.22$, $p < .01$). In addition, about 85% of the dyads revealed themselves as Christians, and the degree of perceived spiritual needs in hospice patients ($M = 53.49$, $SD = 14.37$, possible range = 17–85) were significantly lower than their family caregivers ($M = 57.35$, $SD = 13.61$; $t(658) = 5.02$, $p < .01$). Of these 17 spiritual needs, cancer patients and family caregivers reported a mean of 1.08 ($SD = 1.67$) and 1.22 ($SD = 1.96$) unmet needs, respectively. According to the structure of the SNI, hospice patients and family caregivers required more spiritual needs associated with the community needs and outlook needs in order to fulfill their lives fully, such as being with family ($M = 4.35$ vs 4.15), thinking happy thoughts ($M = 4.12$ vs 4.20), and seeing smiles of others ($M = 4.11$ vs 4.29). The primary unmet spiritual needs identified by the hospice patients were going to religious services (25.5%) and being with friends (9.8%). Most of the family caregivers revealed that going to religious services (13.1%), thinking happy thoughts (13.0%), laughing (12.6%), and being with friends (12.3%) were their primary unmet spiritual needs (Table 3).

Table 2

Frequency and Percent of Patients and Caregivers by Gender, Marital Status, Ethnicity, and Religious Affiliation

Variables	Hospice Patients with Cancer Frequency (%)	Family Caregivers Frequency (%)
Gender		
Male	373 (56.6%)	175 (26.5%)
Female	286 (43.4%)	485 (73.5%)
Unknown	1 (0.2%)	0 (0%)
Marital Status		
Currently Married	416 (63.2%)	507 (77.1%)
Widowed	121 (18.3%)	50 (7.6%)
Divorced	79 (12.0%)	66 (10.0%)
Never Married	34 (5.2%)	31 (4.7%)
Separated	8 (1.2%)	4 (0.6%)
Unknown	2 (0.3%)	2 (0.3%)
Ethnicity		
Caucasian	640 (97.0%)	633 (95.9%)
African American	10 (1.5%)	9 (1.4%)
Hispanic	7 (1.1%)	10 (1.5%)
Others	2 (0.3%)	4 (0.6%)
Asian/Pacific Islander	1 (0.2%)	4 (0.6%)
Religion Affiliation		
Non-Catholic Christian	372 (56.5%)	372 (56.7%)
Catholic Christian	187 (28.3%)	189 (28.8%)
Agnostic	90 (13.6%)	83 (12.6%)
Jewish	7 (1.1%)	10 (1.5%)
Others	4 (0.6%)	6 (0.9%)

Note. $N = 660$.

Table 3

Spiritual Needs within Dyads

Item	Hospice Patients		Family Caregivers	
	<i>M</i> (<i>SD</i>)	Need not being met (%)	<i>M</i> (<i>SD</i>)	Need not being met (%)
Go to religious services	2.52 (1.65)	25.5	2.74 (1.61)	13.1
Be with friends	3.71 (1.21)	9.8	3.74 (1.09)	12.3
Laugh	3.93 (1.04)	9.6	4.09 (0.91)	12.6
Think happy thoughts	4.12 (0.98)	8.2	4.20 (0.94)	13.0
Be around children	3.06 (1.53)	8.1	3.54 (1.32)	9.0
Be with family	4.35 (0.89)	7.7	4.15 (1.00)	9.7
Talk with someone about spiritual beliefs	2.46 (1.47)	6.2	2.63 (1.38)	6.1
Read a religious text	2.21 (1.49)	5.8	2.50 (1.47)	6.2
Read inspirational materials	2.30 (1.45)	5.5	2.66 (1.43)	6.5
Sing or listen to music	2.53 (1.44)	4.7	2.81 (1.37)	5.6
See smiles of others	4.11 (1.12)	4.5	4.29 (0.91)	8.7
Be with people who share spiritual beliefs	2.67 (1.55)	3.5	2.79 (1.48)	4.5
Have information about family and friends	3.85 (1.21)	2.9	4.08 (1.07)	2.9
Talk about day to day things	3.83 (1.22)	1.8	4.05 (1.04)	6.2
Use inspirational materials	2.07 (1.40)	1.5	2.63 (1.52)	3.2
Use phrases from religious texts	2.20 (1.49)	1.1	2.52 (1.53)	3.5
Pray	3.57 (1.56)	1.1	3.93 (1.39)	0.6

Note. *N* = 660. Means and standard deviations were calculated based on 20 imputed datasets.

Assessment of the Measurement Model of Depression

The proposed model based on the Actor-Partner Interdependence Model was depicted in Figure 2, specifying relationships between the exogenous latent variable, depression, and the endogenous latent variable, QOL, along with the corresponding indicators. Prior to verifying the proposed Hypotheses one and two, the measurement model of depression was assessed through confirmatory factor analysis to understand the factorial validity and reliability of the measures as the structure of the CES-D changed by means of parceling. Each indicator of the latent variables, including depression and QOL, was specified to load on one corresponding factor, and

each latent variable correlated with every other latent variables. Maximum likelihood method was then utilized to estimate parameters on the correlation matrix of the indicators (Appendix B) along with means and standard deviations. In addition, the most representative indicators under each latent variable were specified as reference variables, or marker variables, by fixing lambda (λ) coefficients of the indicators to one, so that the unit of measurement was defined for each latent variable with the same variance as marker variables. The results of the confirmatory factor analysis revealed that the measurement model of depression fit the data reasonably based on the χ^2 minimum function ($\chi^2 = 1077.46$, $df = 384$, $p < .01$), and the goodness of fit indices were all in the desired ranges (RMSEA = .05, SRMR = .05, CFI = .86, GFI = .90, and AGFI = .88) (Table 4: Model 1). Even though the significant χ^2 minimum function could lead to rejecting the model, the χ^2 test was overly sensitive with the larger sample size. Therefore, the practical indices as listed above with desirable values were helpful to determine how well the model fit the data. Furthermore, such results confirmed the two indicators of the depression latent variables as a result of parceling were able to provide reliable measures as each composite reliability of depression in hospice patients and family caregivers was .69 and .71, which were over the favorable values of .6 (Bagozzi & Yi, 1988).

Despite the acceptable χ^2 minimum function and goodness of fit, the modification index provided by LISREL indicated the initial measurement model could be improved if the previously fixed indicator, SF10, “Do you have a lot of energy”, could cross-load on the other latent variable as well. That is, this indicator could be influenced by two underlying factors, and such change was observed in the previous research, showing relatively equivalent standardized factor loadings on both the mental and physical health in other populations (Okonkwo, Roth, Pulley, & Howard, 2010). Hence, the factor structure of the SF-12 was modified, and the second

measurement model of depression was estimated and compared to the previous model by using the likelihood-ratio test (Model 2 in Table 4). Freeing the additional parameter resulted in significant improvement in the χ^2 minimum function ($\Delta\chi^2(\Delta df) = 84.99(1), p < .01$), and the fit indices also improved (RMSEA = .05, SRMR = .05, CFI = .88, GFI = .91, and AGFI = .89). Consequently, the factor structure of the SF-12 with one additional cross-loading parameter was applied to the following analysis to examine the proposed causal model, as depicted in Figure 2.

Assessment of the Structural Model of Depression

To address research hypotheses one to four relating to the impact of depression on patient and caregiver QOL, structural equation modeling was employed, as it would estimate the actor and partner effects of depression on QOL, as well as how much of the variance in the subscales of QOL could be explained by depression. Figure 2 illustrated that QOL was regressed on depression; in particular, the curved arrow between the hospice patients' and family caregivers' depression latent variables would account for nonindependence by measuring its Pearson product-moment correlation. The χ^2 minimum function and the fit indices indicated the proposed structural model was consistent with the observed data ($\chi^2 = 1029.02, df = 393, p < .01$; RMSEA = .05, SRMR = .05, CFI = .87, GFI = .90, and AGFI = .89); however, with further inspection of the structural coefficients, such results only supported part of the hypotheses in which hospice patients' depression had significant actor effects on their own QOL with respect to their functional well-being ($\beta = -.84, p < .05$), psychophysiological well-being ($\beta = -.93, p < .05$), and social/spiritual well-being ($\beta = -.39, p < .05$), whereas depression of hospice patients had non-significant partner effects on their family caregivers' physical and mental health (Table 5). Similarly, depression experienced by family caregivers had significant actor effects on their own physical ($\beta = -.33, p < .05$) and mental health ($\beta = -.95, p < .05$) but had a non-significant

partner effect on hospice patients' QOL (Table 5). The depression scores of the members of the dyads were significantly correlated ($r = .13, p < .05$), and such a weak correlation would explain why none of the partner effects were significantly associated within dyads. Approximately 70%, 87%, 15%, 11%, and 90% of the variance in the functional, psychophysiological, social/spiritual well-being, physical health, and mental health was accounted for by the depression experienced in dyads, suggesting that depression specifically had a substantial negative impact on the functional and psychophysiological well-being of patients and the mental health of family caregivers. All the estimated path coefficients are displayed in the form of standardized parameters in Table 5.

Post-Hoc Analysis of Depression in Spousal Dyads

With the interest of knowing potential differences in regard to different relationships in dyads, the post hoc analysis was performed to understand whether the proposed actor effects and partner effects could exist in spouses rather than other close relationships. The procedures as detailed above were followed, and the measurement model of depression in spouses was evaluated using a maximum likelihood estimation on the correlation matrix with the corresponding means and standard deviations. The modification index consistently suggested that the initial measurement model of depression in spouses should also cross-load for the indicator, SF10, on the physical health latent variable, and the second model with the additional path fit the data better as reflected in the decreased values of the χ^2 minimum function and fit indices ($\Delta\chi^2(\Delta df) = 43.01(1), p < .01$; RMSEA = .05, SRMR = .06, GFI = .88, AGFI = .86, and CFI = .87) (Table 4: Models 4 and 5). The proposed causal model for the spouses was then verified, and, similarly, depression in patients exhibited negatively significant actor effects on their own QOL in relation to the psychophysiological well-being ($\beta = -.92, p < .05$), functional

well-being ($\beta = -.88, p < .05$), and social/spiritual well-being ($\beta = -.41, p < .05$), but there were no significant partner effects of depression in patients on their family caregivers' physical ($\beta = .09, p > .05$) and mental health ($\beta = .10, p > .05$). Surprisingly, depression in family caregivers not only had significantly positive actor effects on their own physical health ($\beta = -.26, p < .05$) and mental health ($\beta = -.97, p < .05$), but also had a significant partner effect on the hospice patients' functional well-being ($\beta = .15, p < .05$). In addition, the degree of positive correlation within spousal dyads' depression scores was slightly higher than the overall dyads ($r = .18, p < .05$) (Figure 2).

Assessment of the Measurement Model of Spirituality

For the proposed Hypotheses five to eight relating to the impact of spiritual needs on QOL, the little variance of the *unmet* spiritual needs in hospice patients ($M = 1.08$; $SD = 1.67$) and caregivers ($M = 1.22$; $SD = 1.96$), indicating that only one out of 17 spiritual needs were unmet. The measurement model of spirituality was therefore modified to examine the association between the degree of perceived spiritual needs and QOL in dyads. However, the factor structures of the SNI within dyads were slightly different in which a five-factor solution was extracted in hospice patients with cancer (Hermann, 2006), and a three-factor solution was extracted in family caregivers of advanced cancer patients (Buck & McMillan, 2012). Specifically, in the five-factor solution assessed in patients, three factors (inspiration, spiritual activities, and religion) were collapsed into one of the three factors in family caregivers, and the other two factors, outlook and community, remained the same with only two items loaded differently. Buck, Overcash, and McMillan (2009) also identified measurement issues related to the five factors solution of the SNI in hospice patients. Thus, for the sake of simplicity, the

three-factor solution was utilized to verify whether the construct of the SNI was appropriate for both members of the dyads.

The measurement model of spirituality was evaluated to understand the relationships between the latent variables and their corresponding indicators. The results of the confirmatory factor analysis revealed that the measurement model of spirituality fit the data appropriately with the χ^2 minimum function = 3235.90, $df = 1655$, $p < .01$ and reasonable goodness of fit indices (RMSEA = .04, SRMR = .05, GFI = .86, AGFI = .84, and CFI = .88). The modification index constantly suggested the indicator, SF10, cross-load on the physical health as the previous models; therefore, based on the significant improvement in the χ^2 minimum function ($\Delta\chi^2(\Delta df) = 78.24 (1), p < .01$) as well as the improved goodness of fit indices in RMSEA = .04, SRMR = .05, GFI = .86, AGFI = .85, and CFI = .88, the following causal model incorporating the extra path connecting from the physical health latent variable to the SF10 was verified for Hypotheses five to eight.

Assessment of the Structural Model of Spirituality

The summary of model fit statistics appears in Table 4: Model 9. Although the proposed causal model of spirituality fit the data reasonably, only actor effects exhibited in which outlook needs in patients significantly predicted their own functional well-being ($\beta = .40, p < .05$) and social/spiritual well-being ($\beta = .61, p < .05$) (Table 8). In addition, two family caregivers actor effects exhibited as family caregivers' mental health were significantly predicted by their own outlook needs ($\beta = .43, p < .05$) and community needs ($\beta = -.29, p < .05$) (Table 8). A review of phi matrix revealed that there were significant relationships between dyads in the religious needs ($r = .38, p < .05$) and community needs ($r = .23, p < .05$) with the exception of the outlook needs ($r = .06, p > .05$), indicating that dyads would mutually influence their partners' needs in religion

and community. In terms of post-hoc analysis for spirituality, because there were 60 indicators involved, 375 spousal dyads were not sufficient for such a complex model; thus, the post-hoc analysis did not proceed to test Hypotheses five to eight in the spousal pairs.

Table 4

Summary of Model Fit Statistics

Model	Discrepancy					
	$\chi^2(df)$	RMSEA	SRMR	CFI	GFI	AGFI
Depression						
1. Measurement model	1077.46 (384)*	.05	.05	.86	.90	.88
2. Measurement model with SF10	992.47 (383)*	.05	.05	.88	.91	.89
3. Full Model with SF10	1029.02 (393)*	.05	.05	.87	.90	.89
Depression in Spouses						
4. Measurement model	772.00 (384)*	.05	.06	.86	.88	.85
5. Measurement model with SF10	728.99 (383)*	.05	.06	.88	.88	.86
6. Full Model with SF10	746.56 (393)*	.05	.06	.87	.88	.86
Spirituality						
7. Measurement model	3235.90(1655)*	.04	.05	.88	.86	.84
8. Measurement model with SF10	3157.66(1654)*	.04	.05	.88	.86	.85
9. Full Model with SF10	3178.84(1660)*	.04	.05	.88	.86	.84

Note. χ^2 = minimum fit function test; RMSEA = root mean square error of approximation; SRMR = standardized root mean square residual; CFI = comparative fit index; GFI = goodness of fit index; AGFI = adjusted goodness of fit index. * $p < .05$.

Table 5

Factor Loadings for the Structural Model of Depression in the Overall Dyads (Model 3)

Item	<u>Exogenous Variables</u>		<u>Endogenous Variables</u>				PCS	MCS
	Dep_Pt	Dep_CG	Functional W-B	Social/ Spiritual W-B	Psycho- Physiological W-B			
Pt_Dep1	.68†							
Pt_Dep2	.67 (.08)							
Fc_Dep1		.75 (.06)						
Fc_Dep2		.73†						
HQLI_3			.42†					
HQLI_7			.54 (.13)					
HQLI_8			.64 (.17)					
HQLI_9			.53 (.16)					
HQLI_10				.72†				
HQLI_11				.60 (.10)				
HQLI_12				.39 (.13)				
HQLI_13				.48 (.10)				
HQLI_1					.39†			
HQLI_2					.26 (.14)			
HQLI_4					.23 (.16)			
HQLI_5					.67 (.22)			
HQLI_6					.47 (.21)			
HQLI_14					.27 (.11)			
SF1						.60 (.05)		
SF2						.72 (.03)		
SF3						.64 (.04)		
SF4						.70 (.02)		
SF5						.78 (.02)		
SF8						.71†		
SF6							.53 (.04)	
SF7							.44 (.03)	
SF9							.72 (.13)	
SF10						.38 (.07)	.38 (.10)	
SF11							.70 (.13)	
SF12							.47†	

Note. $N = 660$. Standard errors are in parentheses. †Marker variables. All factor loadings were significant. Pt_Dep = Depression in patients; Fc_Dep = Depression in family caregivers; HQLI_1 to HQLI_14 are the indicators of the Hospice Quality of Life Index; SF1 to SF12 are the indicators of the Short-Form 12 Health Survey; Dep_Pt = Depression latent variable in patients; Dep_CG = Depression latent variable in family caregivers; W-B = Well-Being; PCS = Physical health; MCS = Mental health.

Table 6

Factor Loadings for the Structural Model of Spiritual Needs in the Overall Dyads (Model 9)

Item	<u>Exogenous Variables</u>					
	Religious Needs_P	Outlook Needs_P	Community Needs_P	Religious Needs_FC	Outlook Needs_FC	Community Needs_FC
SNI_P3	.82 (.06)					
SNI_P17	.77 (.06)					
SNI_P6	.78 (.06)	.				
SNI_P9	.68 (.05)					
SNI_P8	.75 (.05)					
SNI_P13	.69 †					
SNI_P1	.56 (.05)					
SNI_P11	.69 (.06)					
SNI_P12	.64 (.06)					
SNI_P14		.62 †				
SNI_P2		.58 (.09)				
SNI_P16		.64 (.10)				
SNI_P15		.57 (.10)				
SNI_P5		.60 (.10)				
SNI_P10			.61 (.21)			
SNI_P4			.51 †			
SNI_P7			.61 (.16)			
SNI_C3				.82 (.06)		
SNI_C17				.78 (.06)		
SNI_C6				.77 (.05)		
SNI_C9				.73 (.06)		
SNI_C8				.74 (.05)		
SNI_C13				.69 †		
SNI_C1				.57 (.05)		
SNI_C11				.69 (.06)		
SNI_C12				.65 (.05)		
SNI_C14					.72 †	
SNI_C2					.57 (.06)	
SNI_C16					.72 (.06)	
SNI_C15					.62 (.07)	
SNI_C5					.45 (.07)	
SNI_C10						.64 (.11)
SNI_C4						.66 †
SNI_C7						.63 (.09)

Table 6

*Factor Loadings for the Structural Model of Spiritual Needs in the Overall Dyads (Model 9)**(Continued)*

Item	<u>Endogenous Variables</u>			PCS	MCS
	Functional W-B	Social/ Spiritual W-B	Psycho- Physiological W-B		
HQLI_3	.42 †				
HQLI_7	.54 (.13)				
HQLI_8	.64 (.17)				
HQLI_9	.52 (.16)				
HQLI_10		.62 †			
HQLI_11		.55 (.12)			
HQLI_12		.46 (.16)			
HQLI_13		.56 (.13)			
HQLI_1			.37 (.22)		
HQLI_2			.30 †		
HQLI_4			.30 (.25)		
HQLI_5			.62 (.34)		
HQLI_6			.48 (.33)		
HQLI_14			.31 (.16)		
SF1				.59 †	
SF2				.73 (.06)	
SF3				.65 (.06)	
SF4				.70 (.04)	
SF5				.78 (.04)	
SF8				.71 (.10)	
SF6					.54 †
SF7					.44 (.08)
SF9					.75 (.33)
SF10				.36 (.09)	.41 (.25)
SF11					.64 (.29)
SF12					.48 (.29)

Note. $N = 660$. Standard errors are in parentheses. †Marker variables. All factor loadings were significant. P = Hospice patients with cancer; FC = Family caregivers; SNI_P1 to SNI_P17 are the indicators of the Spiritual Needs Inventory among hospice patients. SNI_C1 to SNI_C17 are the indicators of the Spiritual Needs Inventory among family caregivers. HQLI_1 to HQLI_14 are the indicators of the Hospice Quality of Life Index; SF1 to SF12 are the indicators of the Short-Form 12 Health Survey; W-B = Well-Being; PCS = Physical health; MCS = Mental health.

Table 7

Standardized Structural Coefficients between Depression and QOL in the Overall Dyads

Factors	Functional W-B	Psycho- Physiological W-B	Social/ Spiritual W-B	PCS	MCS
Depression in Patients	-.84 (.17)*	-.93 (.14)*	-.39 (.06)*	.08 (.05)	.04 (.03)
Depression in Family caregivers	.04 (.08)	-.05 (.06)	.02 (.05)	-.33 (.05)*	-.95 (.07)*

Note. $N = 660$. Standard errors are in parentheses. W-B = Well-Being; PCS = Physical health; MCS = Mental health; * $p < .05$.

Table 8

Standardized structural coefficients between Spiritual Needs and QOL in the Overall Dyads

Factors	Functional W-B	Psycho- Physiological W-B	Social/ Spiritual W-B	PCS	MCS
Hospice patients		Actor Effects		Partner Effects	
Religious Needs	-.01 (.10)	.08 (.06)	.01 (.05)	.07 (.04)	.08 (.02)
Outlook Needs	.40 (.47)*	.11 (.28)	.61 (.25)*	-.15 (.17)	-.10 (.08)
Community Needs	-.26 (.71)	-.17 (.43)	-.30 (.37)	.20 (.26)	.06 (.12)
Family Caregivers		Partner Effects		Actor Effects	
Religious Needs	.06 (.10)	-.02 (.06)	.10 (.05)	-.13 (.04)	-.05 (.02)
Outlook Needs	-.09 (.26)	.13 (.16)	-.13 (.13)	.12 (.10)	.43 (.05)*
Community Needs	.16 (.33)	.08 (.20)	.23 (.17)	.02 (.12)	-.29 (.06)*

Note. $N = 660$. Standard errors are in parentheses. W-B = Well-Being; PCS = Physical health; MCS = Mental health; * $p < .05$.

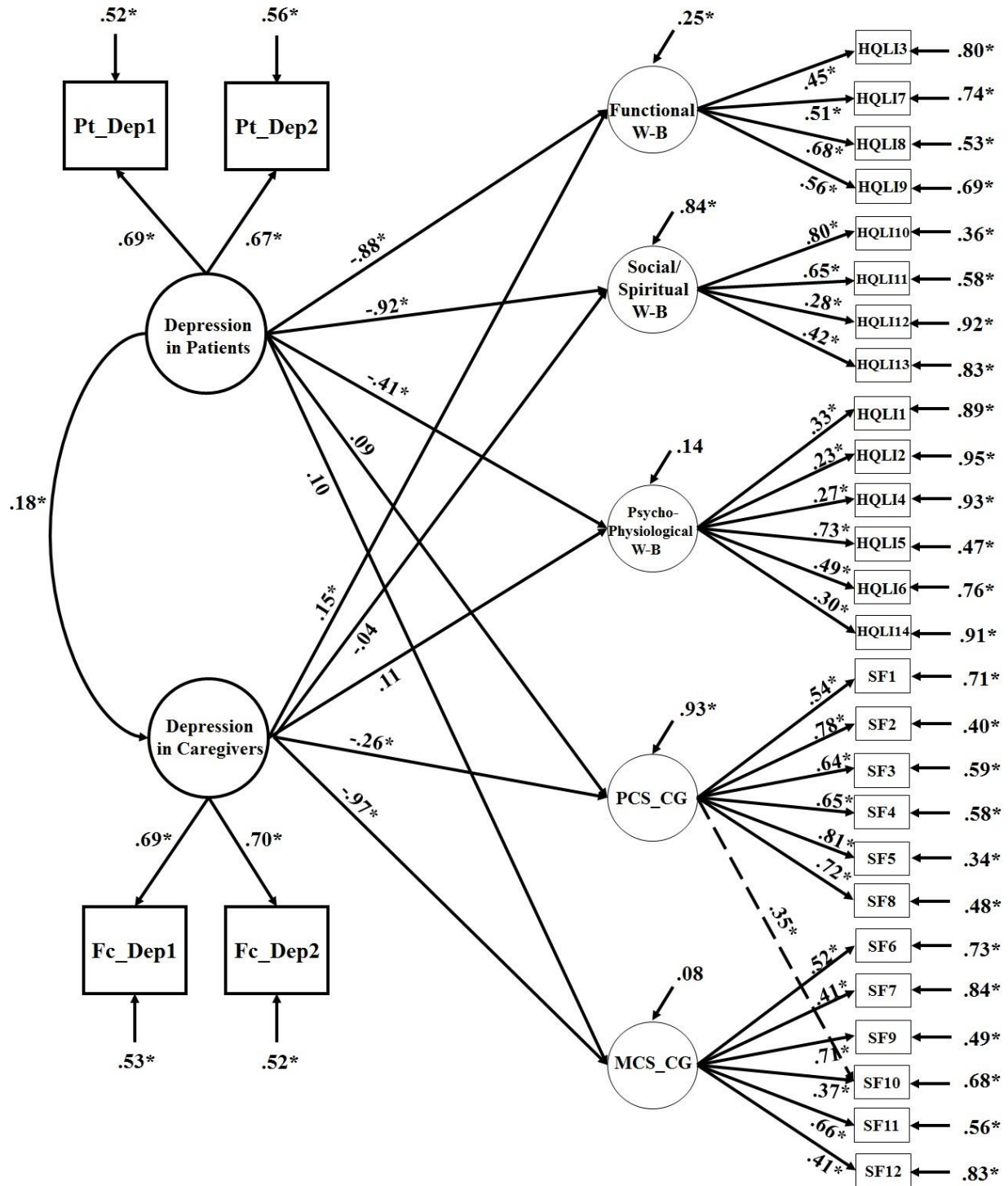


Figure 2. The Structural Model of Depression and Quality of Life in the Spousal Pairs.

CHAPTER FIVE:

DISCUSSION

This chapter first articulates the importance of mutuality in hospice dyads followed by the discussion of the study's results, limitations, implications for nursing, and future directions for research.

Mutuality in Hospice Dyads

Mutuality between patients and family caregivers has been increasingly recognized over the past 10 years, and accumulative, yet limited evidence has been found regarding the cross-over effects of cancer patients on family caregivers or vice versa (Kim et al., 2015; Park & Schumacher, 2014). Despite the emphasis of including family caregivers in hospice care and cancer research, potential challenges in relation to the recruitments, lack of clear definition of mutuality and theoretical framework, and sophisticated statistical analyses might limit the development of dyadic research, and therefore most studies primarily focus on individuals instead of pairs (Fletcher, Miaskowski, Given, & Schumacher, 2012; Park & Schumacher, 2014). Therefore, taking into consideration mutuality within hospice dyads, the purpose of this study was to apply the Actor-Partner Interdependence Model serving as a conceptual and analytic model to verify the effects of depression and spiritual needs on patients' and caregivers' QOL.

A total of nine models, including post-hoc analysis, were examined in the study, and the χ^2 minimum fit function and practical fit indices revealed these nine models fit the data reasonably, indicating the appropriateness of the conceptual model applied in the study. Also,

such results successfully confirmed some of the hypotheses and signified the need of considering mutuality inherent in dyads. After controlling for the partner effects, this study identified the significant actor effects of depression on their own QOL in hospice patients (Hypothesis one) and the family caregivers (Hypothesis two), suggesting that elevated depressive symptoms were associated with lower QOL in both patients and family caregivers. These two actor effects were routinely examined and supported by studies that focused exclusively on hospice patients (Garrison et al., 2011) or family caregivers (Fletcher et al., 2008). However, with respect to the partner effects that most studies ignored, there were no significant partner effects of depression on QOL found in the overall dyads (Hypotheses three and four), and this may be due to the weak correlation between dyads' depression scores of .13. Similar results were found in a longitudinal study of colorectal and lung cancer dyads. Kim et al. (2015) also identified the weak correlation of .17 between lung cancer dyads' depression scores, and depression only predicted individuals' physical and mental health as actor effects after controlling for partner effects in the spouses. Despite the absence of partner effects of depression exhibited in the overall sample, the subgroup analysis revealed a partner effect existing in the spousal pairs in which the higher depression in family caregivers had a significant positive impact on patients' functional well-being. Even though the negative direct effect of depression in hospice patients was relatively greater than the positive partner effect of depression in family caregivers on patients' QOL, such a surprising result extended the current knowledge and warranted further investigations to facilitate the explanation of the finding. In this study, the short version of the HQLI contained four items to reflect functional well-being, including the level of eating, concentration, independence, and enjoyable activities. These activities did not seem to require family caregivers be extensively involved with hospice patients, especially when hospice patients' conditions at the time of

enrollment could still allow them to perform the activities without family caregivers' assistance. In particular, hospice patients still desired to maintain their social role in the family and not rely completely on their family caregivers (Murray et al., 2004). On the other hand, family caregivers' adverse physical and mental conditions due to depression could interfere with their engagement of care for their loved ones. In a study of heart failure dyads, it was found that the more anxiety family caregivers experienced, the lower self-care management they engaged in (Buck, Mogle, Riegel, McMillan, & Bakitas, 2015). Taken together, those combined interactions within the spousal dyads could account for the positive effect of depression on patients' functional well-being, in spite of not being fully investigated.

In addition, gender-related differences would be worthy of discussion regarding the partner effect. Among the spousal pairs, about 70% ($n = 264$) of family caregivers were female, and this amount of female family caregivers could be comparable to U.S. statistics. The Family Caregiver Alliance (2012) indicated females accounted for 66% of family caregivers, and female spouses easily expressed symptoms of depression when compared to non-family caregiver females (Caregiver Action Network, n.d.). Somewhat surprisingly, the female spouses in the sample were not as vulnerable as expected because their depression mean score did not reach the cut-off score of 4 at the time of enrollment nor did their male partners. This could be due to the fact that male cancer patients perceived better QOL and less depressive symptoms (Chang et al., 2015; Larsson, Ljung, & Johansson, 2012), giving rise to lower and similar depression scores within the dyads. However, given the potential gender-related effects, we could not further differentiate the difference between female patient-male family caregiver and male patient-female family caregiver dyads in light of male patients-female family caregivers predominantly included in this study.

With regard to their spiritual needs, the proportion of the unmet needs in this sample was relatively low when compared to the previous study of hospice patients (Hermann, 2007). Hospice patients and family caregivers had satisfied spiritual well-being, as most spiritual needs were perceived as met by at least 87% of the dyads. Among those 17 spiritual needs, going to religious services was identified as unmet by most of the dyads. Despite not going to church, dyads found alternatives, such as praying to satisfy their religious needs. In addition, significant and positive relationships were found between hospice patients' depression and their unmet spiritual needs ($r = .20, p < .01$), perceived religious needs ($r = .10, p < .05$) as well as the community needs ($r = .08, p < .05$), which were reflective of less depressive symptoms and less unmet spiritual needs in the sample. Buck and McMillan (2008) suggested that fulfilling spiritual needs would not be the first priority for newly admitted hospice dyads. Particularly, when patients struggled with physical symptoms, their spiritual concerns may not be as essential as their symptoms, such as pain and shortness of breath. This assertion was supported by the sample with the relatively lower functional and psychophysiological well-being. However, in the quantitative study of two groups of hospice patients with lung cancer and heart failure, Murray et al. (2004) found that lung cancer patients anticipated death once the cancer diagnosis was made. Specifically, their emotional and spiritual concerns predominated at the beginning and later stage of the illness progression. As investigated, QOL in hospice patients encompassed three inter-correlated dimensions in the context of psychophysical well-being, functional well-being, and social/spiritual well-being (McMillan & Weitzner, 1998). Our hospice patients reported relatively lower depression mean scores and lower unmet spiritual needs even in the face of physical symptoms, implying that their perceived spiritual well-being, particularly in the religious needs and being around family and children, could buffer the suffering from cancer.

The mutuality of perceived spiritual needs was shown in the sample as there were significant relationships between the religious needs ($r = .38, p < .05$) and the community needs ($r = .23, p < .05$) within the dyads. However, when testing the actor and partner effects of spiritual needs on QOL, we only found the actor effects after controlling for the partner effects. In particular, the actor effect of the outlook needs significantly predicted the hospice patients' functional well-being as well as the social/spiritual well-being (Hypothesis five). The actor effects in hospice patients were reflective of the relationship between depression and spiritual well-being because the outlook needs were about laughing, seeing smiles of others, being with friends, thinking happy thoughts, and talking about day-to-day things. This finding was slightly different from the relationship found in the previous study as it identified the religious needs, instead of the outlook needs, significantly contributed to part of the QOL of hospice patients (Buck et al., 2009). It should be noted that this study used the five factors of the SNI in the hospice patients (i.e., outlook, inspiration, spiritual activities, religion, and community needs), and the factor of the outlook needs was removed because of the misfit to the model. In terms of the family caregivers, their mental health could be predicted by their own positive outlook needs and negative community needs (Hypothesis six). This result suggested that family caregivers' mental health could be improved when they were distracted from the increased social activities, such as being with friends, laughing, and talking about day-to-day things. On the contrary, the negative effect of community needs on their mental health, such as being with family and children, seemed to bring the family caregivers back to the reality of the impending death. Kanter et al. (2014) also found similar results that family caregivers utilized social support, humor, and other distractions as coping strategies to face uncertainty; simultaneously, they also expressed emotions, such as guilt, selfishness in maintaining their own lives, and anger towards

their family. Such self-contradictory emotions may raise the question regarding how family caregivers react to the responsibilities of being a caregiver and how to cope adequately without any conflicts. This study reinforced the need to consistently assist family caregivers in their spiritual concerns, especially when their loved ones were first admitted to hospice.

Limitations

In an optimal instance, the Actor-Partner Interdependence Model theoretically should incorporate the same measurement instruments when measuring independent and outcome variables for dyads. This would help researchers understand how much of the variance is not explained by the model. However, we only utilized the same measures for independent variables but not the outcome variable as we believed that the construct of QOL in hospice patients with cancer differed from their family caregivers. As a result, we were not able to correlate the residual nonindependence in the outcome measure as represented in Figure one by the curved arrow between U and U' ; therefore, we could not examine the degree to which nonindependence was not explained by the model. In spite of having this limitation in the study, we still acknowledged the Actor-Partner Interdependence Model as it shed light on the importance of mutuality and thus estimated a more accurate model. In addition, considering different types of kinship in the sample, actor and partner effects could vary based on their levels of intimacy and relationships; however, such a complex model requiring a sufficient sample size prevented us from investigating more potential effects based on their kinship. Last but not least, because a large proportion (85%) of the dyads were Christians, we could not further examine how other samples with no religious practices, such as agnostics, buffer their depression symptoms.

Implications for Nursing

Emotions and spiritual well-being have been identified as two of the ten imperative indicators to ensure dyads obtain optimal quality care (Dy et al., 2015). This secondary analysis

highlights the significance of treating dyads as one unit and the importance of consistently assessing hospice patients' as well as family caregivers' emotional and spiritual concerns. As hospice dyads are admitted to hospice, it reflects that dyads face new challenges and require more internal resources to prepare for the anticipated death. Although expressing some emotion is expected from dyads near the end of life, their emotions and spiritual concerns can be transmitted to each other due to mutuality existing within the dyads, resulting in both struggling with similar difficulties and worsening QOL. It should be noted that the presence of family caregivers indeed plays an important role in maintaining QOL for hospice patients, particularly, improving their physical and psychological symptoms while meeting their spiritual needs. Therefore, in addition to predominantly helping hospice patients with cancer, nurses and other professionals need to expend more efforts of assisting family caregivers in rejuvenating their internal resources and managing emotional concerns from their caretaking. By means of having assistance from multidisciplinary professionals, including social workers and chaplains along with nurses and physicians, fewer concerns held by family caregivers are likely to be transmitted to their loved ones; in turn, hospice patients with cancer can further benefit from the positive changes while family caregivers' QOL is improved. On the other hand, for hospice patients with less support from family caregivers, their spiritual and emotion concerns may require additional help from nurses and clinicians.

Given that the focus of the study is about hospice dyads, the results of the study can be applied to all stages of cancer dyads, as their spiritual and emotional well-being continually fluctuates throughout their cancer trajectory. Therefore, nursing educators should incorporate spiritual and psychological assessments and interventions in undergraduate nursing programs to develop nursing students with expertise in providing relevant care for dyads. In addition, nursing

students should be taught the importance of the interdisciplinary team in cancer care. As for the educators in clinical and community settings, oncology nurses specifically should be encouraged to develop their competencies in providing spiritual and psychological care. Moreover, nurse scientists need to be aware of adding partner effects in models, as it can help achieve more accurate results and justifies the additional challenges that may be involved. Hence, more effective interventions based on the results could be implemented to alleviate the sufferings from cancer and the anticipated death.

Future Directions

The value of this study lies in the mutuality within hospice patients and family caregivers and utilizing the Actor-Partner Interdependence Model to estimate a more accurate model. Therefore, the results from this study can serve as a foundation to further examine longitudinally whether the strength of actor and partner effects vary as death approaches. Future studies can use the same measures for dyads as suggested by the model to help extract more information from the model. In addition, the mixed sample included in the study also demonstrate the specific partner effect in the spousal pairs. Therefore, it is essential to recruit relatively equal sample sizes based on different types of kinship to examine different impacts of actor and partner effects. Gender-related differences can be further investigated as males and females may use different coping strategies to deal with difficulties; hence, it can be better understood by recruiting both genders in a specific type of cancer, such as lung cancer or colorectal cancer, to compare the strength of actor and partner effects by using structural equation modeling.

REFERENCES

- Abbas, S. Q., & Dein, S. (2011). The difficulties assessing spiritual distress in palliative care patients: A qualitative study. *Mental Health, Religion & Culture, 14*(4), 341-352. doi: 10.1080/13674671003716780
- Adams, R. N., Mosher, C. E., Cannady, R. S., Lucette, A., & Kim, Y. (2014). Caregiving experiences predict changes in spiritual well-being among family caregivers of cancer patients. *Psychooncology, 23*(10), 1178-1184. doi: 10.1002/pon.3558
- American Cancer Society. (2014a). *Your emotions as you near the end of life*. Retrieved from <http://www.cancer.org/treatment/nearingtheendoflife/nearingtheendoflife/nearing-the-end-of-life-emotions>
- American Cancer Society. (2014b). *The importance of communication*. Retrieved from <http://www.cancer.org/treatment/nearingtheendoflife/nearingtheendoflife/nearing-the-end-of-life-communication>
- American Cancer Society. (2015). *Depression*. Retrieved from <http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/dealingwithsymptomsathome/caring-for-the-patient-with-cancer-at-home-depression>
- Ando, M., Morita, T., Okamoto, T., & Ninosaka, Y. (2008). One-week short-term life review interview can improve spiritual well-being of terminally ill cancer patients. *Psychooncology, 17*(9), 885-890. doi: 10.1002/pon.1299
- Applebaum, A. J., Stein, E. M., Lord-Bessen, J., Pessin, H., Rosenfeld, B., & Breitbart, W. (2014). Optimism, social support, and mental health outcomes in patients with advanced cancer. *Psychooncology, 23*(3), 299-306. doi: 10.1002/pon.3418
- Ardelt, M. & Koenig, C. S. (2006). The role of religion for hospice patients and relatively healthy older adults. *Research on Aging, 28*(2), 184-215. doi: 10.1177/0164027505284165
- Badr, H., & Taylor, C. L. (2006). Social constraints and spousal communication in lung cancer. *Psychooncology, 15*(8), 673-683. doi: 10.1002/pon.996
- Bagozzi, R., & Yi, Y. (1998). On the evaluation of structural equation models. *Journal of the Academy of Marketing Science, 16*(1), 74-94.

- Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Brokaw, F. C., Seville, J., . . . Ahles, T. A. (2009). Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer: The project ENABLE II randomized controlled trial. *JAMA*, *302*(7), 741-749. doi: 10.1001/jama.2009.1198
- Balboni, M. J., Sullivan, A., Amobi, A., Phelps, A. C., Gorman, D. P., Zollfrank, A., . . . Balboni, T. A. (2013). Why is spiritual care infrequent at the end of life? Spiritual care perceptions among patients, nurses, and physicians and the role of training. *Journal of Clinical Oncology*, *31*(4), 461-467. doi: 10.1200/JCO.2012.44.6443
- Balboni, T. A., Vanderwerker, L. C., Block, S. D., Paulk, M. E., Lathan, C. S., Peteet, J. R., & Prigerson, H. G. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology*, *25*(5), 555-560. doi: 10.1200/JCO.2006.07.9046
- Bentler, P. M. (1990). Comparative fit indexes in structural models. *Psychological Bulletin*, *107*(2), 238-246.
- Benson, J., & Fleishman, J. A. (1994). The robustness of maximum likelihood and distribution-free estimators to non-normality in confirmatory factor analysis. *Quality & Quantity*, *28*(2), 117.
- Browne, M. W., & Cudeck, R. (1993). Alternative ways of assessing model fit. In K. A. Bollen, & J. S. Long (Eds.), *Testing Structural Equation Models* (pp. 136-162). Newbury Park, CA: Sage Publications.
- Buck, H. G. (2013). Help family caregivers in the "sandwich generation". *Nursing*, *43*(11), 19-20. doi: 10.1097/01.NURSE.0000435206.88399.c8
- Buck, H. G., & McMillan, S. C. (2008). The unmet spiritual needs of caregivers of patients with advanced cancer. *Journal of Hospice & Palliative Nursing*, *10*(2), 91-99. doi: 10.1097/01.njh.0000306737.08850.71
- Buck, H. G., Mogle, J., Riegel, B., McMillan, S., & Bakitas, M. (2015). Exploring the relationship of patient and informal caregiver characteristics with heart failure self-care using the Actor-Partner Interdependence Model: Implications for outpatient palliative care. *Journal of Palliative Medicine*, *18*(12), 1026-1032. doi: 10.1089/jpm.2015.0086
- Buck, H. G., & McMillan, S. C. (2012). A psychometric analysis of the spiritual needs inventory in informal caregivers of patients with cancer in hospice home care. *Oncology Nursing Forum*, *39*(4), E332-339. doi: 10.1188/12.onf.e332-e339
- Buck, H. G., Overcash, J., & McMillan, S. C. (2009). The geriatric cancer experience at the end of life: Testing an adapted model. *Oncology Nursing Forum*, *36*(6), 664-673. doi: 10.1188/09.onf.664-673

- Caregiver Action Network. (n.d.). *Caregiver statistics*. Retrieved from <http://caregiveraction.org/resources/caregiver-statistics>
- Campbell, C. L., & Campbell, L. C. (2012). A systematic review of cognitive behavioral interventions in advanced cancer. *Patient Education and Counseling*, 89(1), 15-24. doi: 10.1016/j.pec.2012.06.019
- Carlander, I., Sahlberg-Blom, E., Hellstrom, I., & Ternestedt, B. M. (2011). The modified self: Family caregivers' experiences of caring for a dying family member at home. *Journal of Clinical Nursing*, 20(7-8), 1097-1105. doi: 10.1111/j.1365-2702.2010.03331.x
- Centers for Disease Control and Prevention. (2015). *Depression is not a normal part of growing older*. Retrieved from <http://www.cdc.gov/aging/mentalhealth/depression.htm>
- Chang, N. W., Lin, K. C., Hsu, W. H., Lee, S. C., Chan, J. Y., & Wang, K. Y. (2015). The effect of gender on health-related quality of life and related factors in post-lobectomy lung-cancer patients. *European Journal of Oncology Nursing*, 19(3), 292-300. doi: 10.1016/j.ejon.2014.10.015
- Cook, W., & Kenny, D. (2005). The Actor-Partner Interdependence Model: A model of bidirectional effects in developmental studies. *International Journal of Behavioral Development*, 29(2), 101-109. doi: 10.1080/01650250444000405
- Devik, S. A., Enmarker, I., Wiik, G. B., & Hellzen, O. (2013). Meanings of being old, living on one's own and suffering from incurable cancer in rural Norway. *European Journal of Oncology Nursing*, 17(6), 781-787. doi: 10.1016/j.ejon.2013.03.009
- Dy, S. M., Kiley, K. B., Ast, K., Lupu, D., Norton, S. A., McMillan, S. C., . . . Casarett, D. J. (2015). Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain and Symptom Management*, 49(4), 773-781. doi: 10.1016/j.jpainsymman.2015.01.012
- Edwards, A., Pang, N., Shiu, V., & Chan, C. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research. *Palliative Medicine*, 24(8), 753-770. doi: 10.1177/0269216310375860
- Exline, J. J., Prince-Paul, M., Root, B. L., & Peereboom, K. S. (2013). The spiritual struggle of anger toward God: A study with family members of hospice patients. *Journal of Palliative Medicine*, 16(4), 369-375. doi: 10.1089/jpm.2012.0246
- Faller, H., Schuler, M., Richard, M., Heckl, U., Weis, J., & Kuffner, R. (2013). Effects of psycho-oncologic interventions on emotional distress and quality of life in adult patients with cancer: Systematic review and meta-analysis. *Journal of Clinical Oncology*, 31(6), 782-793. doi: 10.1200/JCO.2011.40.8922

- Family Caregiver Alliance. (2012). *Selected caregiver statistics*. Retrieved from <https://www.caregiver.org/selected-caregiver-statistics>
- Fasse, L., Flahault, C., Bredart, A., Dolbeault, S., & Sultan, S. (2015). Describing and understanding depression in spouses of cancer patients in palliative phase. *Psychooncology*. doi: 10.1002/pon.3777
- Fletcher, B. S., Miaskowski, C., Given, B., & Schumacher, K. (2012). The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing*, 16(4), 387-398. doi: 10.1016/j.ejon.2011.09.001
- Fletcher, B. S., Paul, S. M., Dodd, M. J., Schumacher, K., West, C., Cooper, B., . . . Miaskowski, C. A. (2008). Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *Journal of Clinical Oncology*, 26(4), 599-605. doi: 10.1200/jco.2007.12.2838
- Garrison, C. M., Overcash, J., & McMillan, S. C. (2011). Predictors of quality of life in elderly hospice patients with cancer. *Journal of Hospice & Palliative Nursing*, 13(5), 288-297. doi: 10.1097/NJH.0b013e31821adb2d
- Gijsberts, M. J., Echteld, M. A., van der Steen, J. T., Muller, M. T., Otten, R. H., Ribbe, M. W., & Deliens, L. (2011). Spirituality at the end of life: Conceptualization of measurable aspects-a systematic review. *Journal of Palliative Medicine*, 14(7), 852-863. doi: 10.1089/jpm.2010.0356
- Haber, D. (2006). Life review: Implementation, theory, research, and therapy. *International Journal of Aging & Human Development*, 63(2), 153-171.
- Hagedoorn, M., Puterman, E., Sanderman, R., Wiggers, T., Baas, P. C., van Haastert, M., & DeLongis, A. (2011). Is self-disclosure in couples coping with cancer associated with improvement in depressive symptoms? *Health Psychology*, 30(6), 753-762. doi: 10.1037/a0024374
- Haley, W. E. (2003). Family caregivers of elderly patients with cancer: Understanding and minimizing the burden of care. *Journal of supportive oncology*, 1(4 Suppl 2), 25-29.
- Haley, W. E., LaMonde, L. A., Han, B., Burton, A. M., & Schonwetter, R. (2003). Predictors of depression and life satisfaction among spousal caregivers in hospice: Application of a stress process model. *Journal of Palliative Medicine*, 6(2), 215-224. doi: 10.1089/109662103764978461
- Hampton, D. M., Hollis, D. E., Lloyd, D. A., Taylor, J., & McMillan, S. C. (2007). Spiritual needs of persons with advanced cancer. *American Journal of Hospice and Palliative Care*, 24(1), 42-48. doi: 10.1177/1049909106295773

- Haun, M. W., Sklenarova, H., Villalobos, M., Thomas, M., Brechtel, A., Lowe, B., . . . Hartmann, M. (2014). Depression, anxiety and disease-related distress in couples affected by advanced lung cancer. *Lung Cancer*, 86(2), 274-280. doi: 10.1016/j.lungcan.2014.09.009
- Hermann, C. P. (2007). The degree to which spiritual needs of patients near the end of life are met. *Oncology Nursing Forum*, 34(1), 70-78. doi: 10.1188/07.onf.70-78
- Hermann, C. P. (2006). Development and testing of the Spiritual Needs Inventory for patients near the end of life. *Oncology Nursing Forum*, 33(4), 737-744. doi: 10.1188/06.ONF.737-744
- Hermann, C. P., & Looney, S. W. (2011). Determinants of quality of life in patients near the end of life: A longitudinal perspective. *Oncology Nursing Forum*, 38(1), 23-31. doi: 10.1188/11.onf.23-31
- Higginson, I. J., & Costantini, M. (2008). Dying with cancer, living well with advanced cancer. *European Journal of Cancer*, 44(10), 1414-1424. doi: 10.1016/j.ejca.2008.02.024
- Hill, P. C., & Pargament, K. I. (2003). Advances in the conceptualization and measurement of religion and spirituality. Implications for physical and mental health research. *American Psychologist*, 58(1), 64-74.
- Hu, L. t., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal*, 6(1), 1-55. doi: 10.1080/10705519909540118
- Irwin, M., Artin, K. H., & Oxman, M. N. (1999). Screening for depression in the older adult: Criterion validity of the 10-item Center for Epidemiological Studies Depression Scale (CES-D). *Archives of Internal Medicine*, 159(15), 1701-1704.
- Irwin, S. A., Rao, S., Bower, K., Palica, J., Rao, S. S., Maglione, J. E., . . . Ferris, F. D. (2008). Psychiatric issues in palliative care: Recognition of depression in patients enrolled in hospice care. *Journal of Palliative Medicine*, 11(2), 158-163. doi: 10.1089/jpm.2007.0140
- Jackson, D. L., Gillasp, J. A., & Purc-Stephenson, R. (2009). Reporting practices in confirmatory factor analysis: An overview and some recommendations. *Psychological Methods*, 14(1), 6-23. doi: 10.1037/a0014694
- Jöreskog, K.G., Sörbom, D. (1996). *LISREL 8: User's reference guide*. Scientific Software International, Inc., Chicago.
- Kanter, C., D'Agostino, N. M., Daniels, M., Stone, A., & Edelstein, K. (2014). Together and apart: Providing psychosocial support for patients and families living with brain tumors. *Support Care Cancer*, 22(1), 43-52. doi: 10.1007/s00520-013-1933-1

- Kim, Y., Baker, F., & Spillers, R. L. (2007). Cancer caregivers' quality of life: Effects of gender, relationship, and appraisal. *Journal of Pain and Symptom Management*, 34(3), 294-304. doi: 10.1016/j.jpainsymman.2006.11.012
- Kim, Y., Carver, C. S., & Cannady, R. S. (2015). Caregiving motivation predicts long-term spirituality and quality of life of the caregivers. *Annals of Behavioral Medicine*. doi: 10.1007/s12160-014-9674-z
- Kim, Y., Carver, C. S., Rocha-Lima, C., & Shaffer, K. M. (2013). Depressive symptoms among caregivers of colorectal cancer patients during the first year since diagnosis: A longitudinal investigation. *Psychooncology*, 22(2), 362-367. doi: 10.1002/pon.2100
- Kim, Y., & Spillers, R. L. (2010). Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. *Psychooncology*, 19(4), 431-440. doi: 10.1002/pon.1576
- Kim, Y., Spillers, R. L., & Hall, D. L. (2012). Quality of life of family caregivers 5 years after a relative's cancer diagnosis: Follow-up of the national quality of life survey for caregivers. *Psychooncology*, 21(3), 273-281. doi: 10.1002/pon.1888
- Kim, Y., van Ryn, M., Jensen, R. E., Griffin, J. M., Potosky, A., & Rowland, J. (2015). Effects of gender and depressive symptoms on quality of life among colorectal and lung cancer patients and their family caregivers. *Psychooncology*, 24(1), 95-105. doi: 10.1002/pon.3580
- Kline, R. B. (2010). *Principals and practice of structural equation modeling* (3rd ed.). New York, NY: The Guilford Press
- Koenig, H. G., George, L. K., Titus, P., & Meador, K. G. (2004). Religion, spirituality, and acute care hospitalization and long-term care use by older patients. *Archives of Internal Medicine*, 164(14), 1579-1585. doi: 10.1001/archinte.164.14.1579
- Kübler-Ross, E. (1969). *On death and dying*. New York, NY: The Macmillan Company.
- Larsson, M., Ljung, L., & Johansson, B. B. (2012). Health-related quality of life in advanced non-small cell lung cancer: Correlates and comparisons to normative data. *European Journal of Cancer Care(English)*, 21(5), 642-649. doi: 10.1111/j.1365-2354.2012.01346.x
- Lau, F., Downing, G. M., Lesperance, M., Shaw, J., & Kuziemy, C. (2006). Use of Palliative Performance Scale in end-of-life prognostication. *Journal of Palliative Medicine*, 9(5), 1066-1075. doi: 10.1089/jpm.2006.9.1066
- Ling, S. F., Chen, M. L., Li, C. Y., Chang, W. C., Shen, W. C., & Tang, S. T. (2013). Trajectory and influencing factors of depressive symptoms in family caregivers before and after the death of terminally ill patients with cancer. *Oncology Nursing Forum*, 40(1), E32-40. doi: 10.1188/13.onf.e32-e40

- MacCallum, R. C., Widaman, K. F., Zhang, S., & Hong, S. (1999). Sample size in factor analysis. *Psychological Methods*, 4(1), 84-99. doi: 10.1037/1082-989X.4.1.84
- McMillan, S. C., & Small, B. J. (2002). Symptom distress and quality of life in patients with cancer newly admitted to hospice home care. *Oncology Nursing Forum*, 29(10), 1421-1428. doi: 10.1188/02.onf.1421-1428
- McMillan, S. C., & Small, B. J. (2007). Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: A clinical trial. *Oncology Nursing Forum*, 34(2), 313-321. doi: 10.1188/07.onf.313-321
- McMillan, S. C., Small, B. J., & Haley, W. E. (2011). Improving hospice outcomes through systematic assessment: A clinical trial. *Cancer Nursing*, 34(2), 89-97. doi: 10.1097/NCC.0b013e3181f70aee
- McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L., & Haley, W. E. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer*, 106(1), 214-222. doi: 10.1002/cncr.21567
- McMillan, S. C., & Weitzner, M. (1998). Quality of life in cancer patients - Use of a revised hospice index. *Cancer Practice*, 6(5), 282-288. doi: 10.1046/j.1523-5394.1998.00023.x
- Mikulincer, M., Florian, V., & Hirschberger, G. (2003). The existential function of close relationships: Introducing death into the science of love. *Personality and social psychology review*, 7(1), 20-40.
- Murray, S. A., Kendall, M., Boyd, K., Worth, A., & Benton, T. F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: A prospective qualitative interview study of patients and their carers. *Palliative Medicine*, 18(1), 39-45.
- National Alliance for Caregiving. (2015). *Caregiving in the U.S.*. Retrieved from http://www1.prweb.com/prfiles/2015/06/03/12765231/2015_CaregivingintheUS_Executive%20Summary_WEB.pdf
- National Alliance on Mental illness. (2015). *Depression*. Retrieved from http://www2.nami.org/Content/NavigationMenu/Mental_Illnesses/Depression/Depression_Symptoms,_Causes_and_Diagnosis.htm
- National Cancer Institute. (2013). *Family caregivers in cancer (PDQ®). The caregiver's quality of life*. Retrieved from http://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq#section/_22

- National Cancer Institute. (2015). *Spirituality in cancer care (PDQ®). General information about spirituality*. Retrieved from <http://www.cancer.gov/about-cancer/coping/day-to-day/faith-and-spirituality/spirituality-pdq>
- National Comprehensive Cancer Network. (2015). *Distress management*. Retrieved from http://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
- National Hospice and Palliative Care Organization. (2014). *NHPCO's facts and figures hospice care in America*. Retrieved from http://www.nhpco.org/sites/default/files/public/Statistics_Research/2014_Facts_Figures.pdf
- Nik Jaafar, N. R., Selamat Din, S. H., Mohamed Saini, S., Ahmad, S. N., Midin, M., Sidi, H., . . . Baharudin, A. (2014). Clinical depression while caring for loved ones with breast cancer. *Comprehensive psychiatry, 55 Suppl 1*, S52-59. doi: 10.1016/j.comppsy.2013.03.003
- Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., & Mood, D. W. (2010). Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians, 60*(5), 317-339. doi: 10.3322/caac.20081
- Ohnsorge, K., Gudat, H., & Rehmann-Sutter, C. (2014). What a wish to die can mean: Reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care, 13*, 38. doi: 10.1186/1472-684X-13-38
- Okonkwo, O. C., Roth, D. L., Pulley, L., & Howard, G. (2010). Confirmatory factor analysis of the validity of the SF-12 for persons with and without a history of stroke. *Quality of Life Research, 19*(9), 1323-1331. doi: 10.1007/s11136-010-9691-8
- Osse, B. H., Vernooij-Dassen, M. J., Schade, E., & Grol, R. P. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing, 29*(5), 378-388; quiz 389-390.
- Paiva, B. S., Carvalho, A. L., Lucchetti, G., Barroso, E. M., & Paiva, C. E. (2015). "Oh, yeah, I'm getting closer to god": Spirituality and religiousness of family caregivers of cancer patients undergoing palliative care. *Support Care Cancer*. doi: 10.1007/s00520-015-2604-1
- Park, E. O., & Schumacher, K. L. (2014). The state of the science of family caregiver-care receiver mutuality: A systematic review. *Nursing Inquiry, 21*(2), 140-152. doi: 10.1111/nin.12032
- Phelps, A. C., Lauderdale, K. E., Alcorn, S., Dillinger, J., Balboni, M. T., Van Wert, M., . . . Balboni, T. A. (2012). Addressing spirituality within the care of patients at the end of life: Perspectives of patients with advanced cancer, oncologists, and oncology nurses. *Journal of Clinical Oncology, 30*(20), 2538-2544. doi: 10.1200/jco.2011.40.3766


- Price, A., Goodwin, L., Rayner, L., Shaw, E., Hansford, P., Sykes, N., . . . Lee, W. (2012). Illness perceptions, adjustment to illness, and depression in a palliative care population. *Journal of Pain and Symptom Management*, 43(5), 819-832. doi: 10.1016/j.jpainsymman.2011.05.013
- Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., . . . Sulmasy, D. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *Journal of Palliative Medicine*, 12(10), 885-904. doi: 10.1089/jpm.2009.0142
- Rabkin, J. G., McElhiney, M., Moran, P., Acree, M., & Folkman, S. (2009). Depression, distress and positive mood in late-stage cancer: A longitudinal study. *Psychooncology*, 18(1), 79-86. doi: 10.1002/pon.1386
- Rhee, Y. S., Yun, Y. H., Park, S., Shin, D. O., Lee, K. M., Yoo, H. J., . . . Kim, N. S. (2008). Depression in family caregivers of cancer patients: The feeling of burden as a predictor of depression. *Journal of Clinical Oncology*, 26(36), 5890-5895. doi: 10.1200/JCO.2007.15.3957
- Rhondali, W., Chirac, A., Laurent, A., Terra, J. L., & Filbet, M. (2015). Family caregivers' perceptions of depression in patients with advanced cancer: A qualitative study. *Palliative & Supportive Care*, 13(3), 443-450. doi: 10.1017/S1478951513001223
- Rodin, D., Balboni, M., Mitchell, C., Smith, P. T., VanderWeele, T. J., & Balboni, T. A. (2015). Whose role? Oncology practitioners' perceptions of their role in providing spiritual care to advanced cancer patients. *Support Care Cancer*. doi: 10.1007/s00520-015-2611-2
- Roscoe, L. A., Tullis, J. A., Reich, R. R., & McCaffrey, J. C. (2013). Beyond good intentions and patient perceptions: Competing definitions of effective communication in head and neck cancer care at the end of life. *Health Communication*, 28(2), 183-192. doi: 10.1080/10410236.2012.666957
- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, 282(23), 2215-2219.
- SF-36.org. (n.d.). *SF-36® Health Survey Update*. Retrieved from <http://www.sf-36.org/tools/sf36.shtml>
- Sjolander, C., & Ahlstrom, G. (2012). The meaning and validation of social support networks for close family of persons with advanced cancer. *BMC Nursing*, 11, 17. doi: 10.1186/1472-6955-11-17
- Sjolander, C., Hedberg, B., & Ahlstrom, G. (2011). Striving to be prepared for the painful: Management strategies following a family member's diagnosis of advanced cancer. *BMC Nursing*, 10, 18. doi: 10.1186/1472-6955-10-18

- Skalla, K. A., Smith, E. M., Li, Z., & Gates, C. (2013). Multidimensional needs of caregivers for patients with cancer. *Clinical Journal of Oncology Nursing*, 17(5), 500-506. doi: 10.1188/13.cjon.17-05ap
- Song, L., Northouse, L. L., Zhang, L., Braun, T. M., Cimprich, B., Ronis, D. L., & Mood, D. W. (2012). Study of dyadic communication in couples managing prostate cancer: A longitudinal perspective. *Psychooncology*, 21(1), 72-81. doi: 10.1002/pon.1861
- Sprangers, M. A., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine*, 48(11), 1507-1515.
- Stark, L., Tofthagen, C., Visovsky, C., & McMillan, S. C. (2012). The symptom experience of patients with cancer. *Journal of Hospice & Palliative Nursing*, 14(1), 61-70. doi: 10.1097/NJH.0b013e318236de5c
- Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psychooncology*, 19(10), 1013-1025. doi: 10.1002/pon.1670
- Tang, S. T., Chang, W. C., Chen, J. S., Wang, H. M., Shen, W. C., Li, C. Y., & Liao, Y. C. (2013). Course and predictors of depressive symptoms among family caregivers of terminally ill cancer patients until their death. *Psychooncology*, 22(6), 1312-1318. doi: 10.1002/pon.3141
- Taylor, E. J. (2003). Spiritual needs of patients with cancer and family caregivers. *Cancer Nursing*, 26(4), 260-266.
- Taylor, E. J. (2006). Prevalence and associated factors of spiritual needs among patients with cancer and family caregivers. *Oncology Nursing Forum*, 33(4), 729-735. doi: 10.1188/06.onf.729-735
- Tierney, D. K., Facione, N., Padilla, G., & Dodd, M. (2007). Response shift: A theoretical exploration of quality of life following hematopoietic cell transplantation. *Cancer Nursing*, 30(2), 125-138. doi: 10.1097/01.NCC.0000265002.79687.af
- Traa, M. J., Braeken, J., De Vries, J., Roukema, J. A., Orsini, R. G., & Den Ouden, B. L. (2015). Evaluating quality of life and response shift from a couple-based perspective: A study among patients with colorectal cancer and their partners. *Quality of Life Research*, 24(6), 1431-1441. doi: 10.1007/s11136-014-0872-8
- Ullman, J. B. (2007). Structural Equation Modeling. In B. G. Tabachnick & L. S. Fidell (Eds.), *Using Multivariate Statistics* (5th Ed.) (pp.676-780). Boston, MA: Pearson Education.
- Venetis, M. K., Magsamen-Conrad, K., Checton, M. G., & Greene, K. (2014). Cancer communication and partner burden: An exploratory study. *Journal of Communication*, 64(1), 82-102. doi: 10.1111/jcom.12069

- Villagomez, L. R. (2005). Spiritual distress in adult cancer patients: Toward conceptual clarity. *Holistic Nursing Practice*, 19(6), 285-294.
- Wittenberg-Lyles, E., Oliver, D. P., Kruse, R. L., Demiris, G., Gage, L. A., & Wagner, K. (2013). Family caregiver participation in hospice interdisciplinary team meetings: How does it affect the nature and content of communication? *Health Communication*, 28(2), 110-118. doi: 10.1080/10410236.2011.652935
- Wong, W. K., Ussher, J., & Perz, J. (2009). Strength through adversity: Bereaved cancer carers' accounts of rewards and personal growth from caring. *Palliative & Supportive Care*, 7(2), 187-196. doi: 10.1017/S1478951509000248
- World Health Organization. (2015). *WHO definition of palliative care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>
- World Health Organization. (2002). *National cancer control programmes: Policies and managerial guidelines*. Retrieved from <http://www.who.int/reproductivehealth/publications/cancers/9241545577/en/>

APPENDICES

Appendix A: The Approved Letter for Human Subject Research from the Institutional Review Board of the University of South Florida

 <p>UNIVERSITY OF SOUTH FLORIDA</p>	<p>RESEARCH INTEGRITY AND COMPLIANCE Institutional Review Boards, FWA No. 00001669 12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799 (813) 974-5638 • FAX (813) 974-7091</p>
<p>August 21, 2014</p>	
<p>Li-Ting Huang, RN, BSN College of Nursing Tampa, FL 33612</p>	
<p>RE: Expedited Approval for Initial Review IRB#: Pro00017837 Title: Investigating the Effects of Depression and Spiritual Well-Being on Quality of Life in Hospice Patients with Cancer Using an Actor-Partner Interdependence Model</p>	
<p>Study Approval Period: 8/21/2014 to 8/21/2015</p>	
<p>Dear Ms. Huang:</p>	
<p>On 8/21/2014, the Institutional Review Board (IRB) reviewed and APPROVED the above application and all documents outlined below.</p>	
<p>Approved Item(s): Protocol Document(s): Protocol</p>	
<p>Consent/Assent Document(s)*: Waiver of Process granted</p>	
<p>It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:</p>	
<p>(5) Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for nonresearch purposes (such as medical treatment or diagnosis).</p>	

Your study qualifies for a waiver of the requirements for the informed consent process as outlined in the federal regulations at 45CFR46.116 (d) which states that an IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent, or waive the requirements to obtain informed consent provided the IRB finds and documents that (1) the research involves no more than minimal risk to the subjects; (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects; (3) the research could not practicably be carried out without the waiver or alteration; and (4) whenever appropriate, the subjects will be provided with additional pertinent information after participation.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

A handwritten signature in cursive script that reads "John A. Schinka, Ph.D.".

John Schinka, Ph.D., Chairperson
USF Institutional Review Board

Appendix B: The Correlation Matrix of the Indicators

Table A1

The Correlation Matrix of the Indicators

Variables	PSNI_1	PSNI_2	PSNI_3	PSNI_4	PSNI_5	PSNI_6	PSNI_7
PSNI_1	1.000	–	–	–	–	–	–
PSNI_2	0.246	1.000	–	–	–	–	–
PSNI_3	0.471	0.172	1.000	–	–	–	–
PSNI_4	0.099	0.223	0.117	1.000	–	–	–
PSNI_5	0.215	0.405	0.228	0.356	1.000	–	–
PSNI_6	0.436	0.235	0.651	0.150	0.299	1.000	–
PSNI_7	0.173	0.295	0.240	0.291	0.347	0.279	1.000
PSNI_8	0.450	0.263	0.651	0.137	0.279	0.576	0.292
PSNI_9	0.396	0.201	0.537	0.111	0.205	0.512	0.262
PSNI_10	0.191	0.260	0.187	0.356	0.326	0.177	0.361
PSNI_11	0.368	0.261	0.533	0.236	0.317	0.558	0.326
PSNI_12	0.331	0.247	0.536	0.158	0.220	0.518	0.261
PSNI_13	0.375	0.147	0.582	0.097	0.233	0.551	0.179
PSNI_14	0.146	0.385	0.192	0.225	0.292	0.239	0.257
PSNI_15	0.049	0.243	0.115	0.208	0.274	0.150	0.385
PSNI_16	0.185	0.367	0.228	0.211	0.378	0.241	0.311
PSNI_17	0.453	0.153	0.647	0.093	0.198	0.593	0.266
HQLI_1	0.113	0.064	0.065	0.073	-0.003	0.057	0.016
HQLI_2	0.031	0.015	0.065	0.043	0.031	0.085	0.017
HQLI_3	0.063	0.005	0.025	-0.035	-0.013	0.009	-0.040
HQLI_4	-0.035	-0.072	-0.085	0.024	-0.036	-0.053	-0.029
HQLI_5	0.020	0.014	0.053	-0.005	0.001	0.040	-0.019
HQLI_6	0.039	-0.049	0.023	-0.014	-0.034	-0.016	-0.125
HQLI_7	-0.037	0.018	-0.030	0.055	0.022	-0.060	-0.001
HQLI_8	0.103	0.135	0.095	0.069	0.142	0.128	0.116
HQLI_9	0.066	0.030	-0.020	-0.022	-0.021	0.012	-0.083
HQLI_10	0.003	0.101	0.014	0.090	0.078	0.022	0.003
HQLI_11	0.026	0.133	0.071	0.184	0.150	0.043	0.070
HQLI_12	0.171	0.102	0.173	0.066	0.083	0.184	0.011
HQLI_13	0.042	0.178	0.075	0.168	0.166	0.116	0.136
HQLI_14	-0.012	0.030	-0.056	0.066	0.008	-0.008	0.024

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	PSNI_1	PSNI_2	PSNI_3	PSNI_4	PSNI_5	PSNI_6	PSNI_7
CSNI_1	0.201	0.065	0.157	0.051	0.087	0.199	0.026
CSNI_2	-0.011	0.074	-0.030	0.001	0.024	-0.010	-0.034
CSNI_3	0.268	0.069	0.358	0.109	0.127	0.299	0.095
CSNI_4	0.010	0.107	0.040	0.191	0.109	-0.005	0.092
CSNI_5	-0.005	0.075	-0.005	0.067	0.136	-0.030	0.004
CSNI_6	0.240	0.059	0.256	0.138	0.141	0.281	0.084
CSNI_7	0.001	0.019	0.001	0.110	0.039	0.040	-0.003
CSNI_8	0.220	0.061	0.264	0.095	0.118	0.261	0.096
CSNI_9	0.185	0.051	0.254	0.062	0.109	0.253	0.075
CSNI_10	-0.057	0.103	-0.009	0.222	0.108	-0.007	0.095
CSNI_11	0.181	0.049	0.200	0.108	0.127	0.194	0.085
CSNI_12	0.187	0.049	0.233	0.071	0.079	0.224	0.029
CSNI_13	0.262	0.052	0.268	0.117	0.156	0.265	0.081
CSNI_14	0.035	0.039	0.069	0.088	0.063	0.027	0.040
CSNI_15	0.008	0.055	0.066	0.091	0.056	0.031	0.036
CSNI_16	0.027	0.102	0.032	0.107	0.126	-0.027	0.067
CSNI_17	0.213	0.057	0.277	0.074	0.106	0.236	0.022
SF1	-0.023	-0.034	-0.027	0.037	0.018	0.035	0.022
SF2	-0.042	0.036	-0.013	0.065	0.010	0.060	0.071
SF3	-0.011	0.069	0.052	0.121	0.077	0.090	0.137
SF4	-0.058	0.025	0.015	0.025	0.014	0.073	0.070
SF5	-0.055	-0.010	-0.018	0.006	-0.035	0.032	0.007
SF6	-0.052	0.024	-0.038	-0.045	-0.056	-0.059	-0.022
SF7	-0.072	-0.033	-0.005	0.031	-0.009	0.008	0.044
SF8	-0.029	-0.046	-0.026	0.012	-0.021	0.038	0.024
SF9	-0.022	-0.018	0.021	0.002	0.009	0.053	0.021
SF10	-0.012	0.005	0.051	0.054	0.060	0.076	0.070
SF11	0.023	-0.061	0.028	-0.043	0.010	0.024	-0.005
SF12	0.090	-0.079	-0.015	-0.109	-0.064	-0.006	-0.008
Pt_unmet	0.079	0.035	0.134	0.069	0.085	0.205	0.091
Fc_unmet	-0.007	-0.003	-0.052	0.042	-0.008	-0.014	-0.101
Pt_Dep1	-0.100	-0.105	-0.054	-0.068	-0.066	-0.080	-0.033
Pt_Dep2	0.035	0.009	0.054	0.038	0.029	0.022	0.025
Fc_Dep1	0.006	0.062	0.003	0.012	0.012	-0.032	-0.023
Fc_Dep2	-0.030	0.019	-0.027	0.022	-0.003	-0.050	-0.064

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	PSNI_8	PSNI_9	PSNI_10	PSNI_11	PSNI_12	PSNI_13	PSNI_14
PSNI_8	1.000	—	—	—	—	—	—
PSNI_9	0.640	1.000	—	—	—	—	—
PSNI_10	0.230	0.177	1.000	—	—	—	—
PSNI_11	0.482	0.475	0.266	1.000	—	—	—
PSNI_12	0.425	0.392	0.219	0.455	1.000	—	—
PSNI_13	0.455	0.453	0.155	0.510	0.569	1.000	—
PSNI_14	0.202	0.176	0.229	0.280	0.276	0.177	1.000
PSNI_15	0.163	0.118	0.275	0.232	0.219	0.156	0.430
PSNI_16	0.241	0.174	0.279	0.307	0.286	0.171	0.404
PSNI_17	0.577	0.549	0.155	0.554	0.489	0.535	0.187
HQLI_1	0.088	0.049	0.061	0.072	0.032	0.070	0.041
HQLI_2	0.103	0.049	0.042	-0.020	0.065	0.061	0.036
HQLI_3	0.041	0.009	0.019	0.041	-0.051	-0.003	0.078
HQLI_4	-0.079	-0.109	0.052	0.032	-0.075	-0.058	-0.040
HQLI_5	0.046	-0.008	0.015	0.028	0.058	0.038	0.136
HQLI_6	-0.003	0.001	-0.072	-0.012	-0.069	0.003	-0.029
HQLI_7	-0.001	-0.008	0.018	-0.017	-0.029	-0.034	0.098
HQLI_8	0.151	0.099	0.140	0.131	0.122	0.075	0.157
HQLI_9	0.036	-0.029	0.010	-0.007	-0.014	0.005	0.079
HQLI_10	0.040	-0.006	0.026	0.086	0.045	0.006	0.147
HQLI_11	0.081	0.018	0.127	0.090	0.039	0.044	0.209
HQLI_12	0.142	0.128	0.071	0.236	0.282	0.204	0.186
HQLI_13	0.096	0.080	0.123	0.142	0.153	0.066	0.239
HQLI_14	-0.055	-0.052	0.007	-0.007	-0.040	-0.028	0.025
CSNI_1	0.124	0.099	0.045	0.150	0.119	0.135	0.086
CSNI_2	-0.034	-0.027	0.028	-0.048	-0.009	-0.075	0.069
CSNI_3	0.268	0.242	0.079	0.280	0.231	0.222	0.142
CSNI_4	0.001	0.014	0.200	0.081	0.058	-0.020	0.007
CSNI_5	-0.068	-0.009	0.013	-0.026	0.017	-0.007	-0.009
CSNI_6	0.212	0.196	0.110	0.209	0.181	0.170	0.077
CSNI_7	0.004	0.040	0.070	0.039	0.082	0.045	0.006
CSNI_8	0.218	0.207	0.043	0.220	0.206	0.194	0.101
CSNI_9	0.196	0.171	0.054	0.211	0.175	0.186	0.063
CSNI_10	-0.032	-0.066	0.242	0.069	0.060	-0.024	0.075
CSNI_11	0.169	0.155	0.092	0.193	0.130	0.201	0.014
CSNI_12	0.161	0.143	0.033	0.170	0.257	0.207	0.095
CSNI_13	0.197	0.205	0.034	0.248	0.256	0.407	0.006
CSNI_14	0.026	0.002	0.031	-0.008	0.064	-0.024	0.039
CSNI_15	0.065	0.028	0.059	-0.013	0.120	0.056	0.042
CSNI_16	0.001	-0.014	0.084	0.008	0.034	-0.024	0.135
CSNI_17	0.192	0.172	0.038	0.234	0.197	0.201	0.098

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	PSNI_8	PSNI_9	PSNI_10	PSNI_11	PSNI_12	PSNI_13	PSNI_14
SF1	-0.026	0.024	0.040	-0.004	0.026	0.024	-0.046
SF2	0.001	0.002	0.058	0.001	0.076	-0.004	0.010
SF3	0.032	0.034	0.074	0.060	0.131	0.031	-0.003
SF4	0.024	0.035	0.020	0.045	0.077	0.049	-0.016
SF5	-0.013	-0.004	0.034	-0.018	0.053	-0.016	0.014
SF6	-0.066	-0.007	-0.020	-0.048	0.001	0.005	0.018
SF7	-0.018	0.031	-0.046	0.007	0.026	0.019	0.078
SF8	-0.032	-0.026	0.023	0.001	0.110	0.003	-0.029
SF9	-0.013	-0.010	-0.018	0.013	0.064	0.068	0.058
SF10	0.014	0.022	-0.020	0.047	0.083	0.039	-0.004
SF11	0.011	-0.038	-0.047	-0.058	0.073	0.067	0.027
SF12	0.011	0.052	-0.056	-0.036	0.004	0.018	-0.020
Pt_unmet	0.129	0.130	0.078	0.159	0.148	0.203	-0.002
Fc_unmet	0.010	0.027	-0.036	-0.007	-0.002	-0.019	-0.009
Pt_Dep1	-0.093	-0.043	-0.077	-0.073	-0.028	-0.052	-0.177
Pt_Dep2	0.027	0.015	0.035	0.078	0.040	0.012	-0.073
Fc_Dep1	-0.015	0.012	0.045	0.042	-0.027	-0.003	-0.071
Fc_Dep2	-0.039	-0.012	-0.003	0.004	-0.075	-0.076	-0.035

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	PSNI_15	PSNI_16	PSNI_17	HQLI_1	HQLI_2	HQLI_3	HQLI_4
PSNI_15	1.000	—	—	—	—	—	—
PSNI_16	0.418	1.000	—	—	—	—	—
PSNI_17	0.162	0.259	1.000	—	—	—	—
HQLI_1	0.011	0.012	0.089	1.000	—	—	—
HQLI_2	-0.042	-0.038	0.071	0.149	1.000	—	—
HQLI_3	-0.038	-0.034	0.037	0.196	0.122	1.000	—
HQLI_4	0.012	-0.025	-0.071	0.111	0.125	0.230	1.000
HQLI_5	0.085	0.020	0.039	0.155	0.125	0.180	0.149
HQLI_6	0.007	-0.023	0.027	0.180	0.165	0.193	0.117
HQLI_7	0.111	0.024	-0.002	0.184	0.155	0.180	0.158
HQLI_8	0.143	0.133	0.059	0.179	0.188	0.278	0.132
HQLI_9	0.016	-0.007	0.020	0.141	0.109	0.232	0.082
HQLI_10	0.052	0.075	0.019	0.112	0.078	0.083	0.086
HQLI_11	0.102	0.126	0.050	0.145	0.072	0.093	0.092
HQLI_12	0.087	0.163	0.202	0.143	0.089	0.041	0.009
HQLI_13	0.135	0.146	0.081	0.156	0.091	0.073	0.041
HQLI_14	0.012	-0.070	-0.052	0.248	0.054	0.170	0.188
CSNI_1	0.008	0.051	0.167	0.026	0.046	0.082	-0.041

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	PSNI_15	PSNI_16	PSNI_17	HQLI_1	HQLI_2	HQLI_3	HQLI_4
CSNI_2	0.041	0.066	-0.040	-0.007	0.007	0.011	0.061
CSNI_3	0.047	0.107	0.324	0.036	0.069	-0.032	-0.020
CSNI_4	-0.005	0.080	0.038	-0.008	-0.023	0.010	0.027
CSNI_5	0.025	0.031	-0.015	0.014	0.027	-0.036	0.009
CSNI_6	0.037	0.102	0.227	0.047	0.034	-0.008	-0.004
CSNI_7	0.036	0.051	0.023	0.023	0.001	-0.024	0.002
CSNI_8	0.078	0.117	0.267	0.041	0.051	-0.021	-0.044
CSNI_9	0.070	0.055	0.220	0.049	0.018	0.025	0.004
CSNI_10	0.097	0.085	-0.005	0.020	0.035	0.037	0.076
CSNI_11	0.072	0.029	0.184	0.018	0.001	-0.011	-0.001
CSNI_12	0.080	0.051	0.224	0.003	0.049	-0.005	0.005
CSNI_13	0.034	0.055	0.279	0.018	0.056	-0.059	0.008
CSNI_14	0.044	0.078	0.036	0.063	0.066	-0.042	0.075
CSNI_15	0.067	0.055	0.033	0.001	-0.032	-0.047	0.001
CSNI_16	0.088	0.096	0.011	0.008	0.010	0.022	0.070
CSNI_17	0.031	0.076	0.264	0.009	-0.017	-0.014	-0.065
SF1	0.084	0.026	0.019	0.017	-0.030	-0.071	-0.017
SF2	0.073	-0.004	0.001	-0.009	-0.002	-0.041	0.024
SF3	0.115	0.050	0.035	-0.045	-0.022	-0.114	-0.032
SF4	0.062	0.010	0.073	-0.019	-0.026	-0.059	-0.011
SF5	0.090	0.002	0.010	-0.052	0.002	-0.083	-0.002
SF6	-0.013	0.003	0.005	-0.046	0.018	0.031	-0.009
SF7	0.110	0.042	0.040	-0.051	0.015	-0.016	-0.023
SF8	0.051	-0.008	0.020	-0.012	-0.044	-0.050	0.061
SF9	0.053	-0.006	0.084	-0.005	0.007	-0.068	0.011
SF10	0.061	0.006	0.086	-0.037	0.064	-0.043	-0.017
SF11	-0.008	-0.011	0.031	0.027	0.017	-0.016	0.042
SF12	-0.053	-0.005	0.038	-0.012	-0.010	0.022	0.038
Pt_unmet	0.066	0.058	0.132	0.002	-0.087	-0.127	-0.062
Fc_unmet	-0.005	-0.040	-0.035	-0.010	0.007	-0.009	-0.035
Pt_Dep1	-0.111	-0.084	-0.037	-0.392	-0.122	-0.263	-0.120
Pt_Dep2	-0.048	0.044	0.040	-0.157	-0.151	-0.164	-0.015
Fc_Dep1	-0.053	-0.027	-0.031	-0.077	0.001	0.018	-0.057
Fc_Dep2	-0.041	-0.018	-0.065	-0.028	-0.032	0.012	0.034

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	HQLI_5	HQLI_6	HQLI_7	HQLI_8	HQLI_9	HQLI_10	HQLI_11
HQLI_5	1.000	—	—	—	—	—	—
HQLI_6	0.378	1.000	—	—	—	—	—
HQLI_7	0.305	0.242	1.000	—	—	—	—
HQLI_8	0.312	0.187	0.360	1.000	—	—	—
HQLI_9	0.331	0.192	0.243	0.365	1.000	—	—
HQLI_10	0.177	0.059	0.141	0.115	0.144	1.000	—
HQLI_11	0.158	0.033	0.130	0.112	0.130	0.497	1.000
HQLI_12	0.244	0.052	0.116	0.170	0.132	0.228	0.146
HQLI_13	0.216	0.062	0.200	0.258	0.160	0.321	0.201
HQLI_14	0.147	0.115	0.170	0.121	0.102	0.078	0.139
CSNI_1	0.096	0.029	0.075	0.077	0.069	0.055	0.040
CSNI_2	0.053	0.042	-0.032	0.045	0.056	0.019	0.076
CSNI_3	0.097	0.052	0.010	0.092	0.080	0.044	0.087
CSNI_4	0.059	0.008	0.047	0.058	0.036	0.045	0.070
CSNI_5	0.103	0.092	0.049	0.042	0.030	-0.017	0.093
CSNI_6	0.010	0.040	-0.009	0.079	0.046	0.018	0.045
CSNI_7	0.082	0.025	0.012	0.008	-0.010	0.010	0.048
CSNI_8	0.051	0.029	0.020	0.096	0.070	0.049	0.059
CSNI_9	0.085	0.075	0.003	0.137	0.102	0.068	0.067
CSNI_10	0.065	-0.016	0.057	0.059	0.027	0.077	0.152
CSNI_11	0.049	0.034	0.028	0.055	0.098	0.030	0.082
CSNI_12	0.031	0.037	0.017	0.041	0.031	0.051	0.061
CSNI_13	0.042	0.071	-0.019	0.002	0.019	0.056	0.072
CSNI_14	0.115	0.087	0.020	0.046	0.039	0.006	0.087
CSNI_15	0.088	0.044	0.021	0.028	0.074	0.025	0.076
CSNI_16	0.056	0.008	-0.001	0.031	0.075	0.086	0.155
CSNI_17	0.056	0.035	-0.037	0.052	0.091	0.030	0.084
SF1	-0.018	0.060	-0.052	0.051	-0.004	0.024	-0.049
SF2	-0.014	0.022	-0.001	0.039	-0.084	-0.010	-0.027
SF3	-0.043	-0.022	-0.038	-0.001	-0.106	-0.032	-0.033
SF4	-0.005	-0.005	-0.050	-0.007	-0.009	0.026	-0.008
SF5	0.028	0.008	-0.016	0.012	-0.025	0.036	-0.015
SF6	0.083	0.048	-0.012	0.038	0.077	-0.046	-0.076
SF7	0.055	0.035	-0.033	0.006	-0.019	0.033	0.025
SF8	-0.032	-0.023	-0.039	-0.032	-0.055	-0.026	-0.091
SF9	0.020	0.082	-0.028	0.023	0.055	-0.012	0.010
SF10	-0.005	0.010	-0.038	0.031	0.011	0.038	-0.004
SF11	0.069	0.078	-0.044	0.001	0.034	-0.032	0.014
SF12	0.054	0.015	-0.026	0.075	0.112	0.016	-0.065
Pt_unmet	-0.261	-0.173	-0.205	-0.194	-0.218	-0.088	0.026
Fc_unmet	-0.032	-0.032	-0.003	-0.069	-0.113	0.055	0.043
Pt_Dep1	-0.366	-0.210	-0.276	-0.367	-0.277	-0.108	-0.138

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	HQLI_5	HQLI_6	HQLI_7	HQLI_8	HQLI_9	HQLI_10	HQLI_11
Pt_Dep2	-0.494	-0.291	-0.302	-0.318	-0.282	-0.100	-0.044
Fc_Dep1	-0.079	-0.103	-0.043	-0.036	-0.064	-0.031	-0.040
Fc_Dep2	-0.104	-0.113	0.009	-0.060	-0.013	0.005	0.031

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	HQLI_12	HQLI_13	HQLI_14	CSNI_1	CSNI_2	CSNI_3	CSNI_4
HQLI_12	1.000	—	—	—	—	—	—
HQLI_13	0.376	1.000	—	—	—	—	—
HQLI_14	0.033	0.112	1.000	—	—	—	—
CSNI_1	0.134	0.137	-0.029	1.000	—	—	—
CSNI_2	0.056	0.031	0.048	0.165	1.000	—	—
CSNI_3	0.173	0.115	-0.033	0.479	0.132	1.000	—
CSNI_4	0.054	0.086	0.017	0.074	0.204	0.215	1.000
CSNI_5	0.055	0.043	0.025	0.069	0.296	0.169	0.314
CSNI_6	0.149	0.030	0.010	0.446	0.192	0.615	0.241
CSNI_7	0.077	0.018	0.052	0.079	0.219	0.203	0.401
CSNI_8	0.122	0.100	-0.039	0.470	0.180	0.632	0.165
CSNI_9	0.074	0.079	0.021	0.385	0.200	0.530	0.171
CSNI_10	0.046	0.052	0.064	0.089	0.100	0.172	0.435
CSNI_11	0.130	0.094	0.021	0.386	0.171	0.541	0.213
CSNI_12	0.144	0.048	0.011	0.341	0.211	0.519	0.205
CSNI_13	0.144	0.068	0.020	0.374	0.137	0.569	0.178
CSNI_14	0.052	0.021	0.025	0.148	0.461	0.197	0.289
CSNI_15	0.014	0.013	0.030	0.103	0.275	0.149	0.313
CSNI_16	0.025	0.012	0.030	0.105	0.428	0.193	0.299
CSNI_17	0.161	0.077	0.040	0.430	0.168	0.682	0.225
SF1	0.001	0.057	-0.039	0.012	0.026	-0.027	0.036
SF2	-0.022	0.003	0.012	-0.066	-0.026	-0.094	0.087
SF3	-0.014	0.016	-0.003	-0.030	-0.026	-0.040	0.094
SF4	-0.016	0.013	0.004	-0.087	-0.033	-0.033	0.042
SF5	-0.016	-0.006	-0.031	-0.060	-0.046	-0.053	0.055
SF6	0.035	-0.058	0.023	0.017	0.034	-0.029	-0.038
SF7	0.035	0.026	0.028	-0.017	0.014	0.037	0.050
SF8	-0.057	-0.048	0.001	-0.106	-0.079	-0.064	0.008
SF9	0.056	0.042	-0.007	0.049	0.149	0.063	0.088
SF10	0.006	0.069	-0.002	0.019	0.043	0.051	0.082
SF11	0.038	0.023	-0.057	-0.004	0.218	0.019	-0.055
SF12	-0.028	-0.037	-0.029	0.071	0.005	0.011	-0.056

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	HQLI_12	HQLI_13	HQLI_14	CSNI_1	CSNI_2	CSNI_3	CSNI_4
Pt_unmet	-0.058	-0.066	0.014	-0.067	0.011	-0.060	0.046
Fc_unmet	-0.007	0.039	0.029	0.124	-0.034	0.100	-0.026
Pt_Dep1	-0.176	-0.161	-0.162	-0.038	-0.033	-0.025	-0.029
Pt_Dep2	-0.122	-0.137	-0.102	-0.032	0.001	-0.018	-0.006
Fc_Dep1	-0.012	-0.046	-0.013	-0.037	-0.146	-0.023	-0.056
Fc_Dep2	0.001	-0.033	0.008	-0.014	-0.080	0.008	0.005

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	CSNI_5	CSNI_6	CSNI_7	CSNI_8	CSNI_9	CSNI_10	CSNI_11
CSNI_5	1.000	—	—	—	—	—	—
CSNI_6	0.247	1.000	—	—	—	—	—
CSNI_7	0.275	0.267	1.000	—	—	—	—
CSNI_8	0.162	0.568	0.208	1.000	—	—	—
CSNI_9	0.139	0.548	0.231	0.598	1.000	—	—
CSNI_10	0.183	0.224	0.410	0.165	0.162	1.000	—
CSNI_11	0.223	0.576	0.251	0.480	0.444	0.247	1.000
CSNI_12	0.167	0.487	0.301	0.426	0.438	0.246	0.468
CSNI_13	0.192	0.536	0.151	0.500	0.398	0.135	0.565
CSNI_14	0.292	0.239	0.280	0.225	0.260	0.201	0.247
CSNI_15	0.270	0.227	0.393	0.224	0.245	0.339	0.253
CSNI_16	0.276	0.263	0.316	0.242	0.298	0.268	0.291
CSNI_17	0.148	0.588	0.227	0.531	0.616	0.205	0.505
SF1	0.082	0.049	0.005	0.056	-0.006	-0.001	0.055
SF2	0.002	-0.029	0.052	0.023	0.027	0.105	0.012
SF3	0.087	0.014	0.051	0.058	0.072	0.106	0.070
SF4	0.064	-0.044	0.033	-0.019	0.004	0.001	-0.058
SF5	0.012	-0.048	0.004	0.007	-0.010	0.018	-0.027
SF6	0.002	-0.091	-0.092	-0.067	-0.068	-0.053	-0.044
SF7	0.050	-0.053	0.081	-0.050	-0.035	0.010	-0.040
SF8	0.012	-0.065	0.001	-0.021	-0.042	0.003	-0.031
SF9	0.100	0.067	0.003	0.103	0.044	0.031	0.135
SF10	0.101	0.057	-0.030	0.112	0.044	0.030	0.091
SF11	0.025	-0.075	-0.046	-0.012	-0.079	-0.040	0.001
SF12	-0.041	-0.005	-0.128	0.008	-0.031	-0.113	0.049
Pt_unmet	-0.038	0.023	0.049	-0.021	-0.054	-0.002	-0.005
Fc_unmet	-0.042	0.126	0.097	0.088	0.074	0.032	0.066

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	CSNI_5	CSNI_6	CSNI_7	CSNI_8	CSNI_9	CSNI_10	CSNI_11
Pt_Dep1	0.001	0.001	0.013	-0.028	-0.048	-0.011	-0.038
Pt_Dep2	-0.020	-0.020	-0.022	-0.015	-0.038	-0.012	-0.076
Fc_Dep1	-0.049	0.012	0.013	-0.056	-0.021	0.006	-0.040
Fc_Dep2	-0.033	0.057	0.032	-0.008	0.082	0.030	0.029

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	CSNI_12	CSNI_13	CSNI_14	CSNI_15	CSNI_16	CSNI_17	SF1
CSNI_12	1.000	—	—	—	—	—	—
CSNI_13	0.507	1.000	—	—	—	—	—
CSNI_14	0.271	0.209	1.000	—	—	—	—
CSNI_15	0.228	0.177	0.440	1.000	—	—	—
CSNI_16	0.307	0.196	0.531	0.465	1.000	—	—
CSNI_17	0.499	0.500	0.224	0.236	0.261	1.000	—
SF1	-0.049	0.074	0.053	0.086	0.019	-0.048	1.000
SF2	-0.005	-0.010	0.040	0.110	0.032	-0.046	0.408
SF3	0.020	0.076	0.087	0.115	0.078	-0.054	0.379
SF4	-0.040	0.004	0.033	0.028	-0.006	-0.012	0.435
SF5	-0.026	-0.026	0.076	0.077	0.040	-0.036	0.416
SF6	-0.080	-0.034	0.002	-0.037	-0.024	-0.015	0.146
SF7	-0.027	-0.007	0.018	0.027	0.021	0.015	0.129
SF8	-0.074	0.015	-0.016	0.015	-0.028	-0.074	0.428
SF9	0.068	0.125	0.230	0.126	0.108	0.026	0.220
SF10	0.003	0.101	0.115	0.147	0.074	0.020	0.439
SF11	-0.029	0.027	0.192	0.082	0.057	-0.046	0.187
SF12	-0.082	-0.001	0.007	0.013	-0.032	-0.003	0.208
Pt_unmet	0.060	0.054	0.040	0.033	0.070	-0.045	-0.063
Fc_unmet	0.086	0.098	-0.030	-0.064	0.009	0.088	-0.095

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	SF2	SF3	SF4	SF5	SF6	SF7	SF8
SF2	1.000	—	—	—	—	—	—
SF3	0.599	1.000	—	—	—	—	—
SF4	0.445	0.401	1.000	—	—	—	—
SF5	0.553	0.466	0.625	1.000	—	—	—
SF6	0.085	0.022	0.256	0.154	1.000	—	—
SF7	0.134	0.059	0.199	0.128	0.394	1.000	—
SF8	0.521	0.413	0.475	0.574	0.117	0.132	1.000
SF9	0.153	0.110	0.200	0.215	0.350	0.314	0.186
SF10	0.320	0.337	0.331	0.348	0.286	0.238	0.348
SF11	0.048	0.020	0.113	0.091	0.301	0.239	0.132
SF12	0.111	0.049	0.205	0.197	0.386	0.172	0.239
Pt_unmet	0.072	0.078	0.023	0.017	-0.134	0.041	0.016
Fc_unmet	-0.104	-0.123	-0.231	-0.172	-0.278	-0.202	-0.168
Pt_Dep1	0.017	0.053	0.058	0.031	-0.044	0.018	-0.003
Pt_Dep2	-0.027	0.037	0.017	-0.064	-0.089	-0.019	0.003
Fc_Dep1	-0.087	-0.098	-0.171	-0.185	-0.334	-0.302	-0.231
Fc_Dep2	-0.067	-0.038	-0.172	-0.145	-0.383	-0.305	-0.187

Table A1

The Correlation Matrix of the Indicators (Continued)

Variables	Pt_Dep2	Fc_Dep1	Fc_Dep2
Pt_Dep2	1.000	—	—
Fc_Dep1	-0.002	1.000	—
Fc_Dep2	0.067	0.549	1.000

Note. $N = 660$.

Appendix C: Key to the Corresponding Variable Names

Table A2

Key to the Corresponding Variable Names

Latent Variables	Corresponding Indicators
Functional Well-Being	
HQLI_3	How well do you eat?
HQLI_7	How satisfied do you feel with your ability to concentrate on things?
HQLI_8	How much enjoyable activity do you have?
HQLI_9	How satisfied are you with your level of independence?
Social/Spiritual Well-Being	
HQLI_10	How satisfied are you with the physical care that you are receiving?
HQLI_11	How satisfied are you with the emotional support you get from your health care team?
HQLI_12	How satisfied are you with your relationship with God (however you define that relationship)?
HQLI_13	Do your surroundings help improve your sense of well-being?
Psycho-Physiological Well-Being	
HQLI_1	How well do you sleep?
HQLI_2	How breathless do you feel?
HQLI_4	How constipated are you?
HQLI_5	How sad do you feel?
HQLI_6	How worried do you feel about what is happening to you?
HQLI_14	If you experience pain, how completely is it relieved?
Physical Health	
SF1	General health
SF2	Limited in moderate activities
SF3	Limited in climbing several stairs
SF4	Accomplished less due to physical health.
SF5	Limited in kind of work
SF8	Pain interfere with work
Mental Health	
SF6	Accomplished less due to emotional health
SF7	Not work as carefully
SF9	Felt calm and peaceful
SF10	Have a lot of energy
SF11	Felt downhearted and blue
SF12	Physical/emotional interfere with social
Religious Needs	
SNI_1	Sing/listen to inspirational music
SPI_3	Read a religious text
SNI_6	Talk with someone about spiritual issues
SNI_8	Read inspirational materials
SNI_9	Use inspirational materials
SNI_11	Be with people who share my spiritual beliefs

Table A2

Key to the Corresponding Variable Names (Continued)

Latent Variables	Corresponding Indicators
SNI_12	Pray
SNI_13	Go to religious services
SNI_17	Use phrases from religious texts
Outlook Needs	
SNI_2	Laugh
SNI_5	Be with friends
SNI_14	Think happy thoughts
SNI_15	Talk about day to day things
SNI_16	See smiles of others
Community Needs	
SNI_4	Be with family
SNI_7	Have information about family and friends
SNI_10	Be around children (own or others' children)

Appendix D: Hospice Quality of Life Index-14

HOSPICE QUALITY OF LIFE INDEX-14-REVISED

The questions listed below will ask about how you are feeling at the moment and how your illness has affected you. Please **circle the number on the line** under each of the questions that best shows what is happening to you at the present time.

1) How well do you sleep?

not at all 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very well

2) How breathless do you feel?

extremely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

3) How well do you eat?

poorly 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very well

4) How constipated are you?

extremely 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

5) How sad do you feel?

very sad 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

6) How worried do you feel about what is happening to you?

very worried 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 not at all

7) How satisfied do you feel with your ability to concentrate on things?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very
satisfied

8) How much enjoyable activity do you have?

none 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 a great deal

9) How satisfied are you with your level of independence?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very
satisfied

10) How satisfied are you with the physical care that you are receiving?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very
satisfied

11) How satisfied are you with the emotional support you get from your health care team?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very
satisfied

12) How satisfied are you with your relationship with God (however you define that relationship)?

very
dissatisfied 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very
satisfied

13) Do your surroundings help improve your sense of well-being?

not at all 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 very much

14) If you experience pain, how completely is it relieved?

no relief 0 ___ 1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 ___ 8 ___ 9 ___ 10 complete relief

EVALUATION OF MOOD CES-D

Did you experience the following much of the time during the past week?

<u>YES</u>	<u>NO</u>	
_____	_____	I enjoyed life.
_____	_____	I felt that everything I did was an effort.
_____	_____	My sleep was restless.
_____	_____	I was happy.
_____	_____	I felt lonely.
_____	_____	I felt depressed.
_____	_____	People were unfriendly.
_____	_____	I felt sad.
_____	_____	I felt that people disliked me.
_____	_____	I could not get going.

TOTAL: _____

Appendix F: Spiritual Needs Inventory

SPIRITUAL NEEDS INVENTORY

Directions: This questionnaire contains 17 phrases that describe needs (activities, thoughts, or experiences) that some people have said they have during times of stress. For some people these needs relate to the spiritual part of them. They define spiritual as that part of them that tries to find meaning and purpose in life. They believe a spiritual need is something they need or want in order to live their lives fully. Please mark the items that you consider to be your spiritual needs, and which of these are currently not met.

Read the need in column A and then the questions in columns B and C before going on to the next need.

Column A In order to live my life fully, I need to:	Column B Please rate the items in the column below. For every item in the column that you answer 2 or higher, please answer yes or no in Column C Never Rarely Sometimes Frequently Always					Column C Is this need being met in your life right now?	
1. Sing/listen to inspirational music	1	2	3	4	5	Yes	No
2. Laugh	1	2	3	4	5	Yes	No
3. Read a religious text (for example, Bible, Koran, Old Testament)	1	2	3	4	5	Yes	No
4. Be with family	1	2	3	4	5	Yes	No
5. Be with friends	1	2	3	4	5	Yes	No
6. Talk with someone about spiritual issues	1	2	3	4	5	Yes	No
7. Have information about family and friends	1	2	3	4	5	Yes	No
8. Read inspirational materials	1	2	3	4	5	Yes	No
9. Use inspirational materials (for example, repeating or living by phrases or poems)	1	2	3	4	5	Yes	No

Column A In order to live my life fully, I need to:	Column B Please rate the items in the column below. For every item in the column that you answer 2 or higher, please answer yes or no in Column C Never Rarely Sometimes Frequently Always					Column C Is this need being met in your life right now?
10. Be around children (own or others' children)	1	2	3	4	5	Yes No
11. Be with people who share my spiritual beliefs	1	2	3	4	5	Yes No
12. Pray	1	2	3	4	5	Yes No
13. Go to religious services	1	2	3	4	5	Yes No
14. Think happy thoughts	1	2	3	4	5	Yes No
15. Talk about day to day things	1	2	3	4	5	Yes No
16. See smiles of others	1	2	3	4	5	Yes No
17. Use phrases from religious texts (for example: using phrases to guide you each day such as "Greater is He that is in me, than He that is in the world")	1	2	3	4	5	Yes No

Other spiritual needs identified by the caregiver:

TOTAL: _____
