



University of Pennsylvania  
ScholarlyCommons

---

Doctorate in Social Work (DSW) Dissertations

School of Social Policy and Practice

---

Summer 8-8-2014

# Problem-Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled Pilot Study

Christin Ann Gregory

University of Pennsylvania, [annchris@sp2.upenn.edu](mailto:annchris@sp2.upenn.edu)

Follow this and additional works at: [http://repository.upenn.edu/edissertations\\_sp2](http://repository.upenn.edu/edissertations_sp2)

 Part of the [Clinical and Medical Social Work Commons](#), and the [Social Work Commons](#)

---

## Recommended Citation

Gregory, Christin Ann, "Problem-Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled Pilot Study" (2014).  
*Doctorate in Social Work (DSW) Dissertations*. 55.  
[http://repository.upenn.edu/edissertations\\_sp2/55](http://repository.upenn.edu/edissertations_sp2/55)

This paper is posted at ScholarlyCommons. [http://repository.upenn.edu/edissertations\\_sp2/55](http://repository.upenn.edu/edissertations_sp2/55)  
For more information, please contact [libraryrepository@pobox.upenn.edu](mailto:libraryrepository@pobox.upenn.edu).

---

# Problem-Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled Pilot Study

## Abstract

### Abstract

Problem-Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled Pilot Study

Christin Ann Gregory, LCSW, DSW Candidate, University of Pennsylvania

**Problem:** U.S. Hospice care is a growing service for the terminally ill, ever more important as our aging population expands. Informal caregivers are integral to the hospice philosophy, considered to be a part of the hospice unit of care. These caregivers are the major providers of hands-on and emotional care for the dying. They face shift in family role, loss of employment and personal time, and have been shown to suffer from increased mental and physical health issues as a direct effect of caregiving. The predominant unmet need of the hospice caregiver is psychological. The hospice social worker is the major provider of psychological services for the hospice caregiver, but at present, there is a lack of evidence-based research on caregiver interventions in this clinical setting.

**Objectives:** This study examined the feasibility and efficacy of Problem-Solving Therapy (PST) in improving mood, quality of life, and problem-solving skills for primary (informal) caregivers of home-based hospice patients.

**Design:** This study employed a randomized controlled design, comparing the effects of brief problem-solving therapy for hospice caregivers (PST-Hospice) and usual care plus caregiver education (UC+CE) on hospice caregiver outcomes. A baseline survey was collected after informed consent, followed by five weekly forty-five minute sessions of PST treatment or the provision of caregiver coping educational materials. Post-test surveys were administered post intervention completion (6 weeks). Qualitative interviews were also conducted to give voice to the caregiver experience.

**Setting:** This study was conducted between November 15<sup>th</sup>, 2013 and May 16<sup>th</sup>, 2014. Participants were gathered from home-based admissions at two South Jersey hospice agencies: one for-profit agency, and one not-for-profit agency.

**Inclusion Criteria:** (1) Primary informal caregivers, (2) Caring for patients who reside in a home residence or assisted living, (3) age 18 or older, (4) able to speak English, (5) willing to participate.

**Measures:** Demographic information (age, sex, gender, relationship to patient, marital status, ethnicity, employment, education, income, household number, patient diagnosis, assistance with care) was gathered pretreatment. Outcomes measured at pre-treatment and post-treatment (5 weeks post randomization) were: (1) *The Brief Patient Health Questionnaire Mood Scale (PHQ-9)*, (2) *The Caregiver Quality of Life Index- Cancer (CQOLC)*, (3) *The Social Problem Solving Inventory-Revised Short Form (SPSI-R Short)*.

**Data Analysis:** 1) Descriptive statistics were gathered for demographic information. 2) T-tests and Chi-Squares were used to determine differences between groups. 3) To determine mean differences between conditions for primary outcome variables, t-tests were conducted. 4) Qualitative interviews with 3 study participants were completed to gain information about their experience being a part of this study.

---

*Keywords: social work, hospice, palliative care, caregivers, problem-solving therapy, randomized trial, quality of life, social work interventions, evidence-based practice (EBP)*

**Degree Type**

Dissertation

**Degree Name**

Doctor of Social Work (DSW)

**First Advisor**

Zvi D. Gellis, PhD

**Second Advisor**

Holly Nelson-Becker, PhD

**Third Advisor**

Amy M. Corcoran, MD

**Keywords**

social work, hospice, palliative care, caregivers, problem-solving therapy, randomized trial, quality of life, social work interventions, evidence-based practice

**Subject Categories**

Clinical and Medical Social Work | Social and Behavioral Sciences | Social Work

**Problem Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled  
Pilot Study**

**Christin Ann Gregory, LCSW, DSW Candidate**

A DISSERTATION

In

Social Work

Presented to the Faculties of the University of Pennsylvania

In

Partial Fulfillment of the Requirements for the

Degree of Doctor of Clinical Social Work

2014

Zvi D. Gellis, PhD  
Dissertation Chair

Richard Gelles, PhD  
Dean, School of Social Policy and Practice

Dissertation Committee  
Holly Nelson-Becker, PhD  
Amy Corcoran, MD

### **Dedication**

This study is dedicated to the thirty-seven hospice caregivers who welcomed me into their lives and their homes, and allowed me to learn from them for the purposes of research. They took time out of their incredibly busy and stressful lives, they trusted me, and they shared their stories with me. I will be forever grateful for that honor. Through them I became acutely aware of the daily struggles and hardships hospice caregivers face. I am in awe of their strength and ability to carry on despite the physical and emotional strain of caregiving for a loved one who is dying. I truly hope that the knowledge produced from this research will serve to improve hospice social work interventions with caregivers, and lead to better support and enhanced quality of life for future caregivers of the dying.

## Abstract

### Problem-Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled Pilot Study

Christin Ann Gregory, LCSW, DSW Candidate, University of Pennsylvania

**Problem:** U.S. Hospice care is a growing service for the terminally ill, ever more important as our aging population expands. Informal caregivers are integral to the hospice philosophy, considered to be a part of the hospice unit of care. These caregivers are the major providers of hands-on and emotional care for the dying. They face shift in family role, loss of employment and personal time, and have been shown to suffer from increased mental and physical health issues as a direct effect of caregiving. The predominant unmet need of the hospice caregiver is psychological. The hospice social worker is the major provider of psychological services for the hospice caregiver, but at present, there is a lack of evidence-based research on caregiver interventions in this clinical setting.

**Objectives:** This study examined the feasibility and efficacy of Problem-Solving Therapy (PST) in improving mood, quality of life, and problem-solving skills for primary (informal) caregivers of home-based hospice patients.

**Design:** This study employed a randomized controlled design, comparing the effects of brief problem-solving therapy for hospice caregivers (PST-Hospice) and usual care plus caregiver education (UC+CE) on hospice caregiver outcomes. A baseline survey was collected after informed consent, followed by five weekly forty-five minute sessions of PST treatment or the provision of caregiver coping educational materials. Post-test surveys were administered post intervention completion (6 weeks). Qualitative interviews were also conducted to give voice to the caregiver experience.

**Setting:** This study was conducted between November 15<sup>th</sup>, 2013 and May 16<sup>th</sup>, 2014. Participants were gathered from home-based admissions at two South Jersey hospice agencies: one for-profit agency, and one not-for-profit agency.

**Inclusion Criteria:** (1) Primary informal caregivers, (2) Caring for patients who reside in a home residence or assisted living, (3) age 18 or older, (4) able to speak English, (5) willing to participate.

**Measures:** Demographic information (age, sex, gender, relationship to patient, marital status, ethnicity, employment, education, income, household number, patient diagnosis, assistance with care) was gathered pretreatment. Outcomes measured at pre-treatment and post-treatment (5 weeks post randomization) were: (1) *The Brief Patient Health Questionnaire Mood Scale (PHQ-9)*, (2) *The Caregiver Quality of Life Index- Cancer (CQOLC)*, (3) *The Social Problem Solving Inventory-Revised Short Form (SPSI-R Short)*.

**Data Analysis:** 1) Descriptive statistics were gathered for demographic information. 2) T-tests and Chi-Squares were used to determine differences between groups. 3) To determine mean differences between conditions for primary outcome variables, t-tests were conducted. 4) Qualitative interviews with 3 study participants were completed to gain information about their experience being a part of this study.

*Keywords: social work, hospice, palliative care, caregivers, problem-solving therapy, randomized trial, quality of life, social work interventions, evidence-based practice (EBP)*

**Table of Contents**

Chapter 1: Problem Statement.....	10
1.1 Incidence and Prevalence.....	10
1.2 Significance.....	10
1.3 Purpose of the Study.....	12
Chapter 2: Literature Review.....	13
2.1 Hospice Background.....	13
2.2 Hospice Team.....	14
2.3 Hospice Caregivers.....	15
2.4 Caregiver Interventions.....	19
2.5 Problem-Solving Therapy and Hospice and Palliative Care.....	23
2.6 Hospice Social Work.....	27
Chapter 3: Study Aims and Hypothesis.....	30
3.1 Study Aims.....	30
3.2 Hypothesis.....	30
Chapter 4: Methods.....	32
4.1 Study Site.....	32
4.2 Recruitment.....	32
Participants.....	32
Inclusion Criteria.....	32
Exclusion Criteria.....	33
Procedures.....	33
Randomization.....	34

Chapter 5: Measures.....	36
5.1 Variables.....	36
5.2 Demographic Information.....	36
5.3 Outcomes.....	36
5.4 Treatment Conditions.....	37
PST-Hospice.....	37
UC+CE.....	41
5.5 Protection of Human Subjects.....	41
Chapter 6: Analysis.....	42
6.1 Quantitative.....	42
6.2 Qualitative.....	42
Chapter 7: Results.....	43
7.1 Participant Flow.....	43
7.2 Participant Characteristics.....	46
7.3 Primary Outcomes.....	50
7.4 Intervention Effects.....	50
7.5 Secondary Analysis.....	51
7.6 Caregiver Case Study Examples.....	51
7.7 Qualitative Interviews.....	63
Chapter 8: Discussion.....	68
8.1 Findings.....	68
8.2 Implications.....	69
8.3 Application to Social Work Practice.....	72



8.4 Limitations.....72

8.5 Clinical Reflections.....74

References.....78

**List of Tables**

Table 1: PST-Hospice Content by Session.....	39
Table 2: Descriptive Statistics for Baseline Variables.....	47
Table 3: Means and Standard Deviations of Pre-Test and Post-test outcome measures.....	50
Table 4: Results of Independent Samples T-Tests for Change Scores of Primary Outcome Measures.....	51

**List of Illustrations**

Figure 1: Study Flow Diagram.....45

**List of Appendices**

Appendix A: Study Procedures .....92

Appendix B: Study Introduction.....94

Appendix C: Caregiver Coping Informational Pamphlet.....95

Appendix D: Qualitative Interview Guide.....97

## **Chapter 1: Problem Statement**

### **1.1 Incidence and Prevalence**

Each year in the U.S, more than 1.65 million patients receive hospice care, and in 2011, 44.6% of all U.S. deaths occurred while receiving hospice care (National Hospice and Palliative Care Organization [NHPCO] Facts and Figures, 2012). In recent years hospice has been more widely used, which has led to scrutiny by insurers and the State and Federal government (Lang & Cabin, 2011; Cabin, 2010; Miller, Lima, Gozalo, & Mor, 2010; Weisenfluth & Csikai, 2013). Despite evidence that hospice care saves Medicare money at the end of life (Kelley, Deb, Du, Aldridge Carlson, & Morrison, 2013), hospice has been facing funding cuts, which may continue (NHPCO Press Releases, 2013). Meanwhile, little empirical attention has been given to the evaluation of hospice services (Kapp & Nelson-Becker, 2007).

### **1.2 Significance**

Hospice caregivers are a significant piece of the hospice philosophy of care. Informal caregivers are called upon to meet a large proportion of end-of-life care needs (Aoun, Kristjanson, Currow, & Hudson, 2005; Bramwell, MacKenzie, Laschinger, & Cameron, 1995; Hudson et al., 2008; Roberto & Jarrott, 2008). People are living longer, but with increased health problems, which can necessitate assistance with personal and medical tasks (Aoun, Kristjanson, Currow, & Hudson, 2005). For the caregiver, this often causes employment interruption, a shift in family role, lifestyle changes (Chentsova-Dutton et al., 2000; Roberto & Jarrott, 2008), and disruption of routines and leisure activities (Stajduhar & Davies, 1998). The strain of caregiving can negatively affect the health and well-being of the carer (Harding & Higginson, 2003). Providing care for the terminally ill can lead to increased stressors, a lack of sleep and exhaustion (Bramwell, MacKenzie, Laschinger, & Cameron, 1995), and can cause

emotional and physical strain for even for the most capable of caregivers (Empeño, Raming, Irwin, Nelesen, & Lloyd, 2011). Caregiver stress sometimes leads to hospitalization or use of the hospice respite benefit, which may contradict patient end-of-life wishes (Bramwell, MacKenzie, Laschinger, & Cameron, 1995), and can increase caregiver and patient distress (Empeño, Raming, Irwin, Nelesen, & Lloyd, 2011).

Hospice social workers are an integral part of the hospice interdisciplinary team. They provide various psychosocial supportive interventions to patients and families (MacDonald, 1991). Research has demonstrated that social work involvement is related to reduced costs, fewer hospitalizations, on-call, and nursing visits, higher quality of life for patients, and improved satisfaction (Reese & Raymer, 2004). However at present, hospice social workers face role ambiguity, underutilization (Bosma et al., 2010; Reese, 2011), and a lack of evidence-based interventions to draw from their work with patients and caregivers (Altilio, Gardia, & Otis-Green, 2008; Bosma et al., 2010; Jones, Pomeroy, & Sampson, 2009; MacDonald, 1991).

Problem-Solving Therapy (PST), a cognitive-behavioral intervention for enhancing problem-solving abilities (D’Zurilla & Nezu, 2007; Nezu, Nezu, & D’Zurilla, 2013), has been shown effective in use with a wide-range of problems and populations (Alexopoulos, Raue, & Areán, 2003; Dugas et al., 2003; D’Zurilla & Nezu, 2007; Gellis & Bruce, 2010; Gellis, McGinty, Horowitz, Bruce & Misener, 2007; Gellis et al., 2008; Nezu, Nezu, & Perri, 1989; Liberman, Eckman, & Marder, 2001; Lopez & Melmerstein, 1995; Provencher, Dugas, & Ladouceur, 2004; Teri, Logsdon, Uomoto, & McCurry, 1997), and has recently gained empirical attention for its potential benefits in the hospice setting (Demiris et al., 2010; Parker Oliver, Washington, Demiris, Wittenberg-Lyles, & Novak, 2012; Wood & Mynors-Wallis, 1997). PST

may be a useful intervention for social workers as they interact with hospice patients and their caregivers.

### **1.3 Purpose of the Study**

The purpose of this study was to test in a randomized trial, the impact of brief PST-Hospice delivered by a clinical hospice social worker on caregiver outcomes as compared to a usual care condition augmented with caregiver coping education materials.

## Chapter 2: Literature Review

### 2.1 Hospice Background

The term “Hospice” was first used by Dame Cicely Saunders in her work with the terminally ill in the late 1940’s. She established St. Christopher’s Hospice in England in 1967, and soon began training nurse Florence Wald of the Yale School of Nursing. This, in addition to the national attention sparked by Elisabeth Kübler-Ross’s *On Death and Dying* (1969), a book based on interviews with dying persons, led to Wald’s founding of the first U.S Hospice in 1974. In 1983, Medicare began reimbursing hospice under Part A, and now regulates eligibility criteria and sets forth hospice care guidelines for Medicare-certified hospice programs across the nation (NHPCO Facts and Figures 2012; Rhymes, 1990). Hospice utilization has grown steadily over the past thirty years and in 2004 crossed the 1 million mark for persons served nation-wide. In 2011 an estimated 1.65 million Americans were served by about 5,300 programs and 44.6% of all U.S. deaths were receiving hospice care (NHPCO Facts and Figures, 2012).

In the beginning, hospice care serviced mostly cancer patients. Now, as more attention has been given to the field of death and dying and eligibility criteria have expanded, other terminally ill populations are serviced by hospice (NHPCO Facts and Figures, 2012). A recent report from the National Hospice and Palliative Care Organization (NHPCO) shows that in 2011, less than half (37.7%) of all persons admitted to hospice had a primary diagnosis of cancer, the next most prominent diagnoses being debility unspecified (13.9%), dementia (12.5%), heart disease (11.4%) and lung disease (8.5%), with the remaining proportion representing stroke/coma, kidney disease, liver disease, ALS and non-ALS motor neuron disease, HIV/AIDS and other terminally ill diagnoses. In 2011, 56.4% of hospice patients were female, 82.8% identified as Caucasian, 8.5% identified as African American, 6.1% identified as Multi-



race/other, 2.4% identified as Asian, Hawaiian, other Pacific Islander, and 0.2% identified as American Indian or Alaskan Native. Of this total population, 6.2% identified as being of Hispanic or Latino origin. The typical age of patients receiving hospice care is 65 and over (83.3% in 2011), most of whom are 85 years and older. Few hospice patients are under 35 years of age, but hospice does service all age groups including pediatric patients (NHPCO Facts and Figures, 2012).

A majority of hospice patients receive hospice care in a private home. Hospice patients residing at home at the time of their death accounted for 41.6% of the total population in 2011 (NHPCO Fact and Figures, 2012), 26.1% were in an inpatient facility, and 18.3% were residing in a nursing home. Hospice care is also provided to persons in residential facilities and in hospitals. Hospice agencies that deliver this care vary in size and by organization type. The most common agency type in 2011 was free standing/independent (57.5%) and the most common organizational tax status was for-profit (60.0%) (NHPCO Facts and Figures, 2012).

## **2.2 Hospice Team**

Hospice is the major form of palliative care in the United States. Palliative care is defined as:

an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organization [WHO] Definition of Palliative Care, 2013, paragraph 1)

Hospice care is typically provided in the patient's home, and is covered by Medicare, Medicaid, most private insurances, and HMOs. Hospice care is provided by an interdisciplinary team,

which consists of the patient's primary care physician, the hospice physician or medical director, nurses, social workers, clergy/chaplains, home health aides, and volunteers. In addition, there may be physical, speech, or occupational therapists provided as needed (NHPCO Hospice Care: What is Hospice, 2013).

### **2.3 Hospice Caregivers**

Hospice is about caring, not curing (NHPCO Facts and Figures, 2012). It is the philosophy of hospice care to view the dying patient and their family as a single unit of care (Decker & Young, 1991; Demiris, Parker Oliver, Wittenberg-Lyles, 2009; Hudson, 2003), and the goal of hospice is to provide the highest level of quality of life for dying persons and their caregivers (Hudson & Hayman-White, 2006). Typically, a family member, rather than a paid caregiver or medical staff person serves as the primary caregiver (Bramwell, MacKenzie, Laschinger, & Cameron, 1995; Empeño, Raming, Irwin, Neleson, & Lloyd, 2011; NHPCO Facts and Figures, 2012). They are often responsible for symptom and medication management (Hudson et al., 2008; Weitzner, Moody, & McMillan, 1997), as well as personal hygiene care (Hudson et al., 2008), and the hospice team looks to primary caregivers for information about patient symptoms (Weitzner et al., 1997).

Hospice caregivers face mental and physical health issues (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). They have been shown to experience significantly higher levels of life stress, depression, obsessive-compulsive symptoms, anxiety, hostility, psychoticism, and overall psychopathology, than non-caregiver counterparts (Chentsova-Dutton et al., 2000). They have poorer health, lower social functioning, and while caring have worked/volunteered less than non-caregivers (Chentsova-Dutton et al., 2000). They can also face exhaustion and sleeplessness (Harding, List, Epiphaniou, & Jones, 2011) and loss of wages while providing care (Muurinen,

1986). Family caregivers are at risk for developing complicated grief (Ghesquiere, Martí Haidar, & Shear, 2011), and among elderly spousal caregivers, experiencing mental or emotional strain has been shown to be a risk factor for mortality (Schulz & Beach, 1999). Caregivers face multiple stressors, which directly impacts their ability to provide care to their loved one. This also impacts the hospice patients' quality of life (Gill, Kaur, Rummans, Novotny, & Sloan, 2003).

One reason for hospitalization of the terminally ill is caregiver exhaustion (Bramwell, MacKenzie, Laschinger, & Cameron, 1995) or inability to provide care (Skilbeck et al., 2005), which can in turn lead to other issues. Hospitalization of a loved-one in the final few days of life may be perceived as a personal failure if the patient/family goal was for their loved-one to die at home, which can negatively affect the bereavement process (Bramwell, MacKenzie, Laschinger, & Cameron, 1995).

While most patients would rather die at home (Hudson et al., 2008; Hudson, Lobb, et al., 2012; Stajduhar & Davies, 1998; Tang, 2003), in 2011 only 41.6% of hospice patients received care in a private residence. Home death is an important goal in hospice. Due to health care costs and symptom management needs, providing end-of-life care at home may be ideal for patients and families. However the extraordinary time and emotional demands that this presents families can be barriers to death at home (Stajduhar & Davies, 1998). Patients are more likely to die at home when caregivers receive the proper preparation and support to maintain care in the home (Hudson et al., 2008), but this task is challenging for hospice professionals due to family-related and health care system obstacles (Hudson, Aranda, & Kristjanson, 2004).

Respite is a hospice benefit offered to enable caregiver breaks (Centers for Medicare and Medicaid [CMS] Medicare Hospice Benefits, 2011; NHPCO Hospice Inpatient Respite Care,

2008), and is paid for by the primary insurance provider, typically Medicare (CMS Medicare Hospice Benefits, 2011). However, the respite experience is not always positive. Eaton (2008) found that respite care can be experienced negatively by caregivers. Removing a patient from the home environment may offer caregiver rest, but does not necessarily prevent future stress and burnout or need for additional respite stays. Some beneficiaries who utilize the respite benefit have been found to use it multiple times in a year (Weems, 2008). Caregivers may find respite stressful due to feelings of guilt surrounding the removal of their relative from the home, or concern over the quality of care that would be provided in respite. If concerns over care quality exist, caregivers are more likely to be distressed by the respite experience (Skilbeck et al., 2005). Thus respite care may not be the most effective way to address or prevent future caregiver stress, and in some situations, may make stress worse.

The unmet needs of caregivers have been echoed throughout the palliative care literature for over twenty years (Grande, Todd, & Barclay, 1997; Hudson, Aranda, & Kristjanson, 2004; Hudson & Payne, 2011; Hudson et al., 2008; Hudson, Remedios, et al., 2012; Kristjanson & Aoun, 2004; Soothill et al, 2003; Stajduhar & Davies, 1998; Wingate & Lackey, 1989). Unmet needs include practical ones like help with transportation, housework (Grande, Todd, & Barclay, 1997), financial matters and filling out forms (Soothill et al., 2003); as well as psychological needs (Wingate & Lackey, 1989) like reassurance from health care workers (Grande, Todd, & Barclay, 1997), help dealing with guilt and tiredness, addressing sexual needs and identifying opportunities to meet other caregivers. When caregivers have significant unmet needs, it affects their ability to support and care for the patient, and thus may affect the patient negatively (Soothill et al., 2003). One common unmet need is a lack of information regarding the caregiving role (Hudson & Payne, 2011; Hudson, Lobb, et al., 2012). These needs can be

complicated by the many factors that contribute to caregiving. Some caregivers may feel that asking for help in the home conflicts with patients' wishes. Caregivers may be hesitant to ask for help out of concern for the health professionals' time, or a belief that they lack available resources (Grande, Todd, & Barclay, 1997). These unmet needs are significant, considering that a major role of the hospice team is to provide family caregiver support (NHPCO Facts and Figures, 2012).

Unfortunately, there have been questions about the services and quality of care provided to family caregivers (Hudson & Payne, 2011). A recent systematic literature review (Hudson & Payne, 2011) presented the current status of palliative family caregivers. It highlighted the reasons why caregiver support is so important. A few important findings were: caregivers have needs equal or even greater than patient needs; caregivers can improve the care and well-being of palliative patients; caregivers are needed to achieve successful care at home, which is the preferred place of death for most people; caregivers are large financial contributors to the health care system; and caregivers do have the potential to benefit from the caregiver experience.

Empeño, Raming, Irwin, Neleson, & Lloyd (2011) found that the provision of additional in-home services (like direct patient care, help with meals, or housekeeping) for hospice caregivers decreased caregiver stress and reduced the use of the hospice respite benefit. A recent meta-analysis by the Cochrane Collaboration (Candy, Jones, Drake, Leurent, & King, 2011) demonstrated that emotionally supportive interventions may also reduce the psychological distress of caregivers, but evidence of effective interventions is lacking and further research is indicated. They call for providers to consider caregiver needs in formulating appropriate interventions.

Hospice social workers are in the position to provide such interventions. In hospice settings, social work involvement consists of case management and supportive services. Supportive counseling services are a large component of the hospice social work role, and are provided to the patient and patient's family member or caregiver (Social Work Policy Institute, 2010). Thus, hospice social workers are positioned to provide effective interventions to reduce caregiver distress and improve their quality of life.

#### **2.4 Caregiver Interventions**

In hospice, patients and their family caregivers are viewed as a single unit of care (Decker & Young, 1991; Demiris, Parker Oliver, Wittenberg-Lyles, 2009; Hudson, 2003). Caregiver burden is related to patient symptom distress (Andrews, 2001); how caregivers perceive the quality of life of the patient is positively correlated with their own quality of life (McMillan & Mahon, 1994); and their concerns are tied to the hospice patient, or often times reciprocated by the patient (Wittenberg-Lyles, Demiris, Parker Oliver, & Burt, 2011). Previous research demonstrated that hospice caregiver quality of life is correlated with hospice patient quality of life (Gill, Kaur, Rummans, Novotny, & Sloan, 2003). However improving patient quality of life may not improve caregiver burden or quality of life (Clark et al., 2006). Since hospice care targets the caregiver as well as the patient, caregiver-specific interventions have been developed and tested. However, caregiver needs remain unmet. (Harding, List, Epiphaniou, & Jones, 2011).

A 2003 systematic review of caregiver intervention literature (Harding & Higginson) found a lack of cancer and palliative caregiver intervention studies. In this review, twenty-two studies were identified that specifically examined caregivers. Only six of those studies included evaluation, and only two used a randomized controlled design. An updated review (Harding,

List, Epiphaniou, & Jones, 2011) showed that while things have improved in recent years, overall efficacy studies are limited in scope and methodology. Thirty-three intervention studies met review inclusion criteria and were aimed at palliative or cancer caregivers. Seventeen studies were directed solely at caregivers, and sixteen were directed at patients and their caregivers. The review identified six intervention types: one-to-one psychological models (n=8), psychological interventions for patient/caregiver dyads (n=4), palliative care/hospice interventions (n=8), information and training interventions (n=3), respite interventions (n=1), and group interventions (n=10). Although there was a growth of intervention studies and an increase in outcome measures, they found that many limitations still exist for hospice caregiver research. Participant attrition is an ever-present concern due to the nature of hospice care, as is timing of interventions and post-tests. The authors posited that before-during vs. before-after measurement may better suit this population and better pinpoint the effect on caregivers at the time of the caregiving experience, rather than afterwards, when grief is involved.

Despite these limitations, hospice caregiver interventions are feasible and can be effective for a number of caregiver outcomes (Houts, Nezu, Nezu, & Bucher, 1996; Hudson, Aranda, & Hayman-White, 2005; Hudson et al., 2008; McMillan et al., 2006). Caregiver studies have become more prevalent, especially in the past decade (Harding, List, Epiphaniou, & Jones, 2011). It is clear that as the population ages, interventions and supports for caregivers is an ever-growing need, not just for the most distressed (Harding & Higginson, 2003).

Australian palliative caregiver research has shown feasibility (Hudson, Aranda, & Hayman-White, 2005; Hudson et al., 2008; Hudson, Lobb, et al., 2012) and efficacy of the use of psychoeducational group interventions for improving the caregiver experience for family caregivers of palliative patients (Hudson, Aranda, & Hayman-White, 2005), and improving care

preparedness, competence, rewards and having needs met (Hudson et al, 2008). Individual interventions (as opposed to interventions delivered to groups) have also proven effective with this population (Cameron, Shin, Williams, & Stewart, 2004; Carter, 2006; Houts, Nezu, Nezu, & Bucher, 1996; Hudson, Aranda, & Hayman-White, 2005; Hudson et al., 2008; McMillan et al., 2006; Walsh & Schmidt, 2003)

Toseland, Blanchard, & McCallion (1995) studied the effects of a six session problem-solving intervention on caregiver spouses of cancer patients, with a randomized control design. They found that the intervention produced no significant effect on their outcome measures of caregiver depression, anxiety, marital relationship, support, health status, burden, help-seeking, coping, pressing problems, drug and alcohol use, personal change, or patient data. However, secondary analysis of distressed participants revealed that the intervention was effective for some of the primary outcome measures' subscales. They suggest that their findings support the use of triaging services according to assessed need.

The Prepared Family Caregiver (COPE) model, a coping skills intervention teaching structured planning for addressing medical and psychosocial problems, was shown effective in improving quality of life for caregivers of hospice patients with cancer (Houts, Nezu, Nezu, & Bucher, 1996). McMillan et al., (2006) used the COPE intervention in a three-group randomized control trial. Cancer patient-caregiver dyads were assigned to one of the following three conditions: (a) standard hospice care control group, (b) standard hospice care plus three supportive match-timed visits, and (c) standard hospice care plus three coping intervention visits. Caregiver outcomes included quality of life (QOL), caregiver burden due to patient symptoms, caregiver burden due to tasks, and caregiver mastery. The study reported improved QOL and reduced caregiver burden. Caregiver mastery was unchanged by the intervention, which may



suggest that this type of intervention did not target caregiver perception of control and confidence in caregiving. COPE was shown more effective than usual care and usual care plus emotional support. The emotional support condition was not significantly more effective than usual care for any of the outcome measures.

Another intervention, “Coping with Cancer” (CWC) for spouses of cancer patients, was compared to usual Oncology Department care at a regional medical center (Blanchard, Toseland, & McCallion, 1996). It was found that patients whose spouses received the intervention were significantly less depressed at post-test than those patients whose spouses received usual care, and open-ended responses indicated that this may have been due to enhanced patient-caregiver communication from the intervention as well as reduced patient worry about their spouse. This data suggests that patient measures be included in the evaluation of caregiver interventions.

Telephonic interventions have also been used with the caregiver population (Walsh, Estrada, & Hogan, 2004; Walsh & Schmidt, 2003). Walsh and Schmidt (2003) piloted a randomized controlled study, providing a four-week telephonic informative supportive intervention with workbook for hospice caregivers, and showed that the intervention decreased depression, despair and disorganization, despite the fact that the patient’s condition had worsened. However due to patient death prior to completion, only 5 of the 14 participants completed the intervention in full. Another study showed that caregivers of seriously ill cancer patients found brief supportive telephone calls every other week (5 calls total) to be acceptable, as 84% of participants (42 of 50) completed the intervention (Walsh, Estrada, & Hogan, 2004).

A brief behavioral sleep intervention proved to be feasible for caregivers of cancer patients, and improved caregiver sleep measures and depression scores more than the control

group. However, caregiver quality of life improvements were similar for both groups, and generalizability is limited due to its small sample size and group homogeneity (Carter, 2006).

Home visits were shown to be helpful for caregivers. Walsh et al. (2007) carried out a randomized controlled trial sampling 271 informal caregivers of advanced-cancer patients who screened as being psychologically distressed according to the General Health Questionnaire (GHQ-28). The intervention included six weekly visits by caregiver advisors, who provided advice, information and emotional support to the caregiver. At all three follow-up points (4,9 and 12 weeks) caregiver mean GHQ scores were reduced, however this change was not statistically significant, and no difference in secondary outcomes was found between groups. Qualitative data revealed that caregivers reported benefits from the intervention, the most helpful element identified as emotional support (Walsh et al., 2007).

While intervention studies with this population have expanded in the past fifteen years, a recent appraisal of palliative caregiver literature confirmed that research gaps remain, and a key research priority is intervention development and testing for enhancing family caregiver supports (Hudson, Zordan, & Trauer, 2011). Furthermore, 71.1% of family caregivers surveyed (Hudson, 2003) about their experience participating in research reported benefits of participation, and 88.9% reported no negative elements of participation. Thus, researching this population is likely safe and potentially positive for caregivers (Hudson, 2003).

## **2.5 Problem-Solving Therapy and Hospice & Palliative Care**

Problem-solving therapy (PST) is a type of cognitive-behavioral intervention aimed at enhancing problem-solving abilities. It is suitable for helping people cope with everyday stressors or major stress, depression and traumatic events. The main treatment goals of PST are the adoption of an adaptive orientation towards problems and the implementation of positive

problem-solving behaviors (D’Zurilla & Nezu, 2007; Nezu, Nezu, & D’Zurilla, 2013). Problem-Solving Therapy offers an opportunity to address hospice caregiver needs in a time-sensitive and manualized systematic approach.

Over the past twenty-five years, there have been a number of Problem-Solving Therapy outcome studies. PST has been evaluated for use with various mental health problems, as well as with populations in medical settings. PST has been found effective for stress management, mood and anxiety disorders, family relational issues, and a number of other problems. It has been used in individual and group work across the modalities of prevention, maintenance, and clinical interventions (D’Zurilla & Nezu, 2007). It has also been used effectively with vulnerable populations (Nezu, Nezu, & D’Zurilla, 2013).

Studies have begun to examine the application of PST with the caregiver population (Cameron, Shin, Williams, & Stewart, 2004; Demiris et al., 2010; Harding, List, Epiphaniou, & Jones, 2011; Kurylo, Elliott, & Shewchuk, 2001; Wood & Mynors-Wallis, 1997). Cameron, Shin, Williams, & Stewart (2004) evaluated the use of a brief problem-solving intervention for family caregivers of advanced cancer patients. Participants were recruited through oncology clinics of a large Canadian hospital system. Thirty-four participants completed the intervention in full, which included a baseline survey, introduction to problem solving by a research assistant, a home-care guide, and a follow-up phone survey four weeks post intervention. Participants reported a decrease in emotional tension, and an increase in both caregiver confidence and positive problem solving. Interestingly, this particular group of caregivers happened to score as relatively good problem-solvers at baseline. Thus, this data suggests that a brief problem-solving therapy may be helpful for even those caregivers who are not perceived to be struggling in this area, and may indicate an even greater benefit for those caregivers who struggle with problem-

solving. This study is limited due to its lack of a control condition, thus it is not clear if the results indicate a more effective intervention than usual care.

PST-based interventions have improved outcomes for the elderly population (Alexopoulos, Raue, & Areán, 2003; Gellis et al., 2007; Lopez & Mermelstein, 1995; Teri, Logsdon, Uomoto, & McMurry, 1997), and PST has been shown feasible and effective in the home health care setting (Gellis & Bruce, 2010; Gellis et al., 2008; Gellis et al., 2007). A pilot randomized controlled trial compared PST in home care to usual care with older home care patients identified as having severe depressive symptoms (Gellis et al., 2007). Outcome measures for depression were the Beck Depression Inventory (BDI) and the Geriatric Depression Scale (GDS-15). The Quality of Life Index (QoLI) was used to measure quality of life, the SPSI-R was used to measure social problem-solving, and the Patient Satisfaction Questionnaire (PSQ) was adapted to measure patient satisfaction. Participants in the PST-home care condition (PST-HC) received six sessions of PST-HC administered by MSW-level clinical social workers, in addition to usual care. Participants in the usual care condition (UC) received standard home care and were also provided a referral for antidepressants, and educational literature on depression, to be reviewed with their home care social worker. PST-HC was shown to significantly reduce depressive symptoms and improve quality of life and problem-solving ability scores as compared to UC. These effects were maintained at 3 and 6 month follow-up. Participants who received usual care did not show significant change for any measure from baseline to post-treatment.

PST was piloted in an English hospice setting (Wood & Mynors-Wallis, 1997). Hospice home care patients were randomized to receive normal hospice care, or normal hospice care plus PST, in a small single agency study. Twenty participants were recruited, 12 of whom were

randomized into the experimental condition. Due to acuity and death, of those 12, only six completed treatment. Outcomes measured were the Hospital Anxiety and Depression scale (HAD), the Profile of Mood States (POMS) and the modified Social Adjustment Scale (SAS), assessed through patient self-report questionnaires. No significant differences were found between groups. PST was shown to be feasible for the hospice setting, although due to the small sample this breadth of this finding is limited.

Demiris et al. (2010) conducted a pilot study in which they used a problem solving intervention (PSI), based on D’Zurilla and Nezu’s PST model, with hospice caregivers. They used a pre-test-post-test design, enrolling 29 hospice caregivers from Seattle-based hospice agencies. The researchers completed three home visits for structured PSI with participants. Due to patient death and loss at follow-up, only 23 of those 29 participants completed the entire intervention. Outcome measures were the Caregiver Quality of Life Index—Revised (CQLI-R), The State-Trait Anxiety Inventory (STAI), The Problem Solving Inventory (PSI) and The Caregiver Reaction Assessment Scale (CRA). Caregivers reported higher overall quality of life (however for the physical dimension subset of the CQLI-R, the average scores decreased) and lower anxiety levels post-intervention than at baseline. Caregiver reaction scores and problem-solving skills also improved. The research team concluded from their pilot study that this problem-solving intervention is a feasible and appropriate tool to address caregiver problems.

As an alternative to face-to-face PST, the use of videophones to deliver PST for hospice caregivers has been tested, and proved to be feasible. The videophone intervention improved caregiver quality of life and problem-solving abilities, and significantly reduced caregiver anxiety (Demiris, Parker Oliver, Wittenberg-Lyles, & Washington, 2011). Videophones are as effective as in-person delivery of PST (Demiris et al., 2012).

Current PST for hospice caregivers researchers have argued that PST is well-suited for delivery by the hospice social worker, due to the nature of their responsibilities on the hospice team and their expertise. They posited that PST should be further investigated for use by hospice social workers, not only to benefit the clients but to promote the social work role in hospice (Parker Oliver, Washington, Demiris, Wittenberg-Lyles, & Novak, 2012).

## **2.6 Hospice Social Work**

Social workers are major providers of services to patients and families in end-of-life care (Huff, Weisenfluh, Murphy, & Black, 2006), and are important members of the hospice interdisciplinary team (MacDonald, 1991). However they are lacking in evidence-based practices (Altilio, Gardia, & Otis-Green, 2008; Bosma et al., 2010; Jones, Pomeroy, & Sampson, 2009; MacDonald, 1991; Reese et al., 2006), and struggle with advancement in the hospice field. Palliative and end-of-life practice and care standards literature very closely align with core social work values and perspectives, yet in many ways the social work profession is still behind other disciplines in hospice leadership and research (Altilio, Gardia, & Otis-Green, 2008).

Some challenges to social work collaboration with other members of the interdisciplinary team include large social work caseloads, a focus in hospice care on the medical model, and limited social work visits (Parker Oliver & Peck, 2006). A qualitative study that held focus groups with end-of-life long-term care social workers found that they had a difficult time articulating their role, and reported that they most often became involved with cases at the request of the nurse (Munn & Adorno, 2008). There is a lack of role definition for hospice social work (MacDonald, 1991; Sanders, Bullock, & Broussard, 2012) a lack of specialized training (Arnold, Artin, Griffith, Person, & Graham, 2007; Christ & Sormanti, 1999; Sanders, Bullock, & Broussard, 2012), and role overlap with other members of the team (Reese & Brown, 1997;

Nelson-Becker & Ferrell, 2011). Hospice social workers have reported feeling less satisfied in their work than other team members, less rewarded and less autonomous than nurses, and feeling that they have fewer opportunities for career advancement (Monroe & DeLoach, 2004). This is despite the fact that increased social work care can improve patient and caregiver quality of life (Cabin, 2008); and social work involvement has been associated with reduced costs, fewer hospitalizations, fewer on-call visits, fewer nursing visit hours, improved satisfaction for nurses, clients and physicians, and reduced staff turnover (Reese & Raymer, 2004).

Typically, hospice social workers complete psychosocial assessments for each patient and family and develop individualized care plans. They make home visits according to patient/family need, providing patient and family counseling, and assisting with access to community and government resources (Weisenfluth, 2011; Doherty & DeWeaver, 2004). Typical social work interventions include advance care planning education, palliative care discussions with patients and families, counseling to address anxiety and depression for patients and families, assisting with access to resources and benefits, spiritual/philosophical discussions around meaning, advocacy for symptom management, improving coping mechanisms for patients and families, and developing culturally and spiritually competent plans in preparing families for the patient's death (Weisenfluth, 2011). Still, evidence-based practices for hospice social work are lacking (Altilio, Gardia, & Otis-Green, 2008; Bosma et al., 2010; Jones, Pomeroy, & Sampson, 2009; MacDonald, 1991; Reese et al., 2006), as are direct methods of evaluation of hospice social work practice, particularly the practice of gaining hospice patient/family feedback (Doherty & DeWeaver, 2004).

A study of hospice social work perspectives revealed the second most common reason for patient unmet needs, as perceived by hospice social workers, was family conflicts, struggles and

issues (Arnold, Artin, Griffith, Person, & Graham, 2007). A study analyzing interviews with hospice caregivers found that their major concern was psychological (Wittenberg-Lyles et al., 2011). Since social workers are the major mental health providers in hospice care (Colon & Otis-Green, 2008), and many hospice caregiver needs remain unmet, hospice social workers are in a critical position to address these needs. Through the development and testing of evidence-based interventions, social workers may advance their role in hospice (MacDonald, 1991), and offer improved psychosocial care to hospice caregivers.



### **Chapter 3: Study Aims and Hypothesis**

It has been suggested that better understanding of a problem-solving process would benefit family caregivers in their ability to handle patient symptom situations (Weitzner et al., 1997). Since no randomized controlled trial of PST for hospice caregivers has been tested, this study aimed to build on existent literature by evaluating the feasibility and efficacy of implementing Brief Problem-Solving Therapy with hospice caregivers (PST-Hospice) as compared to usual care plus caregiver education (UC+CE). PST was adapted for the hospice care setting. As the 2011 average length of service for hospice patients was 69.1 days, with a median length of service of 19.1 days (NHPCO Facts and Figures, 2012), PST was adapted to a brief five-week intervention. In addition to improving caregiver outcomes, PST-Hospice may be very beneficial to hospice social workers who seek to integrate evidence-based practices into routine care.

#### **3.1 Study Aims**

The goal of this randomized controlled pilot trial was to explore a systematic approach for reducing hospice caregiver distress and improving caregiver coping. The primary aims of this study were to (1) test the feasibility and efficacy of Brief Problem-Solving Therapy on hospice caregiver depression, quality of life, and problem-solving; and secondary, (2) to better understand the experiences and needs of hospice caregivers, and their perception of the PST intervention.

#### **3.2 Hypothesis**

It was hypothesized that compared with patient caregiver participants receiving Usual Care augmented with Caregiver Education (UC+CE), Patient caregiver participants receiving

Problem Solving Therapy for Hospice (PST-Hospice) would experience significant improvements in (1) mood and well-being, (2) quality of life, and (3) problem solving skills.

## **Chapter 4: Methods**

### **4.1 Study Site**

This study was conducted between November 15<sup>th</sup>, 2013 and May 16<sup>th</sup>, 2014. It took place in the homes of hospice caregivers recruited from Lighthouse Hospice and Samaritan Healthcare & Hospice. Lighthouse Hospice is a for-profit agency with an average daily census of 120 patients. Samaritan Healthcare & Hospice is not-for-profit, with an average daily census of 360 patients. Participants were drawn from home-based hospice admissions (as opposed to nursing home or inpatient-based admissions).

### **4.2 Recruitment**

#### **Participants**

Hospice caregivers were recruited from the hospice admissions of two Southern New Jersey Hospice agencies. Participants were primary informal hospice caregivers, introduced to the study upon hospice admission. Those who agreed to be contacted by the study's primary investigator were contacted by phone and invited to participate. Of those who were reached by phone and agreed to scheduling for informed consent, 43 were assessed for participation. Two did not meet inclusion criteria and four dropped out prior to pre-testing. 37 caregivers completed pre-testing, 26 of which completed full participation and post-testing.

#### **Inclusion Criteria**

- Primary informal caregivers.
- Caring for patients who reside in a home residence or assisted living.
- Age 18 or older.
- Able to speak English.
- Willing to participate in the study.

**Exclusion Criteria**

- Caregivers who are caring for patients who reside in a nursing home or hospital.
- Severe depression score of 22+ assessed by the Patient Health Questionnaire-9 scale, or acute suicidal ideation (per self-report when questioned by PI at initial meeting).

**Procedures**

The Principal Investigator (PI) introduced participating hospice agencies to the study and trained staff members on appropriate procedures. A one-page study introduction was included in every hospice admission packet during the study recruitment phase at both participating agencies (see Appendix A for procedures and Appendix B for study introduction). Upon hospice admission, the identified primary informal caregiver of the admitting home-based hospice patient was introduced to the study. The hospice staff member completing the admission provided the one-page study introduction, and alerted the primary caregiver that the study PI may be contacting them to invite them to participate, giving them the opportunity to decline contact.

Lighthouse Hospice employed a study recruitment form provided by the PI. This form was filled out by the hospice admissions worker upon each home-based admission, contained the caregiver's name and contact information, and a check box indicating whether or not they wished to be contacted by the PI. These forms were placed in the PI's mailbox at the agency, where the PI would visit a few times per week to gather the forms and call those caregivers who agreed to be contacted. To accommodate Samaritan Healthcare & Hospice's organizational structure, the procedure developed was a point-person to act as liaison between the admissions workers and the study PI. This point person e-mailed the PI a new admission list via a secure e-mail server a few times per week. Omitted from the list were non home-based admissions and

those caregivers who declined contact. Patient deaths and discharges were also e-mailed to the PI by Samaritan. At Lighthouse, this information was kept in the agency office and checked by the PI. It was important for the PI to check deaths/discharges prior to making initial contact to caregivers, and during study participation to track caregiver status.

The PI made contact with those primary caregivers who met initial inclusion criteria (primary caregiver, home-based admission, age18+, English-speaking), to invite them to participate and schedule an initial visit at a location of the caregiver's choice (home, coffee shop, restaurant, etc...). Upon this initial meeting informed consent was obtained and pre-test screen Patient Health Questionnaire-9 (PHQ-9) was conducted, to rule out severe depression or suicidality. The PI also screened for current use of psychotherapy services and/or psychotropic medication. Following this meeting for included and consenting participants, pre-testing was administered either via Survey Monkey or by a trained Masters-level graduate student research assistant.

### **Randomization**

Participants were randomly assigned to the treatment (n=18) or control condition (n=19). Allocation was determined using an online randomization procedure, which distributed random numbers into two sets, to which participant identification numbers were matched. This study used an un-blinded design, and participants were informed of their condition assignment upon completion of their pre-test survey.

Five weekly PST-Hospice sessions were offered after randomization to participants in the treatment condition. Participants in the usual care condition were mailed a caregiver coping pamphlet, and encouraged to review it with their team social worker at routine visits. Post-test measures were collected at the end of five weeks of PST-Hospice treatment for the experimental

condition and at five weeks post randomization for the Usual Care + Caregiver Education condition via Survey Monkey or a trained graduate student research assistant. The PI remained blinded to data collection, aside from conducting pre-test PHQ-9 measures, until the study's completion. Upon the study's completion, statistical analyses and chart reviews were conducted.

## **Chapter 5: Measures**

### **5.1 Variables**

The independent variables for this randomized controlled pilot trial are the two study conditions: PST-Hospice and UC+CE. Dependent variables are measures for depression (PHQ-9), caregiver quality of life (CQOLC), and problem-solving skills (SPSI-R Short Form).

### **5.2 Demographic Information**

Demographic information (age, sex, gender, relationship to patient, marital status, ethnicity, employment, education, income, household number, patient diagnosis, assistance with care) was gathered pre-treatment. Participants were also asked about use of psychotropic medication and psychotherapy services.

### **5.3 Outcomes**

Primary outcomes measured at baseline and post-treatment (after 5 weeks) include individual caregiver characteristics of (a) depression- PHQ-9, (b) caregiver quality of life- CQOLC, and (c) social problem solving skills- SPSI-R Short Form. Self-report surveys were used to obtain caregiver characteristic outcomes.

The Brief Patient Health Questionnaire Mood Scale (PHQ-9). The PHQ-9, a widely used depression measure, is reliable and valid for diagnosing and measuring depression severity (Kroenke & Spitzer, 2001). Its validity has been shown for detecting not only major depression, but subthreshold depression as well (Martin, Rief, Klaiberg, & Braehler, 2006). It is a brief, 9-item scale, which makes it useful for studies in which multiple measures will be taken (Kroenke & Spitzer, 2001). The PHQ-9 was included to evaluate the hypothesis that Brief PST-Hospice would be associated with increases in caregiver mood and well-being.

The Caregiver Quality of Life Index- Cancer (CQOLC). The CQOLC, a 35-item Likert-

style scale, measures caregiver quality of life, was designed specifically for caregivers of patients with cancer, has shown test-retest reliability and internal consistency (Weitzner, Jacobsen, Wagner, Friedland & Cox, 1999) and has convergent validity (Hudson et al., 2010). The CQOLC was included to evaluate the hypothesis that Brief-PST Hospice would be associated with increases in caregiver quality of life.

The Social Problem Solving Inventory-Revised Short Form (SPSI-R Short). The SPSI-Revised Short is a 25-item multidimensional measure of social problem-solving ability. In addition to a total score, it consists of five scales that measure two productive dimensions (Positive Problem Orientation and Rational Problem Solving) and three dysfunctional dimensions (Negative Problem Orientation, Impulsivity- Carelessness Style, Avoidance Style) (D’Zurilla & Nezu, 2007). Respondents are asked to rate items on a 5-point Likert-type scale ranging from 0 (*not at all true of me*) to 4 (*extremely true of me*). Sample items include: “I go out of my way to avoid having to deal with problems in my life”; “Before I try to solve a problem, I set a specific goal so that I know exactly what I want to accomplish.” SPSI-R has strong internal consistency (alpha range is .75-.95 across the five scales), good test-retest reliability, and has been found to be sensitive to the effects of treatment (D’Zurilla & Nezu, 1990; D’Zurilla, Nezu, & Maydeu-Olivares, 2002). SPSI-R short was included to evaluate the hypothesis that Brief PST-Hospice would be associated with increases in caregiver problem-solving skills.

## **5.4 Treatment Conditions**

### **Brief PST-Hospice Intervention**

In addition to usual hospice care, participants in the treatment condition received five weekly sessions of Brief PST-Hospice, provided by the Principal Investigator (PI), a trained and



licensed clinical social worker. Modeled after Nezu, Nezu & D’Zurilla’s 5-step model (2007) and Gellis et al. (2008)’s model for PST in Home Healthcare, the first session of Brief PST-Hospice was used to introduce the model, assess current problem-solving capacity, and begin problem identification. One initial goal was identified, which the PI worked on with the Participant using the PST model, in order to teach them the process. During each remaining session, the PI assisted the caregiver participant in identifying problems and their weekly goal, generating alternative solutions, choosing solutions and developing a plan. At the beginning of each new session, the PI and the caregiver participant reviewed the previous week’s goal, homework and success of the solution, before moving on to work on a new weekly goal. The final session was used to review overall progress and solution results, review the PST model, and identify next steps for the caregiver to continue to work on their selected problems. Participants were asked to complete homework related to their chosen solution between sessions, and encouraged at each session to identify and complete at least two daily pleasurable activities for the purposes of self-care. Table 1 illustrates the content of Brief Problem-Solving Therapy-Hospice, shaded in each session wherein it was implemented. Intervention steps were based on Nezu, Nezu & D’Zurilla’s 5-step model (2007), as well as Gellis’s model for PST in Home Healthcare (Gellis & Nezu, 2011).

**Table 1: PST-Hospice Content by Session**

Content	Session 1	Session 2	Session 3	Session 4	Session 5
<p><b>Orientation:</b></p> <ul style="list-style-type: none"> <li>• Orient to problem-solving therapy</li> <li>• Explain connections between daily problems, stress, mood, and pleasurable events, identify problem-solving style (rational, impulsive, avoidant)</li> <li>• Teach choosing two pleasurable activities (daily log)</li> <li>• Encourage ongoing use of hospice team social worker support</li> <li>• Provide problem-solving client handout</li> </ul>					
<p><b>Adopt Positive Attitude:</b></p> <ul style="list-style-type: none"> <li>• Normalize problems</li> <li>• Teach connection between attitude and adaptive problem-solving outcomes</li> <li>• Encourage adopting positive attitude</li> <li>• Validate caregiver’s ability</li> </ul>					
<p><b>Define Problems:</b></p> <ul style="list-style-type: none"> <li>• Review caregiver’s problems</li> <li>• Gather facts and discuss obstacles</li> <li>• Identify realistic goal</li> </ul>					
<p><b>Alternative Solutions:</b></p> <ul style="list-style-type: none"> <li>• Brainstorm many alternative solutions to solve problem and achieve goal</li> <li>• Exhaust all options in solution-generation</li> </ul>					
<p><b>Predict Pros and Cons:</b></p> <ul style="list-style-type: none"> <li>• Identify pros and cons of each solution</li> <li>• Ask: is it realistic? Can it be done? Will it solve the problem and achieve the goal? How much time will it take? How difficult will it be? What resources are needed to complete it?</li> <li>• Choose one or two solutions based on the above criteria</li> </ul>					
<p><b>Try Out</b></p> <ul style="list-style-type: none"> <li>• Identify steps to achieve solution and create a plan</li> <li>• Instruct caregiver to try out chosen solutions with action plan and monitor outcome, troubleshoot any difficulties</li> <li>• Remind caregiver to reward self for</li> </ul>					

efforts in attempted problem solving					
<p>Weekly Plan</p> <ul style="list-style-type: none"> <li>• Set homework based on chosen solution and steps needed to achieve it</li> <li>• Choose 2+ pleasurable activities</li> <li>• Encourage use of hospice team for support</li> <li>• Provide weekly log to caregiver, filling out solution action plan and pleasurable activity goals</li> </ul>					
<p>Weekly Review:</p> <ul style="list-style-type: none"> <li>• Review action plan homework</li> <li>• Review log of pleasurable activities</li> <li>• Review performance outcome for chosen solution- ask: were you able to complete it? Did it work? What obstacles got in the way, if any? Do we need to choose an alternative solution for this problem or are you ready to move on to another problem?</li> <li>• Review feelings about and coping responses to problems, focus on the positive</li> <li>• Review goal if solution was less than successful, or examine new problem and goals</li> </ul>					
<p>Ending:</p> <ul style="list-style-type: none"> <li>• Review PST-Hospice steps</li> <li>• Review progress and discuss ongoing implementation of problem-solving steps in future.</li> <li>• Complete clinical termination with caregiver</li> <li>• Provide weekly log and monthly pleasurable activity chart for caregiver to use in their ongoing problem-solving efforts</li> </ul>					

### **Usual Care + Caregiver Education Control**

The control condition received usual care plus caregiver coping education materials, which were mailed to them after pre-testing, in the form of an informational pamphlet (see Appendix C). Usual hospice care is provided on average for 69.1 days (NHPCO Facts and Figures, 2012), by an interdisciplinary team that delivers support and care to patients and their families/caregivers according to their individualized plan of care. It consists of patient personal care provided by hospice aides, comfort care via nursing visits, and chaplain and social work visits for spiritual and emotional support. Hospice staff members are on-call 24/7 to field questions, provide support, and provide nursing visits as needed. Social workers complete initial psychosocial assessments within five days of admission, and make home visits and phone calls as needed to provide psychosocial support to patients and their families/caregivers.

### **5.5 Protection of Human Subjects**

The study received IRB approval from the University of Pennsylvania prior to beginning recruitment. Informed consent procedures were followed, and participants were given the opportunity to drop out from the study at any time. There was some risk associated with this research, as exploring the caregiver experience and caregiver problems could become emotional for some caregivers. Participants were encouraged to utilize the support of their hospice team throughout the study. Emergency procedures and referrals for psychological support were in place to be used if needed, and research assistants who collected the data were trained accordingly. No such emergencies occurred during the study.

## **Chapter 6: Analysis**

### **6.1 Quantitative analysis**

The PI, using SPSS Software version 21, conducted statistical Analyses. Descriptive statistics were collected. T-tests and Chi-Squares were used to determine if there were differences in means for the independent variables. To determine mean differences between conditions for primary outcome variables, t-tests were conducted. Due to the pilot nature of this study, power analysis was not possible.

### **6.2 Qualitative analysis**

Three participants were asked and agreed to being interviewed regarding their study experience. These interviews were recorded and transcribed by the PI. The PI analyzed this data using a basic modified grounded theory, and captured in-vivo statements to give voice to the caregivers represented in this study. In addition, comments made by participants in open-ended sections of the surveys or while meeting with the PI were notated and discussed in this paper, in order to provide a richer account of the participant experience and caregiver needs.

## Chapter 7: Results

### 7.1 Participant Flow

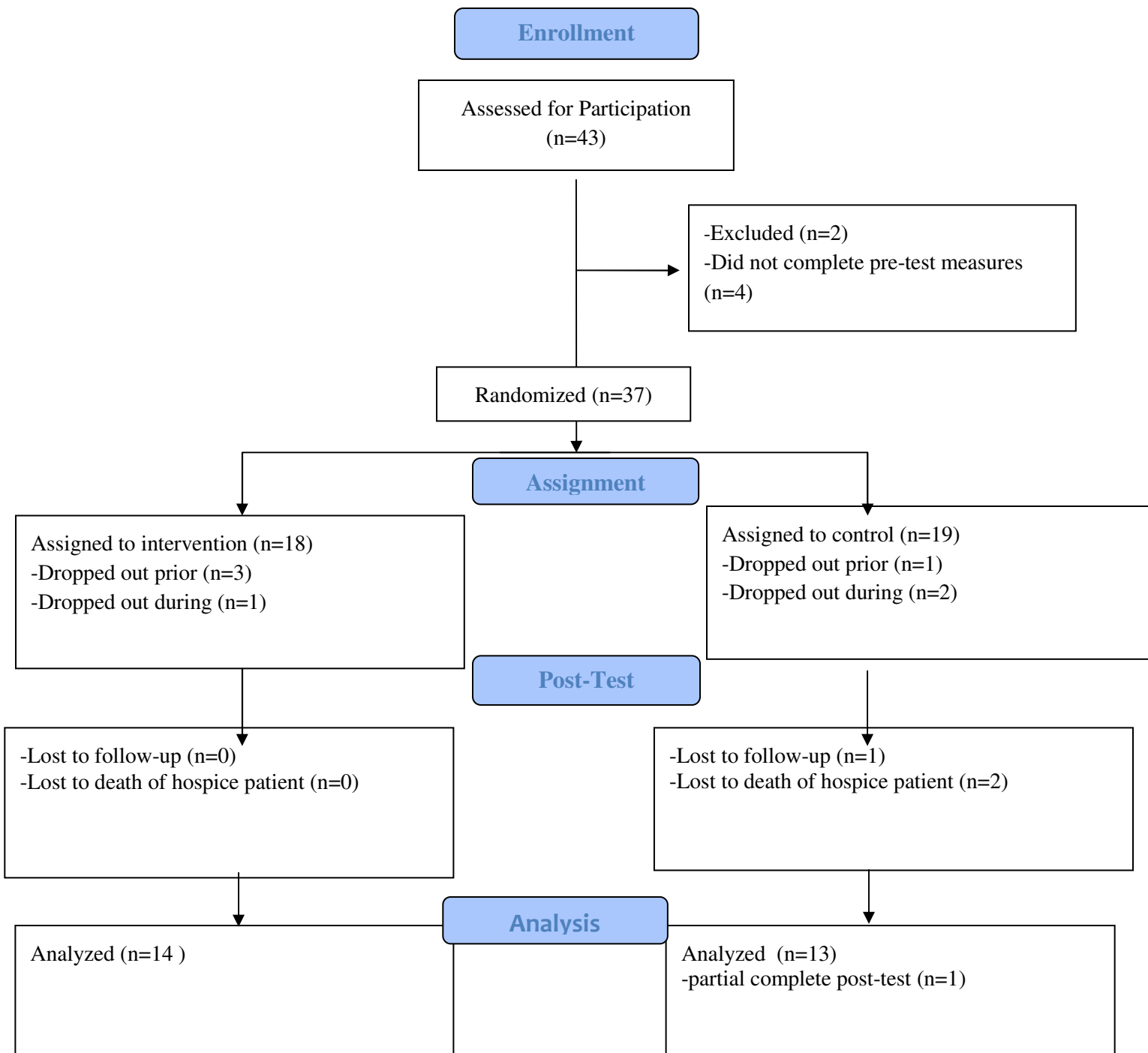
Of the 37 study participants, four dropped out after pre-testing but prior to condition participation, two due to death of their loved one, and two changed their mind. Six participants dropped out during condition participation or at follow-up, five due to death of their loved one, and one due to failure to respond to post-testing contact attempts. Thus 27 participants went on to complete post-testing, 26 of which completed post-testing in full. Figure 1 shows the study flow for participant recruitment, consent, pre-testing, condition participation, and post-testing. While 17 participants lost their loved one during their participation, 13 chose to remain in the study.

Although the goal was to complete five sessions with each intervention group participant, only ten participants received the full intervention. The intervention varied across one session (n=1), two sessions (n=2), three sessions (n=1), four sessions (n=1) and five sessions (n=10). This was due to death of the hospice patient in four of the cases. In one case, the participant ceased the intervention at four weeks due to choice. In all cases but one, participants went on to complete post-testing despite partial intervention completion.

Eight intervention group participants lost their loved one while receiving the intervention. Four of these participants decided to continue with the intervention, completing all five intervention sessions and post-testing. Three ceased the intervention upon their loved one's death, thus receiving a partial intervention, but went on to complete the post-test. One participant dropped out due to the death of their loved one.

In the control condition, ten participants lost their loved one during participation, six of which completed the post-test, four of which dropped out of the study. One person was lost to follow-up. One person completed all but one primary outcome measure at post-testing.

**Figure 1. Study flow diagram**





## 7.2 Participant Characteristics

Table 2 presents participant characteristics at baseline for the entire sample and by condition. Thirty-seven caregiver participants joined the study, 30 of which were female (81.1%) and seven were male (18.9%). The age range was from 42 years of age to 86 years of age, with a mean age of 62.8 and a standard deviation of 12.316. Most of the caregivers were Caucasian (34, 91.9%), the child of the hospice patient (19, 51.4%) married (26, 70.3%), and living in a household with one other person (20, 54.1%). The most common education level among these participants was a high school degree (13, 35.1%) and following that, some college (10, 27.0%), or a college degree (10, 27.0%). The most common income range was \$40,000-\$69,999 (10, 27.0%). However income did vary, with three participants reporting income in the very poor range (8.1%). It was most common for participants to be working full time (12, 32.4%) or retired (12, 32.4%). The predominant primary diagnosis for the hospice patient for which they were caring was Cancer (15, 40.5%), and more than half of participants reported having assistance with hands-on care of the hospice patient from family, friends or other supports separate from the hospice team (21, 56.8%). Only one participant reported outside use of psychotherapy services (2.7%), and three participants reported current use of psychotropic medication (8.1%). Baseline characteristic differences were not significant between condition groups.

**Table 2. Demographics for Baseline Variables**

Characteristic	Study Sample (n=37)	PST-Hospice (n=18)	UC + CE (n=19)
<b>Sex</b>			
Male	7(18.9%)	4(22.2%)	3(15.8%)
Female	30(81.1%)	14(77.8%)	16(84.2%)
<b>Age mean (SD)</b>	62.8(12.316)	64.42(13.705)	61.26(10.994)
<b>Relationship to Patient</b>			
Spouse	14(37.8%)	8(44.4%)	6(31.6%)
Child	19(51.4%)	9(50.0%)	10(52.6%)
Child in-law	2(5.4%)	1(5.6%)	1(5.3%)
Sibling	1(2.7%)	0(0.0%)	1(5.3%)
Other relative	1(2.7%)	0(0.0%)	1(5.3%)
<b>Marital Status</b>			
Married	26(70.3%)	11(61.1%)	15(78.9%)
Widowed	5(13.5%)	3(16.7%)	2(10.5%)
Single	3(8.1%)	2(11.1%)	1(5.3%)
Divorced/Separated	3(8.1%)	2(11.1%)	1(5.3%)
<b>Household mean (SD)</b>	1.86(1.735)	1.67(1.680)	1.86(1.735)
<b>Income</b>			
\$15,510-23,549	3(8.1%)	3(16.7%)	0(0%)
\$23,550-39,999	7(18.9%)	3(16.7%)	4(21.1%)
\$40,000-69,999	10(27.0%)	6(33.3%)	4(21.1%)
\$70,000-99,999	4(10.8%)	2(11.1%)	2(10.5%)
\$100,000-149,999	5(13.5%)	2(11.1%)	3(15.8%)
\$150,000-200,000	1(2.7%)	0(0.0%)	1(5.3%)
Missing	7(18.9%)	2(11.1%)	5(26.3%)
<b>Employment</b>			

Working Full Time	12(32.4%)	3(16.7%)	9(47.4%)
Working Part Time	5(13.5%)	2(11.1%)	3(15.8%)
On Leave	4(10.8%)	4(22.2%)	0(0%)
Retired	12(32.4%)	7(38.9%)	5(26.3%)
Disabled	2(5.4%)	0(0%)	2(10.5%)
Homemaker (never worked for pay)	1(2.7%)	1(5.6%)	0(0%)
Unemployed	1(2.7%)	1(5.6%)	0(0%)
<b>Education</b>			
Grade School	1(2.7%)	0(0%)	1(5.3%)
High School	13(35.1%)	7(38.9%)	6(31.6%)
Some College	10(27.0%)	4(22.2%)	6(31.6%)
College Degree	10(27.0%)	7(38.9%)	3(15.8%)
Graduate	1(2.7%)	0(0%)	1(5.3%)
Post-Grad/PhD/Doc	2(5.4%)	0(0%)	2(10.5%)
<b>Race</b>			
Caucasian	34(91.9%)	18(100%)	16(84.2%)
African American	2(5.4%)	0(0%)	2(10.5%)
Asian	0(0%)	0(0%)	0(0%)
Native American	0(0%)	0(0%)	0(0%)
Other	1(2.7%)	0(0%)	1(5.3%)
Hispanic Descent	2(5.4%)	1(5.6%)	1(5.3%)
<b>Current Use of Psychotherapy Services</b>			
Yes	1(2.7%)	1(5.6%)	0(0%)
No	36(97.3%)	17(94.4%)	19(100%)
<b>Use of Psychotropic Medication</b>			

Yes	3(8.1%)	2(11.1%)	1(5.3%)
No	34(91.9%)	16(88.9%)	18(94.7%)
<b>Diagnosis of Related Hospice Patient</b>			
Cancer	15(40.5%)	7(38.9%)	8(42.1%)
Dementia/Alzheimer's	3(8.1%)	0(0%)	3(15.8%)
COPD	6(16.2%)	3(16.7%)	3(15.8%)
Heart Disease	6(16.2%)	4(22.2%)	2(10.5%)
Other	7(18.9%)	4(22.2%)	3(15.8%)
<b>Assistance with Hands-on Care</b>			
Yes	21(56.8%)	11(61.1%)	10(52.6%)
No	16(43.2%)	7(38.9%)	9(47.4%)

### 7.3 Primary Outcomes

Table 3 presents the means and standard deviations for primary outcomes on the PHQ-9, CQOLC and SPSI-R scales.

**Table 3. Means and Standard Deviations of Pre-Test and Post-Test Outcome Measures by Condition**

Dependent Variable	PST-Hospice (N=18,14)		UC+CE (N=19,13)	
	Pre-Test	Post-test	Pre-test	Post-Test
PHQ-9	4.33(4.215)	4.50(4.958)	4.26(3.827)	6.54(6.253)
CQOLC	53.17(16.457)	34.14(15.869)	48.78(15.016)	45.92(21.891)
SPSI-R Short	28.72(10.034)	23.64(15.179)	26.39(13.138)	28.00(17.565)

### 7.4 Intervention Effects

Table 4 presents the t-test results for change scores of primary outcomes. To test the hypothesis that those participants receiving the PST-Hospice intervention would experience significant improvements in (1) mood and well-being, (2) quality of life, and (3) problem solving skills as compared to those participants receiving UC+CE, independent samples t-tests were used. The intervention condition showed a significant improvement in caregiver quality of life scores (CQOLC) from pre-test to post-test as compared to the control condition. Although SPSI-R Short scores improved more from pre-test to post-test for the intervention condition, the difference was not statistically significant. There was no significant difference for PHQ-9 change scores across the two groups.

**Table 4. Results of Independent Samples T-Tests for Change Scores of Primary Outcome Measures**

Outcome	Condition	Mean	Std. Deviation	Laverne's Test for Equality of Variances	T-test for Equality of Means
				SS	SS
PHQ-9 change	UC (n=13)	-1.46	8.821	.756	.620
	PST (n=14)	-.64	4.584		
CQOLC change	UC (n=13)	2.62	15.430	.717	.014
	PST (n=14)	18.14	15.022		
SPSI-R Short change	UC (n=12)	.50	7.342	.242	.214
	PST (n=14)	5.64	12.182		

### 7.5 Secondary Analysis

SPSI-R and PHQ-9 were analyzed to test for sub-group differences between groups. PST-Hospice scores improved significantly as compared to UC+CE for the scale's positive dimensions (Positive Problem Orientation and Rational Problem Solving). For the three dysfunctional dimensions (Negative Problem Orientation, Impulsivity- Carelessness Style, Avoidance Style), no significant difference was found between groups.

### 7.6 Caregiver Case Study Examples

The following are four case study examples from the PST-Hospice condition. Names and personal details have been changed for the purpose of confidentiality. These case examples highlight the types of stressors that hospice caregivers face, their needs, and opportunities for hospice social workers to provide necessary support and intervention.

**Case #1: Bob**

Bob was a 67 y.o. Caucasian male, divorced many years and recently retired. Bob had one brother, a daughter and her family, and extended family that reside locally. Bob was the primary caregiver for his mother, a hospice patient with the diagnosis of cancer. Bob moved into his mother's home over five years ago, to provide care for her as she aged and required more assistance. In the beginning, Bob was able to work and continue to enjoy his hobbies and social events, as his mother was safe to be left alone. For the past year, as she has declined, it has become increasingly difficult for Bob to find time for himself due to his mother's changing needs, and a couple of weeks after she joined hospice the hospice team noticed that Bob was leaving the house daily for over an hour, which worried them. He was instructed to no longer leave his mother alone due to safety concerns.

Bob joined PST-Hospice upon his mother's admission to hospice, and appeared to be coping well. His initial PHQ-9 score did not reflect depression (1), and he reported that he felt well supported, confident as a caregiver, and optimistic about the future. Upon Bob's first PST session, he engaged and vented about his loss of free time and difficulty completing errands out of the home. He reported that while he always handled things well, lately it had gotten much more difficult. He identified a problem of needing more help with his mom's care, admitting that he did not like to ask for help, and he worked with the PI to choose his target goal of having more support persons available to stay with his mom so that he could get out of the house. He came up with four alternative solutions, worked through pros and cons, and chose to contact a few relatives/friends who have offered to assist him, and ask for help. At the PI's encouragement, he also identified pleasurable activities that he aimed to complete each day for the purposes of self-care.

The following week, Bob reported great success. He had contacted neighbors, an aunt, a friend and community volunteers, scheduled their support visits for the past week and the upcoming week, and was able to get out of the house three times to run errands and be with friends, something he had not done in weeks. He also completed one-two pleasurable activities each day. He said he felt like working logically through his problem with the PI really helped motivate him, and by identifying a small weekly goal he was able to accomplish something.

Throughout the PST sessions, Bob's stressors increased due to the decline of his mother and family dynamics. His mother became bedbound and he had to provide much more hands-on care. He was also arguing with his brother, who had been visiting more often since their mom's decline, and was pushing Bob to place their mom in a nursing home. Bob was determined to keep their mom at home, as this was her wish.

Despite these added stressors, Bob committed to the problem-solving process. He went on to continue using support persons, which enabled him to provide for his mother's needs and still get out of the house for errands and social outlets. Each week he identified additional problems and target goals, and successfully completed his chosen solution. As his mom declined, his sleep suffered, and thus for his two final PST sessions he worked on solutions to improve his sleep.

Bob reported at his final session that he felt he learned a tool that would continue to help him. He stated that for him, being reminded of the importance of working on self-goals and pleasurable activities was something he truly needed, but had not previously realized. His caregiver quality of life score improved significantly pre-test to post-test, from a score of 41 to a score of 8. He also stated that he felt he might not have been able to maintain his mom's care at



home if it weren't for the support he received from the PST sessions and from having solved some of the issues that were making her care at home difficult for him.

### **Case#2 Denise**

Denise was a 56 y.o. Caucasian female. Denise was married and has three college-aged children, who resided outside of the home. Four years ago, Denise's mother-in-law, Fran, moved in with Denise and her husband. She had been living with her daughter (Denise's sister-in-law), who assisted her mother with doctor's appointments, medications, errands and cooking. Denise's sister-in-law died suddenly, which was very traumatic for Fran. When Fran moved in with Denise, she had been ambulatory with sharp mental capacity. Fran declined steadily after the death of her daughter, needing increasing assistance with ambulation and other activities of daily living. Two weeks prior to electing hospice, she suffered a major heart attack that greatly damaged her heart. Due to her age and comorbidities, surgery was unsafe and she was referred to hospice. Her vascular issues began to cause dementia shortly thereafter.

Denise was Fran's primary caregiver, although she did receive assistance with care from her husband and a hired live-in caregiver. Denise and her husband had decided to hire a live-in when Fran's decline necessitated more daily care, which they were unable to provide due to their work schedules. Recently, Denise's job had been allowing her to use vacation time and a more flexible schedule, which enabled Denise to be home more to oversee Fran's care and meet with the hospice team.

Denise joined the hospice caregiver study because she stated she wanted to help others, and if her participation in this study led to knowledge that could benefit future caregivers, she wanted to help. It turned out that Denise also benefitted from the study.

Denise's major reported problem was that she had not been taking care of herself. She stated that caregiver stress and trying to balance work with her mother-in-law's needs made it difficult for her to find time to do things for herself. Her goals were self-care goals, mainly to start exercising again. The first week she chose what turned out to be an unrealistic solution for adding exercise into her schedule- to get up early and go in the morning. She identified that it was *too much too soon*, and worked with the PI to choose a more realistic solution. The following week she had exercised twice and completed daily pleasurable activities.

Over the course of PST, she expressed to the PI that her mother-in-law's dementia was worsening, and causing symptoms of agitation, aggression at times, and scary delusions. For Denise, this brought up past hurt in her relationship with her mother-in-law, as she found herself being the target of the agitation and delusions. Denise reported that while she knew it was *the dementia talking*, and the hospice team had educated her and supported her, she couldn't help how it made her feel. Her stress was increasing, she was becoming resentful and angry at times, and reported that it was hard for her to be around her mother-in-law. Using the problem-solving approach, the PI assisted Denise with breaking down her problem, identifying target goals and generating solutions. Denise learned to choose solutions that would help with stress-reduction and more positive responses to her mother-in-law's symptoms. Despite her increased stress, her success with problem-solving continued to improve and she reported feeling more relaxed and proud of the positive changes she was making. At session four, she reported that without the PST sessions, she would have been far worse off, not handling her stress well or exploding. She explained that having the PI visit weekly *just for her* was extremely helpful. Feeling like someone was there for her, and saw her needs as a caregiver as important, made her feel better.

She reported that her husband had noticed the improvement and she was teaching him the things she had been learning from PST in hopes of helping him deal with his caregiver stress.

Unfortunately, Denise had a set back in between sessions four and five. She had been living with a chronic but controlled condition, which flared up due to stress and caused Denise to be hospitalized for over two weeks. It was over a month until the PI saw Denise again, once she was home and up for the visit. What appeared to be a failure for PST, turned out not to be. Denise reached out to the PI each week during her hospital stay, explaining that she was using her new skills to focus on her goals and continue to progress. At her final session, Denise explained that she felt if it had not been for PST, she would not have recovered so well. She stated that the main thing that was helping with her stress was the problem-solution work she did each week, and had it not been for that, she fears she would have gotten even sicker, and would have not been able to cope with her flare up. She used the experience to motivate her to continue her self-care and positive changes.

While we can never know for sure if PST prevented a worse outcome for Denise, the fact that she believes that it did, and has found a way to organize and exercise changes to deal with problems, is what matters. Denise's initial PHQ-9 score was 0, which remained unchanged pre-test to post-test. Her CQOLC score improved by 36 points (67 to 31), and her SPSI-R Short score improved by two points (17 to 15).

Denise is a good example of a case where the hospice social worker may not assess for enhanced needs, and therefore not provide much one-on-one counseling. Denise presented as high functioning and euthymic, and was not depressed. She also had a live-in caregiver for her mother-in-law, which often times is interpreted as a less stressful caregiving experience. Typically caregivers who make their needs known, report a history of depression, or appear

distressed are the ones who get more attention and visits from hospice social workers. Due to caseloads, social workers find themselves prioritizing and triaging. In Denise's case, she was not receiving much one-on-one time from her hospice team social worker. She reported that the team social worker visited with her mother-in-law, which was helpful and supportive, and checked in with Denise at the end of each visit for a few minutes, but did not engage her for long. In her PST sessions, Denise was directly asked about problems, and encouraged to work on solving them. This created a space in which she opened up about her stress and concerns, and improved her ability to cope with her mother-in-law's care needs. Cases like Denise are lessons on the importance of one-to-one counseling with hospice caregivers, no matter how they present at assessment.

### **Case #3 Joe**

Joe was a 59 y.o. Caucasian male. He had been retired from his career for five years, and had a small farmstead that he continued to care for. Joe was an only child and had no children. He was the primary caregiver of his wife, Missy, who was referred to hospice after a recent hospitalization. Missy had a long history of heart problems, and recently had a recurrence of breast cancer that metastasized. Joe completed informed consent for the study two weeks after his wife joined hospice, completed his pre-test survey the same evening via Survey Monkey, (PHQ-9: 2, CQOLC: 30, SPSI-R Short: 28) and was randomized into the intervention condition. Missy passed away four days later, before Joe's PST sessions had begun.

The PI made contact with Joe to express condolences, and offered to continue with the intended intervention if he so wished. Joe explained that he was happy he was placed in the intervention group as he was looking forward to the extra support, and wanted to go ahead with

the study. Joe asked for a couple of weeks to take care of things, as he was busy with paperwork and planning his wife's funeral.

His first PST session occurred three weeks after the death of his wife. The PI went through all initial PST session steps, and engaged Joe in identifying his current problems. Joe explained that he had had a lot of loss in his life, yet feels he never fully allowed himself to grieve. He explained that he had suppressed his feelings, focusing on tasks and busying himself so as to not have to face his grief. Joe stated that he saw himself doing this again with the loss of his wife, and he wanted to change. Joe's goal was to properly grieve the loss of his wife, engaging in introspection and expression. His initial weekly goal was to work towards this larger goal by taking one step. With the help of the PI, multiple solutions were generated in session. Some of them were: to contact hospice for bereavement support, begin journaling, connect and share feelings with supportive friends/family, and pick a day to not be busy. Joe and the PI exhausted the pros and cons of each solution. Joe chose the most realistic solution that he felt would truly help with his problem. For his first week, he would pick a day to not be busy, allowing himself to relax, take time to breath, and feel. He felt that this would be a challenge, as he had been busying himself with tasks so as not to think about his wife. However he wanted to commit to this solution in order to begin steps towards properly and healthily grieving. He and the PI broke this solution down into a plan and wrote down his chosen pleasurable activities on his worksheet.

The following week, Joe reported that he had achieved his solution, and had been working on daily pleasurable activities like music, television and cooking, for self-care. He expressed that taking a day to *just be* allowed him to get in touch with his feelings and process things. He felt he was on the road to solving his problem.

For the remaining weeks, Joe chose to tackle the same larger problem, as his grief was the most relevant and important need at the time. Each week he chose a new solution to achieve a smaller grief-related goal. He chose to journal, share feelings with support persons, and connect with Missy's sister. Connecting with Missy's sister was extremely meaningful to Joe, as they had had a long history of family discord. He set a goal of making amends now that they both shared this huge loss, and in his final week, he achieved that goal by making contact and inviting his sister-in-law down for a visit. He also chose to give her a lot of Missy's things, as he felt this would be a special gesture for his sister-in-law, and important for him to do.

At his final PST session, the PI reviewed with Joe his overall experience. Joe expressed feeling substantially better than he had prior to starting PST. Although it was less than two months after his wife's death, he felt that he was experiencing a healthy grieving process. Joe explained that the sessions and work that he did really helped him achieve his goals and solve his problem of suppressing his grief. The PI suggested that Joe might wish to contact hospice to access further bereavement services going forward, and Joe stated that for now he felt he was on the right track. He really found peace in his journaling, as he was writing at least a half hour each day; and he was pleased with the amount of support that he had since making contact with friends and family as part of this process. From the PI's standpoint, Joe appeared much more in touch with his feelings and expressive, and was distracting himself with tasks much less often. The solutions that he had chosen each week were effective because they were realistic and doable, and would achieve his grief-related goals without being *too much too soon* emotionally.

Joe completed his post-test (PHQ-9: 1, CQOLC: 2, SPSI-R Short: 4). His scores indicate improvement in problem-solving and quality of life, and a slight improvement in depression (although his initial score was not associated with depression to begin with). It is possible that

his improvement may be due to perception change, as his stressors were no longer related to caring for his wife on hospice, but to his grief. However Joe expressed feeling that the PST sessions were specifically helpful and the cause of his improvement.

This case is a very good example of how PST can be used with a very relevant caregiving need: grief. Grief is relevant during the caregiving experience as anticipatory grief and grief associated with loss of identity, role, or career, finances, etc... In hospice bereavement services, grief is the primary need addressed by bereavement coordinators, social workers or chaplains. This example shows how this manualized systematic approach can fit within the context of grief, a context that is typically more complicated than other less acute problems.

#### **Case #4 Kathy**

Kathy was a 62 y.o. Caucasian female, widowed, mother of two adult sons, working full time. She was the oldest of three children and primary caregiver for her mother, who was on hospice with a primary diagnosis of cancer and resided alone in an independent senior living community. Kathy's brother and sister resided nearby. One of Kathy's sons lived with her, the other lived with his family locally. Kathy joined the study because she wanted to contribute to knowledge about hospice caregiving. At pre-testing, Kathy's scored as mildly depressed (7) and having reduced quality of life and problem-solving skills (CQOLC score of 64, SPSI-R Short: 47). Her scores were in the 75<sup>th</sup> percentile for all three measures. Caregiving was taking a toll on her.

Kathy was randomized into the PST intervention condition, and received 5 weeks of PST-Hospice. At her first session, Kathy presented as sad and overwhelmed by her caregiver responsibilities. While she listed many psychosocial problems, she chose to work on a problem with paperwork, as this was causing her much distress. Her mother had reportedly always relied

on her father to handle their finances, and when he died she had to learn to do a lot more for herself. Kathy explained that her mother's organizational system was never very strong, but she remembered for herself where things were, and it worked for years. Now that she had declined, things began to pile up and become even more confusing. Lately, Kathy's mom had not been able to respond to bills and account inquiries. Kathy stated that every time she visited, she was overwhelmed by the piles of things that needed to get done, and knew that once her mother passed it would only become more complicated. With the help of the PI, she set an initial goal of beginning to tackle the paperwork problem. Of all the possible solutions that were examined in session, she chose to set aside one day that week for her and her sister to go to their mother's home, sort and organize the paperwork, make a list of accounts and tasks, and write down the plan to address it, splitting each task among the three siblings. Kathy had initially planned to take care of the paperwork herself, but through discussing it with the PI, realized that it was best to delegate some things rather than take full responsibility for this problem, when she was already overwhelmed. This would ensure that the solution would be more realistic, as Kathy would have help with it. Kathy was also encouraged to set a goal of completing one to two pleasurable activities each day for self-care and stress reduction.

At session two, Kathy reported that she had had great success. Her demeanor was totally different; her mood neutral, she seemed proud of herself, and more relaxed. Kathy explained that by setting her weekly goal she was finally able to address the paperwork problem, rather than let it loom over her. She had picked a date with her sister as planned, and spent an entire day at their mom's going through the paperwork. She said that not only had they come up with a plan for the three children to address each task, but they had already been paying bills, making calls and addressing account questions. Kathy only had one more thing on her list to do. As for



her pleasurable activities, Kathy had called an old friend, gone for walks, worked on word puzzles and crafts. She stated she was feeling a lot better and realized that by breaking things down into more manageable goals she was able to accomplish more than she realized. For the remaining sessions, Kathy addressed the problems of: stressful family dynamics, planning overnight care for mom, and concern for her son's coping response to his grandmother's decline. Each time, she engaged in the PST process in session, chose a realistic solution to solve her target goal, and succeeded in completing that solution. Each week she reported feeling so successful that she was able to move onto a new problem.

When she began PST, she was not focusing on her self and lacking pleasurable activities. By her fifth and final session, she was completing at least two pleasurable activities each day. She found that word puzzles and crafts were the most enjoyable for her, helped her take her mind off things for a while, and reduced her stress. She felt that her problems were no longer overwhelming her, and that she had more control over things. Kathy's post-test scores were greatly improved (PHQ9: 5, CQOLC: 45, SPSI-R Short: 29). She moved from the 75<sup>th</sup> to the 50<sup>th</sup> percentile for depression and quality of life. She expressed that breaking things down, using the weekly worksheets, and having weekly emotional support were the most helpful components of the intervention to her. Thanks to PST, she was no longer overwhelmed, she felt more autonomy over her problems, and was less fearful about the future.

## **7.7 Qualitative Interviews**

Three participants were interviewed post-participation, two participants from PST-Hospice, and one from UC+CE. Each interview was recorded and later transcribed into a word document for analysis (see Appendix D for the qualitative interview guide).

Overall, feedback was very positive. The four major themes represented in both PST-Hospice interviews were 1) learning, 2) doing something good for oneself, 3) problem-solving, and 4) trust/comfort.

### **Learning**

Both PST-Hospice participants discussed the notion of learning from the PI/interventionist. One participant explained that he felt the PI had new knowledge for him, and therefore he learned things that made him better able to deal with his wife's care, specifically that the "little things mean a lot," referring to the problem-solving approach. The other PST-Hospice participant reported that the PI was "very nice, and very informative, and a natural-born teacher," and reflected on many insights that he learned from the experience.

### **Doing something good for oneself**

Both PST-Hospice participants who were interviewed reported that being reminded to do things for themselves (pleasurable activities) was positive for them. One participant reported that the most important aspect that he took away from the experience, which he continues to do most of all, is something good for himself:

You forget, you forget that it's important. You put that first and foremost in my mind, from ya know meeting with you, and it became part of my life every day, that I have to do something that makes me feel good. Because that's gonna have an effect on

everything else I do. And I did the the gym, the tanning, the going to a movie, which I have continued to do, reading a book...

(PI smiles and says: "that's great")...

Yeah. It's made me so much happier.

### **Problem-solving**

Both interviewed PST-Hospice participants were asked about their experience with PST. Both participants reflected on problem-solving. One framed it in terms of what was difficult for him, stating

the problem solving, looking at things from different directions and angles and trying to figure out, ya know, what the best way to deal with it, um, to solve. Ya know if it's problem-solving. Um that's a hard thing to do when you're dealing with other people, yeah.

For this participant, many of the problems he worked on in session were interpersonal problems, and so here he is talking about how that can be a difficult process. However overall he reported that despite the difficulty, the experience and what he learned from the process was very positive. The other PST-Hospice participant reported that he learned "a lot better how to deal with different situations to plan things out and try different things, ya know, which was excellent, yeah."

### **Trust/Comfort**

Both participants expressed that they felt comfortable with the PI and were therefore able to express themselves and openly discuss their problems. One participant reported that while each member of the hospice team provided support, there was something unique to his experience meeting with the PI for PST sessions:

And all of ya's have went of their way to help me in their own specific profession. But like I've told ya before, Ill tell ya again, I've put my trust confidence and respect in you, that's why I could sit, relax and talk to you. I talked to you about things that I could talk to nobody else about. Cause when I asked when I talk to you and it stayed between us. You said yes, but you said yes in the tone of voice where it meant it, seriously.

When asked what was difficult about the experience, one PST-Hospice participant gave feedback that remembering to write stuff down on the homework worksheets provided by the PI was difficult, as he would get caught up in what he was doing and forget. The other PST-Hospice participant and the UC+CE participant reported no difficulties.

One issue that came up in the UC+ CE participant interview was that the participant did not recognize the caregiver education materials. She reported that she remembered getting the letter in the mail, but does not know what happened to the educational pamphlet. Thus she was unable to reflect on whether or not this was helpful. The PI provided the pamphlet to her again during the interview, and the caregiver did state that it had a lot of good information in it.

Overall she reported that being a part of the study was very nice, and that it did not complicate things for her. When asked about what was most positive about the experience of being a part of the caregiver study, stated "well one thing that was positive is I could add in some things that I believed would be more helpful to other people." When asked to elaborate on what she thought might be helpful, she repeated something that she had written into the final question of her survey, which allowed for a narrative response. She said:

Well when it comes time, when somebody knows that they're actually dying, ya know, that they should have the option or want someone else to stay, a volunteer or anybody, just so somebody else is there. Because when my husband died, sometimes I would leave

the room and ya know my kids would be with him, but if someone else was there to stay with the person that would help.

This participant was caring for her father during her study participation, however had lost her husband less than a year ago. When he was on hospice she and her family *sat vigil* with him as he was actively dying until his death. Here she is identifying a potential unmet need of caregivers, a very poignant example of what hospice caregivers are facing every day.

Feedback like this, offered by the participants who were interviewed, provides voice and depth to the study results. For the PST-Hospice participants, it can be seen in their own words how meaningful and helpful PST was to them. It is remarkable to think that a simple intervention, provided in a supportive manner for about forty-five minutes weekly for five weeks, could have such an effect on a caregiver. The following are quotes directly from the participant interviews.

When asked what the experience was like to be a part of the study, one PST-Hospice participant responded:

It was very positive. Because it made me aware of me where I wasn't doing that before...problem solving, doing something for yourself, um, I forget all the list, but every single thing- I really did do those things. It made a difference, and I'm still doing them. They've become part of me. And it's, it's made a difference, all around... Well I was thinking of myself as poor me, but that doesn't help you. It doesn't work, doesn't put you in a better place, until you do the things that you taught me.

When asked what they learned from PST, one participant responded: "I learned a lot better how to deal with different situations to plan things out and try different things, ya know, which was excellent, yeah." The other stated:

Just being aware, and you forget, it's common sense, but you forget because you're so caught up in BS, you're caught up in drama, and, and you just forget to think to put things in perspective, to put them, line them up and ya know take care of them one at a time and look at each thing and say, 'well what can I do to fix that,' or 'how can I make that better.' You've helped me put it in perspective, and I wasn't doing that, because I was too caught up in the minute.

As a final thought, presented here are two quotes from PST-Hospice participants, when asked to share about what they experienced most positively. One stated:

mmm, could be a number of things, ya know how you taught me to approach different things in a different manner that I would have, a better manner of approach, ya know. Um you taught me how to go from 1-10, 10 bein the top...so... It's a lot of things I would not have done without your help.

The other responded:

The best part was making time for myself and doing stuff that made me feel good... Because in doing that, it affects everything else you do. So, not only... it actually goes ya know, goes further than the caregiving, hospice thing. It's a life thing... it's a life skill. And so is the problem-solving. Everybody needs this! Not too many people do it.

## Chapter 8: Discussion

### 8.1 Findings

The study sample was primarily Caucasian females over the age of 50, similar to previous research on this population (Cameron et al., 2004; Chentsova-Dutton et al., 2002; Demiris et al., 2010). Participants were predominantly caring for a parent, rather than a spouse or other relative. This differs from a previous study of PST for hospice caregivers. That sample was made up of mostly spouses (48.3%), children (37.9%) being the next most common (Demiris et al., 2010).

The primary aim of this study was to test the feasibility and efficacy of PST on hospice caregiver depression, quality of life, and problem-solving. PST proved to be a feasible intervention for the hospice setting in the sense that it is a simple, systematic approach that is manualized and easily taught. The concepts were not difficult for hospice caregivers to grasp, and caregivers were able to learn and practice the problem-solving approach during the initial PST session. A masters-level hospice social worker can implement it, and it can be delivered in a timeframe that fits into a routine social work visit schedule. Its short-term nature makes it a good fit for the hospice setting, as patient length of stay would make it difficult to carry out a long-term intervention.

The PST-Hospice condition improved more than the control condition for the primary outcomes of caregiver quality of life (CQOLC) and social problem solving (SPSIR-Short), but this difference was only statistically significant for caregiver quality of life (CQOLC). Depression scores (PHQ-9) did not improve for either the intervention condition or control condition. It is important to note that at baseline, participants were not depressed (PST-Hospice

mean 4.33, UC+CE mean 4.26). Thus it may not have been reasonable to expect to decrease these scores further with intervention.

All participants who completed the full five sessions of PST expressed positive feedback about their PST experience to the PI at their final session. The information obtained from the qualitative interviews with PST-Hospice participants suggests that establishing a trusting, comfortable environment is of importance to the effective delivery of this intervention, as well as focusing on problem-solving and self-care for caregivers. This intervention could be learned within the five week timeframe, and the two caregivers who were interviewed (one at one week post-intervention and one at eight weeks post-intervention) reported ongoing impact of the intervention. They were able to identify specific benefits of the PST intervention that continued to help them post study participation.

Attrition rates were as expected for a hospice study. However, despite attrition due to death of the hospice patient during caregiver participation, 13 of the 18 caregivers who lost their loved one during participation chose to remain in the study. The participation rate for this study was 72.97%, which is better than previous intervention studies in the palliative care setting (Cameron et al., 2004; Wood & Mynors-Wallis, 1997); but slightly less than Demiris et al. (2010) PST for hospice caregivers non-randomized feasibility study (79.31%), which employed only three sessions of PST. Overall, attrition rates were satisfactory and showed the feasibility of an intervention study within the hospice setting.

## **8.2 Implications**

The findings of this study suggest that PST is acceptable for use in the hospice setting, and is an effective intervention for addressing home-based hospice caregiver needs, particularly to improve caregiver quality of life. Concern for palliative caregiver quality of life has been



widely documented (Aoun et al., 2005; Clark et al., 2006; McMillan & Mahon, 1994; Wilder et al., 2008; Wittenberg-Lyles et al., 2011). The findings of this study show that a brief, five-week PST intervention can significantly improve caregiver quality of life, one of the major unmet needs of hospice caregivers, which is linked to other negative effects like caregiver morbidity, patient experience and quality of life, and depression (Rabow, Hauser, & Adams, 2004; Sothill et al., 2003; Wilder et al., 2008; Wittenberg-Lyles et al., 2011).

D’Zurilla and Nezu’s model of stress and well-being based on Lazarus’ Relational model hypothesizes that there are two types of life stressors: major negative events and daily problems, which impact each other. One major negative event can lead to many new daily problems, or many unresolved daily problems can bring on a major negative event. Both can affect a person’s well-being directly, but well-being also depends on one’s coping and problem-solving abilities. Their PST model therefore aims to improve well-being through enhanced social problem-solving (D’Zurilla & Nezu, 2007). While PST-Hospice did not have a significant effect on social problem-solving skills (SPSI-R Short), the results indicate that PST was still effective in improving caregiver well-being through quality of life. The caregivers in this study were predominantly not depressed, a typical indicator of distress. However results proved that there was still room for growth, as caregiver quality of life, even for good problem-solvers, was improved by the intervention.

This PST intervention offers a great opportunity for social workers to effect meaningful change in the hospice setting in a short period of time. Quantitative and qualitative findings highlight the importance of focused, one-on-one attention on the hospice caregiver, and indicate that if weekly PST sessions were implemented into routine care, caregivers could greatly benefit.

The major obstacle to hospice social workers being able to provide weekly support to all patients and their families is caseloads. Hospice social work caseloads are higher than their team nurse counterparts. This is not uncommon to the medical model, and reflects the perceived hierarchy of needs of hospice patients by Medicare and other regulatory bodies that influence hospice services. The 2012 hospice social work caseload mean was 26.5, with a median of 26.0 (NHPCO National Summary, 2013; NHPCO Staffing Guidelines, 2013), showing a slight increase from 2011, and more of an increase when compared to 2005 and before. NHPCO identifies that it may be appropriate to lower caseloads for certain circumstances. Some of which are: hospices that lack their own general inpatient (GIP) unit and need to contract with hospitals for GIP beds, team members who serve multiple roles, team members who provide community outreach, a high proportion of patients or families with complex psychosocial issues or patients who live alone (NHPCO Staffing Guidelines, 2013). In an era with a widely growing aging population and economic instability, the occurrence of complex psychosocial issues and patients who live alone can be expected to rise. Hospice social workers will likely continue to be called on to provide community outreach and serve multiple roles within hospice care. It is clear that caseloads should be lowered in order for social workers to provide the necessary supports for this population.

However, with current caseloads where they are, it is still possible to adapt PST to fit routine hospice social work care. During routine visits, hospice social workers can help frame caregiver needs using the PST model. As found in this study, it is possible to teach the model and choose an initial problem, generate solution and pros/cons, choose a solution and come up with a weekly plan in one forty-five minute session. Feedback from caregivers in this study and a previous PST study (Dimiris et al., 2010) suggest that tangible, structured assistance better aids

in caregiver identification of needs and solution-generation. PST-Hospice offers a specific, effective approach for addressing hospice caregiver needs in this evolving health care climate.

### **8.3 Application to Social Work Practice**

This study is very applicable to social work practice. From the start, an over-arching goal has been to add to evidence-based research for social workers and advance the social work profession in hospice care. This study offers an evidence-based intervention for hospice social workers to implement into routine care. It improves caregiver quality of life- a common goal in hospice social work care planning. It leads to caregiver accountability for their problems, not dependency on the hospice team. It aligns with social work values in that it promotes self-determination, confidence, and self-care. It is potentially beneficial to the entire patient and family system, and larger environmental systems. It is measurable and can be used for clinical evaluation. It advances the social work role in hospice by presenting concrete evidence of the benefits of hospice social work and the unique clinical skillset that social worker's are trained in and qualified to carry out. It also may enhance social work satisfaction. As social workers have been found to have the least job satisfaction of hospice professionals (Monroe & DeLoach, 2004), this meaningful tool may promote the social work role in hospice, showing improved outcomes to affirm their value and elicit the respect of other professionals.

### **8.4 Study Limitations**

This dissertation study was a randomized controlled pilot study, with the primary purpose of testing the feasibility of Brief-PST for caregivers in the home-based hospice setting. The sample was small, and thus may have contributed to the lack of statistically significant findings for depression (PHQ-9) and problem-solving (SPSI-R Short). A larger study would likely be able to further test the effects of PST on depression, quality of life, and problem-solving. The

PST intervention was limited to a brief 5-week intervention. While previous PST studies in palliative care have used three sessions of PST (Demiris et al., 2010) and three to five weeks (Wood & Mynors-Wallis, 1997), six weeks of the intervention is typical for studies of PST on depression in home care (Gellis & Bruce, 2010; Gellis et al., 2007; Gellis, McGinty, Tierney et al., 2008). It is possible that including a sixth session may have contributed to the strength of effect of the PST intervention. However due to attrition concerns the intervention was planned for five weeks. Attrition was an issue for this study, as the unpredictability of patient length-of-stay is natural to hospice. While some participants' loved ones remained on hospice throughout the study and even months post-study participation, others passed away during participation. It may be possible to utilize prognosis data and exclude those patients who are not expected to live beyond five weeks. Future research on PST in Hospice should do so. For the dissertation purposes of this study, prognosis was not considered. Study duration was affected by many factors. Duration was planned for six weeks, including consent and post-testing. However due to caregiver schedules, patient decline or emergency, and practical concerns like weather, which are normal considerations of home visits, study duration varied. In addition, in order to prevent abandonment, caregivers were given the option of remaining in the study despite death of their hospice patient and changed caregiver status from active to bereaved. This caused variance in number of PST sessions and caregiver status for analyzed participants.

The study sample was comprised of a homogenous group, primarily Caucasian females. There was a lack of ethnic diversity among participants, which in some part may be attributable to the larger issues of underserved populations in hospice care (Colón & Lyke, 2003; Johnson, 1998; National Institutes of Health [NIH], 2004; Spruill, Mayer, & Hamilton, 2013). This sample included only home-based hospice caregivers thus excluding an entire group of hospice

caregivers, those whose loved one resides in a nursing home or hospital. This study utilized a convenience sampling strategy, which limits the generalizability of its findings. Future research should look at the impact of PST on hospice caregivers across regions and employ a random sampling strategy to improve generalizability of findings.

One major limitation of this study is that the PI served as the interventionist. Due to timing and feasibility of this dissertation study, it was not possible to train multiple hospice social workers to carry out the intervention. Future research may wish to employ many hospice social workers delivering the intervention during routine care, to test acceptability of its use by hospice social workers, and feasibility for implementation across a normal five-week period of routine hospice social work visits. While for the purposes of testing the intervention the PI met with caregivers once weekly for five weeks, it is not the norm for hospice social workers to visit each caregiver weekly. Modifications to the intervention's implementation would need to be made in order for it to be carried out more naturally and integrated with routine hospice care.

### **8.5 Clinical Reflections**

As a Clinical Social Worker who has worked in the hospice field for over five years, the idea that hospice caregivers had unmet needs that required intervening with a systematic approach was built from anecdotal evidence, which was then heavily researched and affirmed. Engaging caregivers in this format was odd at first, because in my own experience of routine hospice social work, structured sessions are not as common as narrative-style support. I was blown away by the ease of engagement with this approach. I found that the caregivers who received the intervention appreciated that I brought to the table a tool that could be learned. So often in hospice I have felt that caregivers were calling out *Help me! Help me! Please do something to help me*, and really seeking tangible support. While the benefits of hospice social

work have been documented, there remains a lack of evidence-based research on what the most helpful aspects of social work support are, and a lack of evidence-based interventions for social workers in the hospice settings.

I found that the problem-solving tool was very easy to teach. Caregivers were able to grasp it within the initial visit, and practice it during sessions. While some caregivers seemed more focused on the tool, others did require more directing of attention to the task at hand. However, even for those caregivers who seemed more comfortable talking narratively, it was not difficult to relate their expressions back to problem-solving and complete the tool upon each session.

I was surprised by how caregivers responded so positively to their weekly homework. I have found in routine hospice care that suggestions provided or plans made upon social work support visits were rarely carried out by the next visit, presumably due to the overwhelming stressors at hand that prevented caregivers from tackling new tasks. In reflecting on this, it seems that the use of a tool, writing things down, and repeating the same process each week led to stronger accountability for the caregiver. I got the sense that they were glad to be receiving support in a measurable manner. Each week when we reviewed their homework and pleasurable activities, it showed them that I remembered what their needs were, what they were working towards; and that I remained accountable to them. I believe that this helped build trust, validated the caregiver experience and motivated them to continue to work through the problem-solving process to achieve their goals.

One of the major themes that emerged in sessions with PST-Hospice participants was the idea that I was *there for them*. In hospice, the social worker serves both the patient and the family separately, as well as the patient and family as a unit. Home visits can consist of family

meetings, individual support to the patient, or to the caregiver/family. Caregivers who are assessed to be in need of extra support, social resources, end-of-life education or counseling may receive one-on-one support from the social worker. However in my experience, this does not happen across the board. Often home visit style is dictated by family preference. If the patient/family seem more comfortable all meeting with the social worker together at visits, then that is what they do. If a patient requests or appears in need of individual support, the social worker may schedule visits to meet with them alone. Too often the family gets less one-on-one time from the social worker. Visit content often surrounds patient needs, planning for patient care, case management tasks like applications for family leave or Medicaid, and end-of-life education. It is not the norm for the caregiver to receive weekly support visits focused solely on them, their problems and goals. This study showed me just how valuable consistent one-on-one time with caregivers is. I became acutely aware of the fact that caregivers who I may have assessed as low-need in my hospice social work role, benefitted from the intervention just as much as caregivers with more complex needs. In routine hospice care, these low-need caregivers may have been overlooked, apparently coping effectively and utilizing their own strengths and resources. This study served as a reminder that all caregivers face problems. All caregivers should receive specialized and individualized attention, regardless of their assessed level of need. There is opportunity for change and growth in all hospice cases.

A major clinical strength of this intervention is that it teaches clients a process that they can replicate on their own. It does not lead to dependency, but rather quite the opposite. It promotes self-determination and self-confidence. Throughout the study, when a caregiver successfully completed their solution and solved a problem, they felt pride in their achievements, no matter how small. After multiple weeks, this growth proved to enhance their sense of power

and control, and belief that they can solve their daily problems as well as more complicated problems that come their way.

In my opinion, PST is very well-suited for the hospice setting. It provides short-term, concrete support in a systematic way that can be easily taught. It is client-centered, and it can be tailored to fit any problem a client is facing, whether big or small, personal or interpersonal. Long-term goals can be broken down into smaller weekly goals which aides in progress and shows the power of taking things a step at a time. It removes issues of client dependency on the helper, as the process is taught to the client, client-generated and is intended to lead to ongoing effective problem-solving. As a hospice social worker, I found this approach fit well with the time constraints of a routine hospice visit, its repetition led to learning and a sense of safety for caregivers, as visit content was predictable and I remained accountable to them, their experience and struggles throughout the process. The termination process went smoothly, as caregivers were informed of the five-week intervention timeline and anticipated termination from the start. Also, framing the intervention as a process to be learned and carried out on their own once the intervention ended helped caregivers conceptualize our work together, focus, and prepare for ending. I would highly recommend PST as an excellent clinical approach for hospice social workers to employ in their routine care of patients and families.



## References

- Alexopoulos, G. S., Raue, P., & Areán, P. (2003). Problem-solving therapy versus supportive therapy in geriatric major depression with executive dysfunction. *The American Journal of Geriatric Psychiatry, 11*(1), 46-52.
- Altilio, T., Gardia, G., & Otis-Green, S. (2008). Social work practice in palliative and end-of-life care: A report from the summit. *Journal of Social Work in End-of-Life & Palliative Care, 3*(4), 68-86.
- Andrews, S. C. (2001). Caregiver burden and symptom distress in people with cancer receiving hospice care. *Oncology Nursing Forum, 28*(9), 1469-1474.
- Aoun, S. M., Kristjanson, L. J., Currow, D. C., & Hudson, P. L. (2005). Caregiving for the terminally ill: At what cost? *Palliative Medicine, 19*(7), 551-555.
- Arnold, E.M., Artin, K.A., Griffith, D., Person, J.L., Graham, K.G. (2007). Unmet needs at the end of life: perceptions of hospice social workers journal of social work. *End-of-Life & Palliative Care, 2*(4), 61-83.
- Blanchard, C.G., Toseland, R.W., McCallion, P. (1996). The effects of a problem-solving intervention with spouses of cancer patients. *Journal of Psychosocial Oncology, 14*(2), 1-20.
- Bosma, H., Johnston, M., Cadell, S., Wainwright, W., Abernethy, N., Feron, A.,...  
Nelson, F. (2010). Creating social work competencies for practice in hospice palliative care. *Palliative Medicine, 24*(1), 79-87.
- Bramwell, L., MacKenzie, J., Laschinger, H., & Cameron, N. (1995). Need for overnight respite for primary caregivers of hospice clients. *Cancer Nursing, 18*(5), 337-343.
- Cabin, W.D. (2008). Actualizing "professional altruism:" A comparison of home health care and

- hospice social workers. *Home Health Care Management & Practice*, 20(6), 474-481.
- Cabin, W.D. (2010). CMS and Congress increase home health scrutiny through PSCs, ZPICs, and therapy visit reviews. *Home Health Care Management & Practice*, 22, 531-532.
- Cabin, W.D. (2008). Revaluing social work in home care: Lessons from innovators, rebels, and hospice. *Home Health Care Management & Practice*, 20(3), 265-272.
- Cameron, J. I., Shin, J. L., Williams, D., & Stewart, D. E. (2004). A brief problem-solving intervention for family caregivers to individuals with advanced cancer. *Journal of Psychosomatic Research*, 57(2), 137-143.
- Candy, B., Jones, L., Drake, R., Leurent, B., & King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *The Cochrane Library*, 2011(9).
- Carter, P.A. (2006). A brief behavioral sleep intervention for family caregivers of persons with cancer. *Cancer Nursing*, 29, 95-103.
- Centers for Medicare and Medicaid Services. (2011). Medicare hospice benefits. Baltimore, MD: Centers for Medicare & Medicaid Services.
- Chentsova-Dutton, Y., Shucter, S., Hutchin, S., Strause, L., Burns, K., Dunn, L.,... Zisook, S. (2002). Depression and grief reactions in hospice caregivers: from pre-death to 1 year afterwards. *Journal of Affective Disorders*, 69, 53-60.
- Chentsova-Dutton, Y., Shucter, S., Hutchin, S., Strause, L., Burns, K., & Zisook, S. (2000). □The psychological and physical health of hospice caregivers. *Annals of Clinical Psychiatry*, 12(1), 19-27.
- Christ, G.H., & Sormanti, M. (1999). Advancing social work practice in end-of-life care. *Social Work in Health Care*, 30(2), 81-99.

- Clark, M.M., Rummans, T.A., Sloan, J.A., Jensen, A., Athertor, P.J., Frost, M.H., Jarrett, W. (2006). Quality of life of caregivers of patients with advanced-stage cancer. *American Journal of Hospice & Palliative Medicine*, 23(3), 185-191.
- Colón, M. & Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, African Americans and Latinos. *American Journal of Hospice & Palliative Care*, 20(3), 182-190.
- Colón, Y., Otis-Green, S. (2008). Roles of social workers in interdisciplinary pain management. *Journal of Pain & Palliative Care Pharmacotherapy*, 22(4), 303-305.  
48(1/2), 219-231.
- Decker, S.D., & Young, E. (1991). Self-perceived needs of primary caregivers of home-hospice clients. *Journal of Community Health Nursing*, 8(3), 147-154.
- Demiris, G., Parker Oliver, D., Wittenberg-Lyles, E. (2009). Assessing caregivers for team interventions (ACT): A new paradigm for comprehensive hospice quality care. *American Journal of Hospice and Palliative Care*, 26(2), 128-134.
- Demiris, G., Parker Oliver, D., Washington, K., Fruehling, L. T., Haggarty-Robbins, D., Doorenbos, A., . . . Berry, D. (2010). A problem solving intervention for hospice caregivers: A pilot study. *Journal of Palliative Medicine*, 13(8), 1005-1011.
- Demiris, G., Parker Oliver, D., Wittenberg-Lyles, E., & Washington, K. (2011). Use of videophones to deliver a cognitive-behavioural therapy to hospice caregivers. *Journal of Telemedicine and Telecare*, 17(3), 142-145.
- Demiris, G., Parker Oliver, D., Wittenberg-Lyles, E., Washington, K., Doorenbos, A., Rue, T., & Berry, D. (2012). A noninferiority trial of a problem-solving intervention for hospice caregivers: In person versus videophone. *Journal of Palliative Medicine*, 15(6), 653-660.

- Doherty, J.B., DeWeaver, K.L. (2004). A survey of evaluation practices for hospice social workers. *Home Health Care Services Quarterly*, 23(4), 1-13.
- Dugas, M.J., Ladouceur, R., Léger, E., Freeston, M.H., Langolis, F., Provencher, M.D., Boisvert, J.-M. (2003). Group cognitive-behavioral therapy for generalized anxiety disorder: Treatment outcome and long-term follow-up. *Journal of Counseling and Clinical Psychology*, 71(4), 821-825.
- D’Zurilla, T.J. & Nezu, A.M. (1990). Development and preliminary evaluation of the Social Problem-Solving Inventory. *Psychological Assessment: A Journal of Consulting and Clinical Psychology*, 2(2), 156-163.
- D’Zurilla, T. J., Nezu, A. M., & Maydeu-Olivares, A. (2002). *The social problem-solving inventory-revised (SPSI-R): Technical manual*. North Tonawanda, NY: Multi-Health Systems, Inc.
- D’Zurilla, T.J. & Nezu, A.M. (2007). *Problem-solving therapy: A positive approach to clinical intervention*. New York, NY: Springer Publishing Company.
- Eaton, N. (2008). “I don’t know how we coped before’: A study of respite care for children in the home and hospice. *Journal of Clinical Nursing*, 17, 3196-3204.
- Empeño, J., Raming, N.T.J., Irwin, S.A., Neleson, R.A., & Lloyd, L.S. (2011). The hospice caregiver support project: Providing support to reduce caregiver stress. *Journal of Palliative Medicine*, 14(5), 593-597.
- Gellis, Z.D., & Bruce, M.L. (2010). Problem solving therapy for subthreshold depression in home healthcare patients with cardiovascular disease. *American Journal of Geriatric Psychiatry*, 18(6), 464–474.
- Gellis, Z.D., McGinty, J., Horowitz, A., Bruce, M.L., & Misener, E. (2007). Problem-solving

- therapy for late-life depression in home care: A randomized field trial. *American Journal of Geriatric Psychiatry*, 15(11), 968-978.
- Gellis, Z.D., McGinty, J., Tierney, L., Jordan, C., Burton, J., Misener, E. (2008). Randomized controlled trial of problem-solving therapy for minor depression in home care. *Research on Social Work Practice*, 18, 596-606.
- Gellis, Z.D., & Nezu, A.M. (2011). Integrated depression care for homebound medically ill older adults: Using evidence-based problem-solving therapy. In Sorocco, K.H., & Lauderdale, S. (Ed.), *Cognitive Behavior Therapy with Older Adults* (pp. 391-420). New York, NY: Springer Publishing Company.
- Ghesquiere, A., Martí Haidar, Y.M., & Shear, M.K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work in End-of-Life & Palliative Care*, 7, 216–240.
- Gill, P., Kaur, J. S., Rummans, T., Novotny, P. J., & Sloan, J. A. (2003). The hospice patient's primary caregiver: What is their quality of life? *Journal of Psychosomatic Research*, 55(5), 445-451.
- Grande, G., Todd, C., & Barclay, S. (1997). Support needs in the last year of life: Patient and carer dilemmas. *Palliative Medicine*, 11, 202-208.
- 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.
- Harding, R., Higginson, I.J. (2003). What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 17, 63-74.
- Harding, R., List, S., Epiphaniou, E., & Jones, H. (2011). How can informal caregivers in

- cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative Medicine*, 26(1), 7-22.
- Houts, P. S., Nezu, A. M., Nezu, C. M., & Bucher, J. A. (1996). The prepared family caregiver: A problem-solving approach to family caregiver education. *Patient Education and Counseling*, 27(1), 63-73.
- Hudson, P. (2003). The experience of research participation for family caregivers of palliative cancer patients. *International Journal of Palliative Nursing*, 9(3), 120-123.
- Hudson, P. L., Aranda, S., & Hayman-White, K. (2005). A psycho-educational intervention for family caregivers of patients receiving palliative care: A randomized controlled trial. *Journal of Pain and Symptom Management*, 30(4), 329-341.
- Hudson, P. L., Aranda, S., & Kristjanson, L. J. (2004). Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. *Journal of Palliative Medicine*, 7(1), 19-25.
- Hudson, P. L., & Hayman-White, K. (2006). Measuring the psychosocial characteristics of family caregivers of palliative care patients: Psychometric properties of nine self-report instruments. *Journal of Pain and Symptom Management*, 31(3), 215-228.
- Hudson, P. L., Lobb, E. A., Thomas, K., Zordan, R. D., Trauer, T., Quinn, K., . . . Summers, M. (2012). Psycho-educational group intervention for family caregivers of hospitalized palliative care patients: Pilot study. *Journal of Palliative Medicine*, 15(3), 277-281.
- Hudson, P., & Payne, S. (2011). Family caregivers and palliative care: Current status and agenda for the future. *Journal of Palliative Medicine*, 14(7), 864-869.
- Hudson, P., Quinn, K., Kristjanson, L., Thomas, T., Braithwaite, M., Fisher, J., & Cockayne, M. (2008). Evaluation of a psycho-educational group programme for family caregivers in

- home-based palliative care. *Palliative Medicine*, 22(3), 270-280.
- Hudson, P., Remedios, C., Zordan, R., Thomas, K., Clifton, D., Crewdson, M.,... Bauld, C. (2012). Guidelines for the psychological and bereavement support of family caregivers of palliative care patients. *Journal of Palliative Medicine*, 15(6), 696-702.
- Hudson, P.L., Trauer, T., Graham, S., Grande, G., Ewing, G., Payne, S., Stajduhar, K.I., & Thomas, K. (2010). A systematic review of instruments related to family caregivers of palliative care patients. *Journal of Palliative Medicine*, 24(7), 656-668.
- Hudson, P.L., Zordan, R., & Trauer, T. (2011). Research priorities associated with family caregivers in palliative care: International perspectives. *Journal of Palliative Medicine*, 14(4), 397-401.
- Huff, M.B., Weisenfluh, S., Murphy, M., Black, P.J. (2006). End-of-life care and social work education: What do students need to know? *Journal of Gerontological Social Work*,
- Johnson, C.B. (1998). Hospice: What gets in the way of appropriate and timely access. *Holistic Nursing Practice*, 13(1), 8-21.
- Jones, B.L.; Pomeroy, E.C., & Sampson, M. (2009). University-community partnerships and community-based participatory research: One community's approach to enhance capacity in end-of-life and bereavement practice, research and education. *Journal of Social Work in End-Of-Life & Palliative Care*, 5(1-2), 94-104.
- Kapp, S.A., & Nelson-Becker, H.B. (2007). Evaluating hospice services for improvement: A manageable approach. *Journal of Pain & Palliative Care Pharmacotherapy*, 21(2), 17-26.
- Kelley, A.S., Deb, P., Du, Q., Aldridge Carlson, M.D., & Morrison, S. (2013). Hospice enrollment saves money for Medicare and improves care quality across a number

- of different lengths-of-stay. *Health Affairs*, 32(3), 552-561.
- Kristjanson, L. J., & Aoun, S. (2004). Palliative care for families: Remembering the hidden patients. *Canadian Journal of Psychiatry*, 49(6), 359-365.
- Kroenke, K. & Spitzer, R. (2001). The PHQ-9. *Journal of General Internal Medicine*, 16(9), 606 -613.
- Kübler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan Publishers.
- Kurylo, M. F., Elliott, T. R., & Shewchuk, R. M. (2001). FOCUS on the family caregiver: A problem-solving training intervention. *Journal of Counseling & Development*, 79(3), 275.
- Lang, S.H. & Cabin, W.D. (2011). Tightening the regulatory knot: Hospice regulatory and health care legislative reform converge on hospice clinical management. *Home Health Care Management & Practice*, 23 (4), 252-259.
- Lieberman, R.P., Eckman, T., & Marder, S.R. (2001). Rehab rounds: Training in social problem solving among persons with schizophrenia. *Psychiatric Services*, 52(1), 31-33.
- Lopez, M.A., & Mermelstein, R.J. (1995). A cognitive-behavioral program to improve geriatric rehabilitation outcome. *Gerontologist*, 35(5),696-700.
- MacDonald, D. (1991). Hospice social work: A search for identity, *Health and Social Work*, 16(4), 274-280.
- Martin, A., Rief, W., Klaiberg, A., & Braehler, E. (2006). Validity of the Brief Patient Health Questionnaire Mood Scale (PHQ-9) in the general population. *General Hospital Psychiatry*, 28(1), 71-77.
- McMillan, S. C., & Mahon, M. (1994). The impact of hospice services on the quality of life of primary caregivers. *Oncology Nursing Forum*, 21(7), 1189-1195.
- 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. *Cancer, 106*(1), 214-222.
- Miller, S. C., Lima, J., Gozalo, P. L., & Mor, V. (2010). The growth of hospice care in U.S. nursing homes. *Journal of the American Geriatrics Society, 58*(8), 1481-1488.
- Monroe, J., & DeLoach, R. J. (2004). Job satisfaction: How do social workers fare with other interdisciplinary team members in hospice settings? *Omega: Journal of Death & Dying, 49*(4), 327-346.
- Munn, J.C., & Adorno, G. (2008). By invitation only: Social work involvement at the end of life in long-term care. *Journal of Social Work in End-of-Life & Palliative Care, 4*(4), 333-357.
- Muurinen, J. (1986). The economics of informal care: Labor market effects in the national hospice study. *Medical Care, 24*(11), 1007-1017.
- National Hospice and Palliative Care Organization. (2008). Hospice inpatient respite care. Retrieved from [http://www.nhpco.org/files/public/regulatory/Inpatient\\_Respite\\_Care.pdf](http://www.nhpco.org/files/public/regulatory/Inpatient_Respite_Care.pdf)
- National Hospice and Palliative Care Organization. (2013). Hospice care: What is hospice? Retrieved from <http://www.nhpco.org/about/hospice-care>
- National Hospice and Palliative Care Organization. (2012). NHPCO facts and figures: Hospice care in America. Retrieved from [http://www.nhpco.org/sites/default/files/public/Statistics\\_Research/2012\\_Facts\\_Figures.pdf](http://www.nhpco.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf)
- National Hospice and Palliative Care Organization. (2013). NHPCO 2012 national summary

of hospice care. Retrieved from

[http://www.nhpco.org/sites/default/files/public/NDS\\_2012\\_National\\_Summary\\_20131106.pdf](http://www.nhpco.org/sites/default/files/public/NDS_2012_National_Summary_20131106.pdf)

National Hospice and Palliative Care Organization. (2013). Staffing guidelines for hospice home care teams. Retrieved from

[http://www.nhpco.org/sites/default/files/public/quality/Staffing\\_Guidelines.pdf](http://www.nhpco.org/sites/default/files/public/quality/Staffing_Guidelines.pdf)

National Hospice and Palliative Organization. (2013). NHPCO 2013 press releases. Retrieved from <http://www.nhpco.org/press-room/press-releases-2013>

National Institutes of Health. (2004). Improving End-of-Life Care. *NIH Consensus and State-of-the-Science Statements*. 2004 Dec 6-8; 21(3) 1–28.

Nelson-Becker, H., & Ferrell, B.R. (2011). Social work and nursing: Creating effective collaborations in palliative care. In T. Altilio & S. Otis-Green (Eds.), *Oxford Textbook of Palliative Social Work* (pp. 477-481). New York: Oxford University Press.

Nezu, A.M., Nezu, C.M., & D’Zurilla, T.J. (2013). *Problem-solving therapy: A treatment manual*. New York, NY: Springer Publishing Company.

Nezu, A.M., Nezu, C.M., & Perri, M.G. (1989). *Problem-solving therapy for depression*. New York, NY: John Wiley & Sons.

Parker Oliver, D., & Peck, M. (2006). Inside the interdisciplinary team experiences of hospice social workers. *Journal of Social Work in End-of-Life & Palliative Care*, 2(3), 7-21.

Parker Oliver, D., Washington, K., Demiris, G., Wittenberg-Lyles, E., & Novak, H. (2012).

Problem solving interventions: An opportunity for hospice social workers to better meet

- caregiver needs. *Journal of Social Work in End-of-Life & Palliative Care*, 8(1), 3-9.
- Provencher, M.D., Dugas, M.J., & Ladouceur, R. (2004). Efficacy of problem-solving training and cognitive exposure in the treatment of generalized anxiety disorder: A case replication series. *Cognitive and Behavioral Practice*, 11(4), 404-414.
- Rabow, M.W., Hauser, J.M., & Adams, J. (2004). Supporting family caregiver at the end of life: They don't know what they don't know. *Journal of the American Medical Association*, 291(4), 483-491.
- Reese, D. J. (2011). Interdisciplinary perceptions of the social work role in hospice: Building upon the classic Kulys and Davis study. *Journal of Social Work in End-of-Life & Palliative Care*, 7(4), 383-406.
- Reese, D. J., & Brown, D. R. (1997). Psychosocial and spiritual care in hospice: Differences between nursing, social work, and clergy. *Hospice Journal*, 12(1), 29.
- Reese, D.J., & Raymer, M. (2004). Relationships between Social Work involvement and hospice outcomes: Results of the National Hospice Social Work Survey, *Social Work*, 49(3), 415-422.
- Reese, D.J., Raymer, M., Orloff, S.F., Gerbino, S., Valade, R., Dawson... Huber, R. (2006). The social work assessment tool (SWAT). *Journal of Social Work in End-of-Life & Palliative Care*, 2(1), 65-95.
- Rhymes, J. (1990). Hospice Care in America. *JAMA*, 264(3), 369-372.
- Roberto, K.A. & Jarrot, S.E. (2008). Family caregivers of older adults: A life span perspective. *Family Relations*, 57, 100-111.
- Sanders, S., Bullock, K., & Broussard, C. (2012). Exploring professional boundaries in end-of-life care: Considerations for hospice social workers and other members of the team.

- Journal of Social Work in End-of-Life & Palliative Care*, 8, 10-28.
- Schulz, R. & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, 282(23), 2215-2219.
- Spruill, A.D., Mayer, D.K., & Hamilton, J.B. (2013). Barriers in hospice use among African Americans with cancer. *Journal of Hospice & Palliative Nursing*, 15(3), 136-144.
- Skilbeck, J.K., Payne, S.A., Ingleton, M.C., Nolan, M., Carey, I., & Hanson, A. (2005). *Palliative Medicine*, 19, 610-618.
- Social Work Policy Institute. (2010). *Hospice social work: Linking policy, practice and research*, Washington, D.C.: National Association of Social Workers.
- Soothill, K., Morris, S. M., Thomas, C., Harman, J. C., Francis, B., & McIllmurray, M. B. (2003). The universal, situational, and personal needs of cancer patients and their main carers. *European Journal of Oncology Nursing*, 7(1), 5-13.
- Stajduhar, K. I. & Davies, B. (1998). Death at home: Challenges for families and directions for the future. *Journal of Palliative Care*, 14(3), 8-14.
- Tang, S. T. (2003). When death is imminent: Where terminally ill patients with cancer prefer to die and why. *Cancer Nursing*, 26(3), 245-251.
- Teri, L., Logsdon, R.G., Uomoto, J., & McCurry, S.M. (1997). Behavioral treatment of depression in dementia patients: A controlled clinical trial. *Journals of Gerontology Series B—Psychological Sciences and Social Sciences*, 52B(4), 159-166.
- Toseland, R. W., Blanchard, C. G., & McCallion, P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science & Medicine*, 40(4), 517-528.
- Walsh, K., Jones, L., Tookman, A., Mason, C., McLoughlin, J., Blizard, R., & King, M. (2007). Reducing emotional distress in people caring for patients receiving specialist palliative

- care: Randomised trial. *British Journal of Psychiatry*, 190(2), 142-147.
- Walsh, S. M., & Schmidt, L. A. (2003). Telephone support for caregivers of patients with cancer. *Cancer Nursing*, 26(6), 448-453.
- Walsh, S. M., Estrada, G. B., & Hogan, N. (2004). Individual telephone support for family caregivers of seriously ill cancer patients. *MEDSURG Nursing*, 13(3), 181-189.
- Weems, K. (2008). Memorandum report: "The hospice beneficiaries' use of respite care," OEI-02-06-00222. Department of Health and Human Services, March 31, 2008.
- Weisenfluth, S.A. & Csikai, E.L. (2013). Professional and educational needs of hospice and palliative care social workers. *Journal of Social Work in End-of-Life & Palliative Care*, 9, 58-73.
- Weisenfluth, S. (2011). Social Work and Palliative Care in Hospice. In T. Altilio & S. Otis-Green (Eds.), *Oxford Textbook of Palliative Social Work* (pp. 71-78). New York, NY: Oxford University Press.
- Weitzner, M.A., Jacobsen, P.B., Wagner Jr., H., Friedland, J., & Cox, C. (1999). The Caregiver quality of life index-Cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research*, 8, 55-63.
- Weitzner, M.A., Moody, L.N., & McMillan, S.C. (1997). Symptom management issues in hospice care. *American Journal of Hospice and Palliative Care*, 14, 190-195.
- Wilder, H.M., Parker Oliver, D., Demiris, G., & Washington, K. (2008). Informal hospice caregiving: The toll on quality of life. *Journal of Social Work in End-of-Life and Palliative Care*, 4(4), 312-332.
- Wingate, A. & Lackey, N. (1989). A description of the needs of noninstitutionalized cancer

patients and their primary caregivers. *Cancer Nursing*, 12(4), 216-225.

Wittenberg-Lyles, E., Demiris, G., Parker Oliver, D., & Burt, S. (2011). Reciprocal suffering: Caregiver concerns during hospice care. *Journal of Pain and Symptom Management*, 41(2), 383-393.

Wood, B.C., & Mynors-Wallis L.M. (1997). Problem-solving therapy in palliative care. *Palliative Medicine*, 49-54.

World Health Organization. (2013). Definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

## Appendix A

### Problem-Solving Therapy for Informal Hospice Caregivers: A Randomized Controlled Pilot Study

#### Study Procedures

- 1) The Study's Co-Principal Investigator (Co-PI), Christin Gregory, will introduce participating hospice agencies to the study and train staff members on appropriate procedures. Staff will be requested to direct all study-related questions to the Co-PI, and the Co-PI will instruct agency staff to maintain their usual care procedures throughout the study.
- 2) Samaritan Healthcare & Hospice and Lighthouse Hospice staff members who complete admissions will be trained on a one-page introduction to the study (recruitment flyer), to be handed out at each admission (placed in each admission packet alongside the routine paperwork), and will be instructed to inform the eligible caregiver that they will receive a call from the Co-PI, who will further explain the study and answer any of their questions.
- 3) Upon admission to the participating hospice agencies, the identified primary caregiver of the admitting patient will be introduced to the study via the 1-page study introduction and will be informed that they will receive a call for further details (primary caregivers are identified at admission). Caregivers will be given the opportunity to decline a call at this time.
- 4) The hospice admission staff person/point person at the agency office will then alert the Co-PI to the hospice admission.
- 5) The Co-PI will make contact with those primary caregivers that appear to meet initial inclusion criteria (primary caregiver, age 18+, English-speaking), to invite them to participate and schedule an initial visit at a location of the caregivers choice (home, coffee shop, restaurant, etc...), and at a convenient time. The Co-PI will make three attempts to contact the eligible caregiver, and will cease attempting contact after these three attempts. Messages will be left requesting a returned call to be made to the Co-PI.
- 6) Upon this initial meeting, the Co-PI will describe the study, answer any questions and ask those eligible caregivers if they are interested in consenting to be part of the study. Written informed consent will be obtained from caregiver participants, and a copy will be given to the participant. Written informed consent and combined HIPAA Authorization for chart reviews will be obtained from capable and willing patients, and a copy will be provided to the patient. Following informed consent, the Co-PI will complete The PHQ9 and complete a suicide assessment. The caregiver will also be asked about current psychotropic medication use and current use of psychotherapy services, since these will be an indicator of psychiatric treatment and may be a study confounder in relation to the PST intervention.
- 7) Caregivers who score in the severely depressed range (22+) according to the PHQ-9 will be encouraged to contact their primary care physician to seek depression treatment, referred to community resources, and excluded from the study.

- 8) If a person reports acute suicidality, the Co-PI will follow the study emergency procedures which are as follows:  
contact local crisis services (using study emergency procedures list), and if crisis is unavailable, the local police, for caregivers who report acute suicidal ideation. The hospice agency will also be informed of suicidality, so that the special needs of the caregiver are made aware to the hospice team, and so that their team social worker may continue to assess for suicidality. They will be excluded from the study.  
\*These procedures will be included in the informed consent document and will be reviewed with the participant.
- 9) During this introductory meeting with the Co-PI, the participant will be asked to provide their e-mail address, as a pre-test survey will be e-mailed to them. For those who do not have smart phone or internet access, they will be informed that a research assistant will be contacting them to schedule a pre-test survey, and then after the intervention is completed (or after 5 weeks), a post-test survey.
- 10) Following this meeting for included and consenting participants, pre-testing will be administered by either Survey Monkey or a research assistant. This will happen within two days, or later, with respect to the participant's schedule.
- 11) Randomization will follow pre-test completion. Randomization will be conducted using a web-based program, randomizer.org. Each participant will be assigned a random participant # and then will be informed by phone of the intervention they will be receiving.
- 12) Five weekly PST-Hospice sessions will be offered after randomization to participants in the experimental condition.  
Participants in the usual care condition will be provided with caregiver coping education materials by mail, to review with their team social worker at routine visits if they so choose.
- 13) The post-test survey will be e-mailed via Survey Monkey immediately post-treatment (or after 5 weeks), and for those without access to the internet, a research assistant will arrange a home visit and complete the post-test survey in person.
- 14) Four randomly selected participants (2 from each condition) will be asked to complete an interview with the Co-PI after completion of their study interaction.
- 15) The Co-PI will remain blinded to data collection (except for the pre-test PHQ9 used at screening) until the intervention is complete, at which point, patient chart reviews and statistical analyses will begin.



## Appendix B

### Research Study for Hospice Caregivers

#### Purpose of the Study

Samaritan Healthcare and Hospice is participating in a research study with the University of Pennsylvania. We are interested in looking at a potentially beneficial intervention for hospice caregivers.

Caregivers face many changes in their daily routine, physical and psychological strain, in addition to ongoing grief. Caregiving presents unique challenges for many families, and is an important topic of study as hospice agencies strive to continuously improve their services for the dying and their loved ones.

In order to provide you with the highest quality of care, we need to understand more about the problems you face throughout the caregiving experience and ways we may better assist you.

#### Volunteer Participation

We are asking for caregiver volunteers to participate in a short-term, 6 week study that will involve completing a survey on two separate occasions and may involve receiving a weekly psychosocial intervention from a Clinical Social Worker, in addition to your usual hospice team care. At the end of the 6 weeks, you may be asked to complete a 30-minute interview with the Clinical Social Worker. The intervention will take place in your home, or at an alternate location of your choosing.

#### Why Participate

We are asking for your participation so that we may learn more about the caregiver experience, and potential ways to better help serve you. Your involvement in this study is completely voluntary, and will result in improved care for families and caregivers of hospice patients.

#### How to Participate

You may receive a call from the primary researcher for this study to invite you to participate. If you do not wish to receive a call, please let the admission worker know.

*If you are interested in learning more, you may contact:*

*Christin Gregory, LCSW  
DSW Candidate  
University of Pennsylvania  
School of Social Policy and Practice  
(504) 460-2691*



## Appendix C

## Caregiver Coping Pamphlet

Caregiving	Coping Strategies	Coping Strategies
<p>Caring for a loved is very rewarding, but can also be very difficult.</p> <p>If you are feeling stressed, exhausted, frustrated, confused, depressed or anxious,</p> <p><b>You are not alone.</b></p> <p>Caregivers face many changes like shift in family role, loss of work and personal <u>time</u>.</p> <p>Caregivers often experience sadness, anger, fear, guilt, depression, or lethargy.</p>	<p>There are many things you can do to improve your experience and cope more effectively. Try:</p> <p><u>A support group or caregiver helpline.</u></p> <p>Educating yourself by talking to your hospice team, your loved one's doctors, and reading.</p> <p>Breathing when you're feeling tense: Take a moment, breathe in for five counts, <u>exhale</u> for five counts. Repeat three times or more.</p> <p>Using a caregiving calendar. Write down important information about your loved one's care, appointments, reminders to call people back, and reminders to do things for yourself. Schedule visits at times that are best for you and your loved one. A feeling of control over your schedule and tasks may help prevent you from getting overwhelmed.</p> <p>Talking with your primary care doctor about your symptoms and seeking treatment if needed.</p> <p><a href="#">A...</a></p>	<p>Set a goal of doing one to two pleasurable activities a day for yourself.</p> <p>Some ideas are:</p> <ul style="list-style-type: none"> <li>-Call a friend</li> <li>-Watch a funny show or <u>favorite</u> movie</li> <li>-Take a nap (maybe try doing this when your loved one is napping too)</li> <li>-Exercise</li> <li>-Take a bath</li> <li>-Eat a favorite meal</li> <li>-Treat yourself to a massage or pedicure</li> <li>-Spend some time outdoors</li> <li>-Play a game</li> <li>-Look through old pictures</li> <li>-Read</li> <li>-Journal</li> <li>-Have support persons over</li> <li>-Garden</li> <li>-Attend a sporting event</li> </ul> <p>-Or do anything else that you enjoy!!!</p>

**Caregiver Resources**

Alzheimer's Association offer support via phone 24/7: 1-800-272-3900  
And online:  
<http://www.alz.org/care/alzheimers-dementia-caregiver-notebook.asp>

Caregiver.com is a great online resource, you can also subscribe to their magazine or newsletter  
<http://www.caregiver.com>

Family Caregiver Alliance  
<http://www.caregiver.org/caregiver/jsp/home.jsp>

New Jersey Aging and Disability Resource Connection  
<http://www.adrcnj.org>

Family and Caregiver Resources New Jersey  
[https://www.nrd.gov/family\\_and\\_caregiver\\_support/states\\_and\\_territories/new\\_jersey](https://www.nrd.gov/family_and_caregiver_support/states_and_territories/new_jersey)

**Important Information for Caregivers**

Caregiver Information Pamphlet,  
Created by Christin Gregory 2013  
UPENN DSW Dissertation: PST for Hospice Caregivers

A...

## **Appendix D**

Problem-Solving Therapy for Informal Hospice Caregivers:  
A Randomized Controlled Pilot Study

### **Qualitative Interview Guide**

1. What was the experience of being a part of this study like for you?
  
2. (for Brief PST-Hospice) Please share what you learned from PST;  
(for UC+CE) Please share what you learned from the caregiver education materials.
  
3. Throughout this experience, what was the most difficult part for you?
  
4. Throughout this experience, what did you experience the most positively?
  
5. What changes would you make to this experience, if any?
  
6. Is there anything else you'd wish to share?

\*I will also be asking prompting questions like “tell me more,” “can you please explain that,” to open up the conversation.