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## Quality of Life of Older Adults with Complicated Grief Receiving Accelerated Resolution Therapy: A Mixed Methods Study

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Quality of Life of Older Adults with Complicated Grief  
Receiving Accelerated Resolution Therapy: A Mixed Methods Study

by

Tina M. Mason

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy  
Department of Nursing  
College of Nursing  
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## **DEDICATION**

To family caregivers

*"The simple act of caring is heroic."* - Edward Albert, actor

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## TABLE OF CONTENTS

List of Tables .....	vi
List of Figures .....	vii
List of Boxes .....	viii
List of Abbreviations .....	ix
Abstract .....	x
Chapter One: Introduction .....	1
Background .....	1
Conceptual Underpinning of Study .....	3
Statement of the Problem.....	4
Purpose of the Study .....	4
Specific Aims.....	5
Aim # 1 .....	5
Aim #2 .....	5
Hypothesis.....	5
Aim #3 .....	5
Definition of Key Terms .....	6
Summary .....	7
Chapter Two: Review of the Literature .....	8
Conceptual Underpinning: The Stress Process .....	8
Proposed Model .....	9
Linkage between Model and Dissertation.....	10
Stress .....	11
Stress and Caregiving .....	13
Stress and Complicated Grief .....	14
Quality of Life.....	15
Quality of Life Domains .....	18
Quality of Life and Caregiving .....	19
Quality of Life and Complicated Grief.....	21
Summary .....	22

Chapter Three: Research Design and Methodology .....	23
Study Design .....	23
Setting and Recruitment.....	24
Sample.....	25
Inclusion Criteria .....	25
Exclusion Criteria .....	25
Instruments.....	26
Qualitative - Interview Guide .....	26
Quantitative - CDC HRQOL-14 .....	27
Demographics Form.....	28
Charlson Comorbidity Index.....	28
Procedures .....	29
Regulatory Approval.....	29
Data Collection .....	29
Data Analysis Plan for Specific Aims .....	29
Aim #1 .....	29
Trustworthiness.....	31
Aim #2 .....	32
Aim #3 .....	35
Demographic and Clinical Characteristics.....	36
Limitations and Assumptions .....	37
Summary .....	38
Chapter Four: Results .....	39
Aim #1: Semi-structured Interviews.....	39
Demographic and Clinical Characteristics.....	40
Bivariate Analyses .....	40
Thematic Analysis .....	40
Aim #2: CDC-HRQOL-14.....	45
Healthy Days Module .....	45
Demographics and Clinical Characteristics .....	47
Bivariate Relationships between Continuous Variables .....	48
Paired t-Tests and RMANOVA .....	50
Multilevel Linear Model .....	54
Aim # 3: Mixed Methods Analysis.....	55
Demographic and Clinical Characteristics.....	55
Bivariate Relationships between Continuous Variables .....	58
Data Integration .....	58
Caregivers' Characteristics Examined with Qualitative Data .....	61
Qualitative Data Examined with Caregivers' Characteristics .....	62
Caregivers' Characteristics Examined with Quantitative Data .....	62
Full Integration of Data Results.....	63
Chapter Five: Discussion, Implications, and Conclusion .....	65
Discussion .....	65
Aim #1 Qualitative Description of Quality of Life of Older Adults with	

Complicated Grief.....	65
Aim #2 Quantitative Examination of Quality of Life of Older Adults with Complicated Grief .....	68
Aim #3 Integration of Data to Understand Quality of Life of Older Adults with Complicated Grief.....	70
Limitations .....	72
Implications for Nursing.....	73
Implications for Research .....	74
Conclusion .....	75
References .....	77
Appendices.....	103
Appendix A: Interview Guide.....	104
Appendix B: CDC HRQOL-14.....	106
Appendix C: Demographics Form .....	109
Appendix D: Charlson Comorbidity Index.....	111
Appendix E: IRB Approval Letter.....	113
Appendix F: Codebook .....	114
About the Author .....	End Page

## LIST OF TABLES

Table 1: Demographic and Clinical Characteristics Comparing Groups with Test Statistics .....	41
Table 2: Quality of Life Themes and Sub-themes Extracted from Semi-structured Interviews.....	42
Table 3: Eigenvalues and Variance Explained .....	46
Table 4: Demographic Characteristics Comparing Groups with Test Statistics.....	49
Table 5: Clinical Characteristics Comparing Groups with Test Statistics.....	50
Table 6: Pearson Correlations Among Continuous Variables .....	53
Table 7: Descriptive Statistics for Total Quality of Life Scores: Time 1, Time 2, & Time 3 .....	54
Table 8: Demographic Characteristics Comparing Groups with Test Statistics.....	56
Table 9: Clinical Characteristics Comparing Groups with Test Statistics.....	57
Table 10: Pearson Correlations Among Continuous Variables .....	58
Table 11: Informational Matrix Components .....	59
Table 12: Caregiver Characteristics in Informational Matrix (N = 21) .....	60
Table 13: Quality of Life Themes and Sub-themes in Informational Matrix (N = 21) .....	61
Table 14: Comparison of Quality of Life Themes Across Studies with Dissertation .....	67



## LIST OF FIGURES

Figure 1: Conceptual Model Based on The Stress Process .....	9
Figure 2: Quality of Life Domains Extracted from Semi-structured Interviews .....	44
Figure 3: Scree Plot.....	46
Figure 4: Quality of Life Over Time by Participants (N = 27) .....	51
Figure 5: Quality of Life Over Time by Group .....	52

## **LIST OF BOXES**

Box 1: Steps to a Thematic Analysis .....	30
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## LIST OF ABBREVIATIONS

AIC	Akaike's Information Criterion
CDC	Centers for Disease Control and Prevention
DSM-5	<i>Diagnostic and Statistical Manual of Mental Disorders - Fifth Edition</i>
HRQOL	Health-related quality of life
IRB	Institutional review board
PCA	Principal component analysis
PDSQ	Psychiatric Diagnostic Screening Questionnaire™
PTSD	Post-traumatic stress disorder
RMANOVA	Repeated measures analysis of variance
SF-36	36-Item Short Form Health Survey

## ABSTRACT

**Background:** It is estimated that 10-15% of bereaved people in the general population are experiencing prolonged, complicated grief after a loss. Persons with complicated grief experience a disruption of usual, pre-death activities, destructive thoughts and actions, and can develop or find a worsening of comorbidities and impairments. All of these, in turn, worsen the experience. Complicated grief reactions can compound the stress of the loss, disrupting the normal functioning of the central nervous, immune, cardiovascular, neuroendocrine, and gastrointestinal systems, which in turn can contribute to poor quality of life for the surviving family member. However, due to a paucity of research, the effects of complicated grief on quality of life are not well known.

**Purpose:** The purpose of this mixed methods study was to describe quality of life of older adults with complicated grief via the analyses and integration of qualitative and quantitative data in three aims. *Aim #1:* To qualitatively describe self-reported quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy as measured by transcription and coding of semi-structured interviews. *Aim #2:* To quantitatively examine changes in quality of life of older adults with complicated grief pre-, post-, and eight-weeks after Accelerated Resolution Therapy as measured by the CDC HRQOL-14, Healthy Days Module testing the hypothesis that older adults experiencing complicated grief will report improved quality of life with completion of Accelerated Resolution Therapy. *Aim #3:* To understand changes in quality

of life of older adults with complicated grief treated with Accelerated Resolution Therapy by integrating the qualitative and quantitative data.

**Methods:** This study was a sub-analysis of a randomized wait list controlled treatment study titled “Accelerated Resolution Therapy for Treatment of Complicated Grief in Senior Adults” (R21AG056584). The parent study measured quality of life qualitatively and quantitatively for this sub-analysis. Demographic and clinical characteristics were analyzed with descriptive statistics. Thematic analysis techniques were used to code the qualitative data for Aim #1. Paired t-tests and repeated measures analysis of variance were conducted on the CDC HRQOL-14 aggregate responses. Then a multilevel linear model was fitted to the data to test for a significant change in quality of life over the course of the Accelerated Resolution Therapy intervention and if there was a significant effect of the intervention for Aim #2. Lastly, an informational matrix with select patient characteristics, qualitative themes, and quality of life scores at the end of study and change in scores from baseline to end of study was created to compare variables to variables and groups of variables to individual variables for Aim #3.

**Results:** The majority of participants ( $n = 29$ ) were female, widowed, White, non-Hispanic/Latino, retired, educated at a bachelor's or graduate level, and had a mean age 68 years. Four main themes or domains emerged from the thematic analysis. Quality of life includes: Mental Function (sub-themes were mental health, joy, and happiness), Self-management (sub-themes were self-efficacy and self-agency), Social Support, and Physical Function for Aim #1. For Aim #2, the older adults who were experiencing complicated grief reported improved quality of life with the completion of Accelerated Resolution Therapy. Quality of life scores statistically decreased (improved) over time. Both time and group contributed to the model suggesting that Accelerated Resolution Therapy had a positive effect on participants' quality of life. When

bringing the two types of data together to create a richer understanding of changes in quality of life with treatment it was found that those who endorsed the most themes had at least one comorbidity and those reporting the greatest improvement in quality of life scores all had a history of multiple deaths.

**Conclusion:** The results of this study contribute to the body of knowledge related to older adults, caregiving, complicated grief, mind-body therapies, and quality of life. Participants reported between one and four quality of life themes. These former family caregivers with complicated grief who received Accelerated Resolution Therapy reported improved quality of life which sustained eight weeks after active treatment. Integrated data revealed having at least one comorbidity may lead to a richer description and endorsement of quality of life and a history of multiple deaths may contribute to a greater response to treatment. Additionally, this is the first longitudinal, randomized controlled trial to examine the quality of life of family caregivers with complicated grief receiving Accelerated Resolution Therapy. This study provides encouraging preliminary data supporting further research on the effect of treatment on complicated grief and quality of life.

## **CHAPTER ONE:**

### **INTRODUCTION**

According to The Center for Complicated Grief (2017), an estimated 10-15% of bereaved people in the general population experience complicated grief. In addition, it is estimated that 20% of people receiving mental health treatment also have unrecognized and therefore untreated complicated grief. These figures translate to tens of millions of people battling complicated grief worldwide (The Center for Complicated Grief, 2017) and represents a public health concern (Shear et al., 2014). In this chapter an overview of the background, conceptual underpinning, statement of the problem, purpose, specific aims, and definition of key words is provided for this study.

#### **Background**

Grief is a natural response to the loss of something meaningful such as a family member (The Center for Complicated Grief, 2017). Normally, over time, bereavement responses diminish (Jordan & Litz, 2014; Shear et al., 2011; Zisook & Shear, 2009). When these responses become persistent and intense, one may be experiencing complicated grief. Complicated grief also includes continued yearning, longing, sadness along with maladaptive thoughts and dysfunctional behaviors (Mason & Tofthagen, 2019; The Center for Complicated Grief, 2017; Zisook & Shear, 2009).

Potential consequences of complicated grief are the development or worsening of comorbidities or psychological and physical impairments (Mason & Tofthagen, 2019; Stroebe et al., 2007). Added to this, when psychiatric disorders are present, complicated grief may be difficult to diagnose (Olaolu et al., 2020). Individuals with complicated grief experience psychological consequences of social isolation and feelings of loneliness and have negative health outcomes of anxiety, clinical depression, cognition impairment, and post-traumatic stress disorder (PTSD) (Robbins-Welty et al., 2018; Schulz et al., 2006; Shear, 2010; Stroebe et al., 2007; Tofthagen et al., 2017). Complicated grief may also be associated with increased alcohol consumption (Stroebe et al., 2007). Physical consequences may include an increased risk of mortality, including suicide and higher rates of disability, medication use, and hospitalizations than non-complicated bereaved individuals (Stroebe et al., 2007). Other consequences of complicated grief include decline in cognitive function (Hall et al., 2014) and sleep disturbances (Germain et al., 2005; Hardison et al., 2005). These may impact perceptions of quality of life.

Domains of quality of life are typically classified as physical, mental/psychological, social, and environmental (World Health Organization, 2021). The death of a care recipient is reportedly one of the top sources of stress (Buckley et al., 2012). Intense or prolonged grief reactions can compound this stress, affect sleep, and disrupt the normal functioning of the central nervous, immune, cardiovascular, neuroendocrine, and gastrointestinal systems, all contributing to poor quality of life for the surviving family member (Buckley et al., 2012; Yaribeygi et al., 2017). If untreated, the development or worsening of comorbidities and impairments may occur impeding the ability to recover (Mason & Tofthagen, 2019). Thus, an individual's quality of life may be impacted by complicated grief; however, this has not been definitively established. The



former caregiver may need assistance with dealing with complicated grief if the resolution of grief is not attained in a normo-adaptive manner.

### **Conceptual Underpinning of the Study**

The theoretical framework selected for this study is The Stress Process (Pearlin et al., 1981). In this theory, life events along with chronic strains, self-concepts, coping, and social support structures together contribute to the stress process in humans (Pearlin et al., 1981). A life event change can produce disequilibrium creating a period of readjustment during which a struggle to reestablish homeostasis may occur. This struggle can be wearing and exhausting, increasing vulnerability to stress and its physical and psychological consequences (Pearlin et al., 1981). The Stress Process is a specific, concrete middle-range theory that is useful in identifying risk factors that may predispose caregivers to stress thus interfering with their roles and tasks (Bolden & Wicks, 2008). This theoretical framework has been previously used in more than 6,500 studies (Google Scholar, 2020) suggesting its utility for this study.

The stressful life event in question is the death of a family member. Appraisal of an individual's circumstances can be useful in determining risk for developing prolonged and complicated grief versus resolution of acute grief and integration of the loss into a new normal (Mason et al., 2020). With a loss an individual may experience grief, and if unresolved, can result in the concept of complicated grief. While acute grief is considered normal and convalesces with time, complicated grief is prolonged, interferes with normal activities, and accompanied by destructive thoughts and/or actions (Mason & Tofthagen, 2019; Shear et al., 2016; Shear et al., 2011; Zisook & Shear, 2009). If untreated, consequences may occur including the development or worsening of psychological and/or physical comorbidities and impairments

impeding the ability to recover from the loss and thus, impacting one's quality of life (Boelen & Prigerson, 2007; Kim et al., 2013; Mason & Toftthagen, 2019).

### **Statement of the Problem**

It is known that persons with complicated grief experience a disruption of usual, pre-death activities, destructive thoughts and action, and develop or experience exacerbation of comorbidities and impairments (Mason & Toftthagen, 2019; Shear et al., 2011). Similarly known, is that these comorbidities such as major depressive disorder (Shear, 2010), PTSD (Shear, 2010; Waller et al., 2016), and anxiety disorder (Newson et al., 2011) can then compound the experience of complicated grief in a downward spiral of deleterious outcomes. However, what is not well known are the effects of complicated grief on quality of life.

### **Purpose of the Study**

This study was a pre-planned sub-analysis of a randomized wait list controlled treatment study titled “Accelerated Resolution Therapy for Treatment of Complicated Grief in Senior Adults” (R21AG056584) (Buck et al., 2020). Accelerated Resolution Therapy is an evidence-based psychotherapy for the treatment of mental health issues that includes the core components of trauma-focused therapy: imaginal exposure and imagery rescripting using guided visualization and eye movements to desensitize and process distressing memories, (Finnegan et al., 2016; Kip, Rosenzweig, et al., 2013; Kip, Sullivan, et al., 2013). Quality of life was qualitatively and quantitatively measured in the parent study but was reserved for this sub-analysis.

The purpose of the current mixed methods study was to describe quality of life of older adults with complicated grief via the analyses and integration of qualitative and quantitative data. The convergent design provided a richer understanding of quality of life for older adults

experiencing complicated grief (Creswell & Plano Clark, 2018; Schoonenboom & Burke Johnson, 2017). Quality of life was assessed qualitatively with an optional interview conducted 8 weeks after the intervention in the parent study. Quality of life was also quantitatively measured with the CDC HRQOL-14 (Centers for Disease Control and Prevention, 2018) at baseline, completion of each intervention session, and eight weeks post-intervention.

## **Specific Aims**

### ***Aim #1***

To qualitatively describe self-reported quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy as measured by transcription and coding of semi-structured interviews

### ***Aim #2***

To quantitatively examine changes in quality of life of older adults with complicated grief pre-, post-, and eight weeks after Accelerated Resolution Therapy as measured by the CDC HRQOL-14, Health Days Module

**Hypothesis.** Older adults experiencing complicated grief will report improved quality of life with completion of Accelerated Resolution Therapy.

### ***Aim #3***

To understand changes in quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy by integrating the qualitative and quantitative data

## Definition of Key Terms

***Accelerated Resolution Therapy.*** An evidence-based psychotherapy for the treatment of mental health issues that includes the core components of trauma-focused therapy: imaginal exposure and imagery rescripting using guided visualization and eye movements to desensitize and process distressing memories (Finnegan et al., 2016; Kip, Rosenzweig, et al., 2013; Kip, Sullivan, et al., 2013).

***Complicated Grief.*** Persistent, beyond 6 months after the loss, and intense grief that includes continued yearning, longing, sadness along with maladaptive thoughts and dysfunctional behaviors (American Psychiatric Association, 2013; The Center for Complicated Grief, 2017).

***Grief.*** A natural response to the loss of something meaningful such as a family member (The Center for Complicated Grief, 2017).

***Health-related Quality of Life.*** An individual's perceived and self-reported quality of life in relation to health for the physical and mental health domains (Centers for Disease Control and Prevention, 2018).

***Mixed Methods Research Design.*** An integration of quantitative and qualitative methods for the purpose of data collection, analysis, and interpretation within a study (Schoonenboom, 2018; Shorten & Smith, 2017).

***Quality of Life.*** Basic concepts for older adults include subjective satisfaction with life conditions, general-well-being, and fulfilment of dimensions of human life (Boggatz, 2016).

***Stress.*** A particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984).

***Sub-analysis.*** An analysis that is planned and documented prior to data examination, preferable in the study protocol (Wang et al., 2007).

***Thematic Analysis.*** A qualitative research approach in which a researcher identifies and analyzes themes told by the participants (Creswell & Poth, 2018).

## **Summary**

The role of this study was to examine the patient outcome of quality of life for older adults receiving Accelerated Resolution Therapy for complicated grief. This patient outcome was assessed qualitatively with an optional interview conducted 8 weeks after the intervention in the parent study. Quality of life was also quantitatively measured with the CDC HRQOL-14 (Centers for Disease Control and Prevention, 2018) at baseline, completion of intervention, and eight weeks post-intervention. Both the qualitative and quantitative data were integrated in a mixed methods approach for analysis (Creswell & Plano Clark, 2018; Shorten & Smith, 2017; Waltz et al., 2017).

The remainder of the dissertation is presented in the following four chapters. Chapter 2 provides a review of related literature; Chapter 3 the research design and methodology; Chapter 4 the results; and Chapter 5 the discussion, implications, and conclusion respectively.

## **CHAPTER 2:**

### **REVIEW OF THE LITERATURE**

This chapter begins with a review of The Stress Process, the conceptual underpinning of this study. A model is proposed for complicated grief and quality of life within this framework. The chapter continues with a review of the literature focusing on stress and quality of life, their impact on caregiving, and the interwoven concept of complicated grief.

#### **Conceptual Underpinning: The Stress Process**

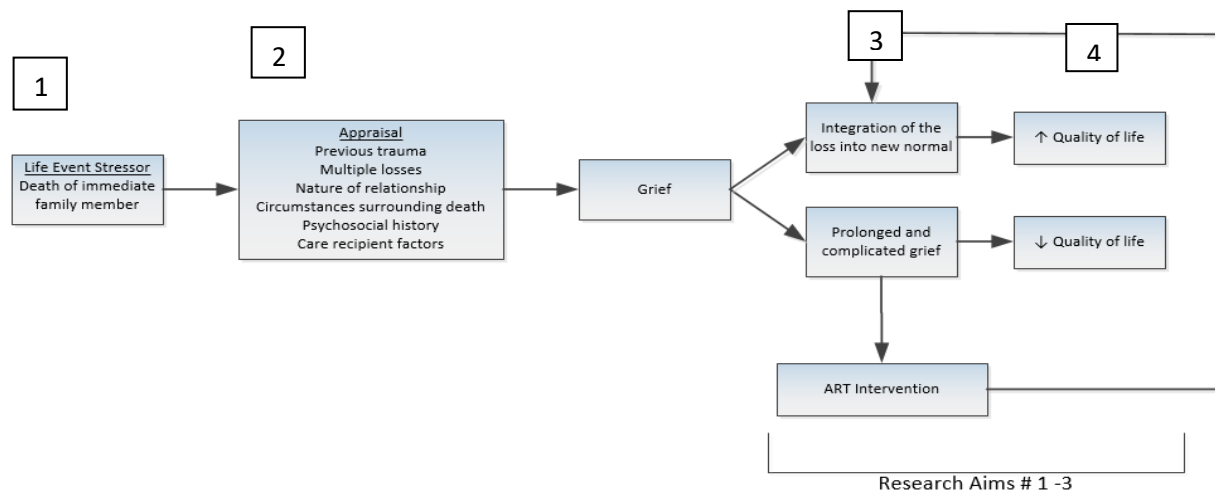
The theoretical framework selected for this study is The Stress Process (Pearlin et al., 1981). Life events for an individual along with his/her chronic strains, self-concepts, coping, and social support structures together contribute to the stress process (Pearlin et al., 1981). A life event change can produce disequilibrium creating a period of readjustment during which a struggle to reestablish homeostasis may occur (Pearlin et al., 1981). This struggle can be taxing and exhausting, increasing vulnerability to stress and its physical and psychological consequences (Pearlin et al., 1981). The Stress Process is a specific, middle-range theory that is useful in identifying risk factors that may predispose caregivers to stress thus interfering with their roles and tasks (Bolden & Wicks, 2008). This conceptual framework was used to develop the following proposed conceptual model of complicated grief and quality of life after experiencing the death of an immediate family member.

## ***Proposed Model***

A systematic method was used to guide the development of the following conceptual model utilizing Fawcett's approach (Fawcett, 1999). This proposed model (Figure 1) recognizes the existence of a relationship between complicated grief and quality of life. This proposition was extracted from the conceptual model of The Stress Process (Pearlin et al., 1981). There is a negative linear relationship between complicated grief and quality of life, such that an increase in symptoms of complicated grief is associated with a decrease in one's perceived quality of life, and a decrease in symptoms of complicated grief is associated with an increase in one's perceived quality of life. Hence, there is a symmetrical and reciprocal relationship between complicated grief and quality of life.

**Figure 1**

### *Conceptual Model Based on The Stress Process*



Abbreviation: ART, Accelerated Resolution Therapy.

The proposed model starts at the time of a stressful life event (Figure 1, #1). The stressful life event in question is the death of an immediate family member (Buckley et al., 2012). Appraisal of an individual's circumstances (Figure 1, #2) can be useful in determining risk for developing prolonged and complicated grief versus resolution of acute grief and integration of the loss into a new normal (Mason et al., 2020). With a loss an individual may experience grief, and if unresolved, can result in the concept of complicated grief (Figure 1, #3). While acute grief is considered normal and convalesces with time, complicated grief is prolonged, interferes with normal activities, and accompanied by destructive thoughts and/or actions (Mason & Tofthagen, 2019; Shear et al., 2016; Shear et al., 2011; Zisook & Shear, 2009). If untreated, consequences may occur including the development or worsening of psychological and/or physical comorbidities and impairments impeding the ability to recover from the loss and thus, impacting one's quality of life (Figure 1, #4) (Boelen & Prigerson, 2007; Kim et al., 2013; Mason & Tofthagen, 2019).

### ***Linkage between Model and Dissertation***

The proposed conceptual model based on The Stress Process guides this sub-analysis. Considering the death of an immediate family member as a life event stressor, quality of life of former caregivers who have not adjusted to the loss; hence, are experiencing complicated grief and receiving Accelerated Resolution Therapy will be analyzed pre-, during, and post-therapy sessions, as well as eight-weeks after completion of therapy (Aims #1-3). The hypothesis accompanying the quantitative analysis (Aim #2) is that older adults experiencing complicated grief will report improved quality of life with completion of Accelerated Resolution Therapy.



This sub-analysis, of a randomized wait list controlled treatment study (Buck et al., 2020), will describe, examine, and integrate data on quality of life for older adult caregivers who are experiencing complicated grief after the loss of an immediate family member receiving Accelerated Resolution Therapy (Buck et al., 2020). Quality of life will be explored via the semi-structured interview at the 8-week post completion data collection point. Quality of life will also be assessed via the CDC HRQOL-14 Health Days Module before, during, after completion of the Accelerated Resolution Therapy intervention, and eight weeks post completion. The following literature review explores stress and quality of life with a focus on caregiving and complicated grief.

## **Stress**

The meaning of the term stress varies according to its use among the various scientific communities and laymen (Goodnite, 2014). Lazarus and Folkman (1984) define stress as “a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (p. 19). While stress can be beneficial to survival (eustress), it is most often associated as being harmful or distressful (Yaribeygi et al., 2017). Goodnite (2014) summarizes the attributes of stress as “the application of tension, force, or pressure (a stimulus) to an organism; the appraisal of the stimulus as overwhelming with a perceived inability to meet the challenge; and a measurable response by the organism to the stimulus” (p. 72). Similarly the term distress includes a perceived inability to cope effectively with an change in emotional status, discomfort, and harm (Ridner, 2004).

Physiologically stress hormones, such as cortisol, can be measured via blood, saliva, urine, or hair samples (Gottfried, 2018). A systematic review and meta-analysis ( $n = 80$  studies) supported findings that diurnal cortisol slopes were flattened and associated with worse mental and physical health outcomes (Adam et al., 2017). While the number of studies is limited, research has shown that complicated grief also is associated with a flattening of the diurnal cortisol slope (Mason & Duffy, 2019). A flatter diurnal cortisol slope can negatively affect appetite, metabolism, and fat storage, inflammatory response, and contribute to fatigue (Adam et al., 2017). No studies were found searching three databases over the past 10 years for using validated survey instruments measuring stress specifically, such as the Perceived Stress Scale (Cohen et al., 1983), and complicated grief (Mason et al., 2020). However, an interventional study utilizing Complicated Grief Treatment showed a reduction in anxiety, which is one reaction to stress, as complicated grief improved as measured by the Beck Anxiety Inventory (Glickman et al., 2016).

Stressors can be a real or perceived threat elicited by an organism's perception of unpredictability and/or uncontrollability (Del Giudice et al., 2018). Stress can be both a trigger for diseases (e.g. cancer and Crohn's disease) and pathologies (e.g., hypertension), as well as be an aggravating factor for preexisting conditions (Yaribeygi et al., 2017). Physiologically, the harmful effects of stress, especially if prolonged, result in responses of the body's central nervous, immune, cardiovascular, neuroendocrine, and gastrointestinal systems (Buckley et al., 2012; Yaribeygi et al., 2017). Social support can be a moderator for better health outcomes during time of stress (Cohen & Wills, 1985). Stress can be experienced by caregivers and depending on the situation, may include a prolonged caregiver-care recipient relationship (Andreakou et al., 2016; Kim et al., 2019).

## *Stress and Caregiving*

Not all deaths are sudden and unexpected (Hui, 2015). Some occur after an illness and may have consisted of a family caregiver-care recipient relationship. Appraisal of the caregiver's risk factors for stress, and potentially complicated grief, will aid in the therapeutic plan of care. Caregiver stress may occur if there is an imbalance of support and aid between the caregiver and the care recipient, and this, in turn, results in both physical and mental stress for the caregiver (Llanque et al., 2016). In an examination of the literature on caregiver stress and caring for patient with Alzheimer's disease, precipitating factors noted were chronic illness, lack of support, limited social pursuits, duration of caregiving, and problematic behaviors and functional status of the care recipient (Llanque et al., 2016). Providing care to a family member near the end of life can also be demanding and exhausting (Masterson et al., 2015). Surrogate decision making, symptom management, and sadness all impact the caregiver.

Caregivers experience stress as decision makers while striving to meet the needs of the care recipient and providing a good death (Goy & Ganzini, 2003). Family caregivers of cancer and cardiopulmonary patients in the hospice setting reported patients' symptoms as contributing to their stress and the majority were psychological symptoms (Ratkowski et al., 2015). In caring for family member with cancer, sadness was reported as the most stressful symptom while worrying was the most commonly reported symptoms for family caregivers of cardiopulmonary patients in hospice (Ratkowski et al., 2015). These negative psychosocial consequences may resolve after the death but may also continue to exist beyond the expected bereavement period (Masterson et al., 2015). One study found that although family caregivers' reported an improvement in depressive symptoms one year after death, their reports of distress of social

functioning did not (Masterson et al., 2015), thus highlighting the importance of positive instrumental and emotional support for caregivers (Goy & Ganzini, 2003).

### ***Stress and Complicated Grief***

Complicated grief is a prolonged and maladaptive bereavement response to a personal loss (Mason & Toftthagen, 2019; Shear et al., 2011; Shear et al., 2014; Waller et al., 2016).

Complicated grief is also referred to as prolonged grief disorder or persistent complex bereavement disorder, the latter as listed in the *Diagnostic and Statistical Manual of Mental Disorders*, 5<sup>th</sup> edition (DSM-5) (American Psychiatric Association, 2013). Attributes of complicated grief include the inability to return to normal activities and destructive thoughts and action such as, self-neglect, social isolation, substance abuse, and suicidal ideations (Mason & Toftthagen, 2019; Zisook & Shear, 2009). In adjusting for this loss, stress may also be realized in various forms such as learning to tackle responsibilities previously carried out by the deceased, coping with a change in income, and participating in social activities (Mason & Duffy, 2019). Difficulty accepting the loss, avoiding painful memories, preoccupation in activities related to the deceased, and feeling estranged from others can add to the stress experienced by the bereaved individual (Zisook & Shear, 2009).

The bereavement process is associated with an increased risk of mortality, including suicide (Buckley et al., 2012; Stroebe et al., 2007; Szanto et al., 2006). Complicated grief may contribute to these outcomes. Potential consequences of complicated grief are the development or worsening of comorbidities or psychological and physical impairments (Mason & Toftthagen, 2019; Stroebe et al., 2007; Szanto et al., 2006). There is an increased risk for cancer, cardiac disease (Szanto et al., 2006), and suicidal thoughts (Boelen & Prigerson, 2007; Szanto et al.,

2006). Other consequences of complicated grief include decline in cognitive function (Hall et al., 2014) and sleep disturbances (Germain et al., 2005; Hardison et al., 2005).

Health outcomes related to complicated grief have been identified to include feelings of loneliness, social isolation, anxiety, clinical depression, cognition impairment, and PTSD (Toftthagen et al., 2017). Added to this, when psychiatric disorders are present, complicated grief may be difficult to diagnose (Olaolu et al., 2020). Complicated grief may be associated with negative health outcomes such as, increased alcohol consumption (Stroebe et al., 2007) and substance abuse (Szanto et al., 2006). Bereaved individuals have higher rates of disability, medication use, and hospitalizations than non-bereaved individuals (Stroebe et al., 2007).

A high correlation and significant overlap in symptoms between complicated grief and PTSD has been found (Shear, 2010). Co-occurring depressive symptoms were found to be associated with complicated grief (Robbins-Welty et al., 2018; Schulz et al., 2006). Comorbidities can compound the experience of complicated grief. Approximately 10-20% of individuals with complicated grief also have major depressive disorder, 12-27% have PTSD, (Waller et al., 2016) and 17% have an anxiety disorder (Newson et al., 2011). Thus, an individual's quality of life may be impacted by the consequences of caregiving, comorbidities, and living with complicated grief.

## **Quality of Life**

The root of 'quality of life' is often traced back to the Who Health Organization's 1947 use of 'well-being' in their definition of health ("CONSTITUTION of the World Health Organization," 1947; Post, 2014). The first article in the PubMed database to use the term quality of life appeared in 1959 in regard to the increasing population growth, family planning, and threats to human fulfillment (Huxley, 1959; U. S. National Library of Medicine, 2020).

However, the first public use of the term quality of life is credited to Lyndon B. Johnson in his 1964 presidential campaign speech on social-policy issues (Rescher, 1972). President Johnson stated, “These goals cannot be measured by the size of our bank balances. They can only be measured in the quality of lives that our people lead” (p. 60). His agenda on quality of life included education, diseases, Medicare and health care, urban renewal, development of depressed regions and poverty, crime, and the right to vote (Freidel, 2006). Quality of life began making an appearance in the medical literature shortly afterwards in regard to ethical aspects of treatment outcomes (Elkinton, 1966) and has increased in frequency since (Post, 2014) along with publications from nursing, sociology, and psychology regarding patient care. In 1975, PubMed created a MESH heading for quality of life (NCBI, n.d.). The 1970s also saw the introduction of quality of life health domains in research to supplement the patient outcomes of mortality and morbidity (Feder et al., 2015) and publications from epidemiology (e.g., survival) and psychiatry (e.g., abortion, genetic testing).

In 1990, the *Healthy People 2000: National Health Promotion and Disease Prevention Objectives* was produced with 22 goals focusing on health and quality of life (Centers for Disease Control and Prevention, 2015). Concept analyses by the nursing discipline began to appear in the early 1990s (Kleinpell, 1991; Meeberg, 1993). Meeberg (1993) listed the attributes of quality of life as “feeling satisfaction with one's life in general, mental capacity to evaluate one's own life as satisfactory or otherwise; acceptable state of physical, mental, social and emotional health as determined by the individual, and an objective assessment by another that the person's living conditions are adequate and not life-threatening” (pp. 34-35).

By the beginning of the 21<sup>st</sup> century nearly 6,000 articles on quality of life from multiple disciplines were published (NCBI, n.d.). PubMed search results revealed that in 2019, there were

28,846 articles on quality of life compared to 12 in the 1960s (U. S. National Library of Medicine, 2020). Recent concept analyses on quality of life are more focused on a specific interest of study, such as ethics (Fumincelli et al., 2019), older adults (Boggatz, 2016), disease state (Dignani et al., 2015), and futility of care (Morata, 2018). In comparison to Meeberg (1993), a recent concept analysis of quality of life lists the attributes as perceptions of one's own life through personal beliefs and values, independence and the sense of freedom, and satisfaction across the physical, psychological, social, and spiritual domains (Pinto et al., 2017).

There have been numerous approaches to defining and researching the concept of quality of life creating a challenge for its clarity (Haraldstad et al., 2019; Karimi & Brazier, 2016; Sredl, 2004). Quality of life is both an outcome of health care and a health status (e.g., functional ability, current disease state) (Glozman, 2004). Quality of life is often used interchangeably with health status and health-related quality of life contributing to confusion of the term (Karimi & Brazier, 2016). Health status was first defined by the World Health Organization in 1946 (Grad, 2002) as “a state of physical, mental, and social well-being, and not merely the absence of disease and infirmity” (p. 984). Health-related quality of life often refers to how one functions and perceives their well-being within the domains of quality of life for those factors that refer to health, (Centers for Disease Control and Prevention, 2019; Haraldstad et al., 2019; Karimi & Brazier, 2016; Sredl, 2004). Quality of life evaluations can be both positive and negative (Centers for Disease Control and Prevention, 2019; Sredl, 2004). Common to these numerous descriptions, quality of life also refers to the value or degree of self-satisfaction an individual places on their life (Glozman, 2004; Haraldstad et al., 2019; Karimi & Brazier, 2016; Post, 2014). Boggatz (2016) describes three separate attributes that older adults ascribe to quality of life: 1) satisfying life situations, 2) overall general well-being, and 3) fulfilment of life (Boggatz,

2016). Quality of life varies among individuals and is relative to their expectations (Boggatz, 2016) and is in a dynamic state according to their perceptions of priorities of current situations (Glozman, 2004). Most quality of life measures rely on a subjective perception by the participant (Post, 2014). Another challenge for defining quality of life are the varying cultural perspectives found among research studies (Haraldstad et al., 2019).

### ***Quality of Life Domains***

Domains of quality of life are typically classified as physical, mental/psychological, social, and environmental (World Health Organization, 2021). The physical domain pertains to the body, generally in respect to a level of feeling healthy and full of energy, while the mental/psychological domain refers to the mind, and can include level of satisfaction with life, contentment, and happiness (Centers for Disease Control and Prevention, 2019). The social domain encompasses a sense of belonging and inclusion, relationships, support, and participation (Waite, 2018). The environmental domain consists of the health of the living and physical environment (e.g., pollutants versus unspoiled), environmentally responsible behaviors of conserving resources and energy savings, and consumption of environmental services (e.g., fresh water, renewable resources) (Streimikiene, 2015). All these domains in turn can affect's one's satisfaction with or subjective view of their health-related quality of life (Karimi & Brazier, 2016). Defining quality of life within research also can include specific variables to the research topic such as body image with surgery (Post, 2014; Reis et al., 2010). In a Delphi consensus procedure, participants, consisting of patients, their family members, clinicians, scientists, and the general public, distinguished the mental and social domains as more essential for health-related quality of life compared to the physical domain (Pietersma et al., 2014). Self-acceptance,



self-esteem, and good social contacts were the top-rated items for all the groups of participants (Pietersma et al., 2014).

### ***Quality of Life and Caregiving***

It is estimated that there are 53 million family caregivers providing care to a sick or disabled adult in the United States (The National Alliance for Caregiving & AARP, 2020). Approximately one quarter are caring for more than one adult (24%) and experiencing difficulty coordinating care (26%) (The National Alliance for Caregiving & AARP, 2020). Caring for an ill family member, especially in a palliative care setting can cause psychological distress impacting the mental health domain for the caregiver (Lobb et al., 2006). Social relationships, expectations of pending death, spiritual or existential concerns, and worries contribute to distress (Lobb et al., 2006). Caring for a cancer patient at the end of life can increase caregiver burden and depressive symptoms while decreasing quality of life (Wen et al., 2019). Particularly in the last 6 months of cancer patients' lives, caregivers reported decreasing quality of life as the patients' symptoms worsened and functional status declined (Wen et al., 2019). Caregivers appraised as having poorer mental health and social support, while caring for someone with poor performance status are more likely to report poorer quality of life (Hsu et al., 2019). Support for caregivers after a loss is important. The support that the caregiver provides can be structural or functional in nature. Structural support has a linear relationship with quality of life in that being part of a social group and having the presence of others around enriches quality of life while functional support (i.e., the availability of resources) produces a stress buffering effect (Helgeson, 2003).

During the illness trajectory quality of life of the caregivers is impacted by their experiences of frustration, anxiety, distress over their family member's deterioration, and perhaps guilt for unrelieved suffering (Wen et al., 2019). The daily demands caregivers face may

limit their ability to provide support and aid (Glozman, 2004). Following the loss of a spouse, quality of life may continue to be impacted due to the high levels of burden and overwhelm experienced by the caregiver pre death (Schulz et al., 2008). Clinical, psychological, and socio-demographics factors can contribute to a diminished quality of life for caregivers (Glozman, 2004). For example, time and energy spent providing care, decreased or loss of employment during caregiving period, increased household duties, decreased social and enjoyable interactions along with limited affectionate interactions, and uncertainty (Glozman, 2004). In a study of patients with Parkinson's disease, illness severity and functional dependencies on activities of daily living was the main determinant of poor caregiver quality of life (Glozman, 2004). Similar results were found in studies of caregivers for patients with Alzheimer's disease and emotional disorders (Andreakou et al., 2016; González-Blanch et al., 2018). Later stages of Alzheimer's disease, living with the patient, poor finances, and experiencing a chronic illness oneself negatively correlated with the reported health-related quality of life for the caregiver (Andreakou et al., 2016). The intensity of depression, anxiety, or somatization was also significantly associated with poor quality of life for caregivers and this was more profound with care recipients having more than one of these diagnoses (González-Blanch et al., 2018). Primary caregivers reported worse health, more doctor visits, anxiety, depression, and weight loss than non-caregivers for the elderly in Hong Kong (Ho et al., 2009). Female primary caregivers had significantly lower quality of life scores across all domains of 36-Item Short Form Health Survey (SF-36) as compared to male primary caregivers who had significant scores for six of the eight domains (all but role emotion and mental health) (Ho et al., 2009). Caregiver burden was associated with adverse physical and psychological health resulting in poorer quality of life for the primary caregivers (Ho et al., 2009).

Post loss the perceived competency for handling routine activities was found to be similar for men and women in a study of recently bereaved spouses (Utz et al., 2011). When measured, perceived competency was highest for health care and household activities and found to be related to greater personal resources and longer length of marriages. In addition, higher competency provided protection against the negative psycho-emotional effects of grief (Utz et al., 2011).

Losing a child can also decrease quality of life. A qualitative study utilizing a focus group format found that parents who lost a child described three subcategories post death that were perceived as contributing to a decrease in their quality of life, two affective and one social (interpersonal) (Smith et al., 2011). Broken heart/decreased joy, survivors' guilt, and a decreased involvement or increased worry for their grandchildren affected both the physical and mental domains of quality of life for the surviving caregiver (Smith et al., 2011).

### ***Quality of Life and Complicated Grief***

The death of a care recipient is reportedly one of the top sources of stress (Buckley et al., 2012). Intense or prolonged grief reactions, complicated grief, can compound this stress, affect sleep, and disrupt the normally functioning of the central nervous, immune, cardiovascular, neuroendocrine, and gastrointestinal systems, all contributing to poor quality of life for the surviving family member (Buckley et al., 2012; Yaribeygi et al., 2017). The caregiver may need assistance with dealing with complicated grief if the resolution of grief is not attained in a normo-adaptive manner. Very little is known about the impact of the bereavement process on quality of life especially for those experiencing complicated grief.

Caregivers with an inability to manage the loss reported more intense loss-related emotional, complicated grief, and PTSD symptoms up to 8 years after the death (Kim et al., 2019). Complicated grief negatively affects the mental and physical health domains of quality of life (Boelen & Prigerson, 2007; Newson et al., 2011) and this is independent of depression or anxiety (Boelen & Prigerson, 2007). Poorer physical and mental health of caregivers before the death were found to be predictors of complicated grief (Lenger et al., 2020). The risk of complicated grief has been found to increase in widows with poor health at the time of spousal death and their physical health was found to be a significant predictor of poor psychological well-being (Utz et al., 2012). Kim and colleagues conducted a literature review ( $n = 41$  studies, 7,657 participants) on bereavement related to cancer and support these conclusions that the bereaved experience psychological distress and reported poorer quality of life (Kim et al., 2013).

## **Summary**

The preceding literature review lays out the existing empirical evidence for the proposed model for the relationship of stress, caregiving, and complicated grief, and quality of life. Individuals' have varying risk factors that impact their response to a loss and result in the development of complicated grief. Left unaddressed, complicated grief leads to negative consequences and can result in a worsening of their perceived quality of life. There is a paucity of literature regarding the impact that complicated grief has on quality of life. Therefore, this sub-analysis will address this gap by describing, examining, and integrating qualitative and quantitative quality of life data for older adults with complicated grief receiving Accelerated Resolution Therapy.

## **CHAPTER 3:**

### **RESEARCH DESIGN AND METHODOLOGY**

This chapter presents the research design and methodology for a mixed methods study investigating quality of life of older adults with complicated grief receiving Accelerated Resolution Therapy. Design, setting, sample, instruments, and procedures are described. The chapter concludes with a data analysis plan addressing the three aims of the study.

#### **Study Design**

This study was a sub-analysis of a randomized wait list controlled treatment study titled “Accelerated Resolution Therapy for Treatment of Complicated Grief in Senior Adults” (R21AG056584). This sub-analysis was developed during the study design phase and was included in the study protocol (Wang et al., 2007). The larger study screened 65 and recruited 54 primary caregivers (age > 60 years) of an immediate family member who died after enrollment in hospice, and who indicated significant symptoms of prolonged complicated grief and psychological trauma after 12 months. All persons recruited for study participation underwent a clinical intake assessment by a licensed clinical therapist, to determine study eligibility. Eligible participants received up to four weekly sessions of Accelerated Resolution Therapy. Participants were randomly assigned to receive Accelerated Resolution Therapy either during the first four weeks after enrollment or beginning four weeks after enrollment. This 4-week delay in treatment

served as a formal control condition to compare acute response (American Psychological Association, 2020). Assessments occurred upon enrollment, at the end of the wait list period (control group only), weekly during Accelerated Resolution Therapy and at 8-week follow-up. After the 4-week wait list period, the participants in the control group received the Accelerated Resolution Therapy.

The convergent design, or concurrent sampling, of this sub-analysis study was intended to support the combined differences of qualitative and quantitative measures for a mixed method approach (Creswell & Plano Clark, 2018; NIH Office of Behavioral and Social Sciences, 2018). With a convergent design, either the qualitative or quantitative question/aim can be posed first and the mixed methods question presented in the order reflecting the integration (Creswell & Plano Clark, 2018). The qualitative aim was ordered first as it was deemed principal to the exploration of the meanings of quality of life within the context of the complicated grief for this sub-analysis. This was followed by the quantitative aim and lastly, the mixed methods aim.

This sub-analysis was comprised of qualitative, quantitative, and mixed methods analyses focusing on quality of life data. The aims describe, examine, and integrate the data on quality of life of these former caregivers receiving Accelerated Resolution Therapy for complicated grief as described later in this chapter.

### **Setting and Recruitment**

As part of the parent study, participants were recruited from Suncoast Hospice, a member of Empath Health. Grief counselors there identified persons who met criteria for prolonged complicated grief as they neared the end of the 13 months of grief support provided through the hospice program. They provided a brief summary of the study either verbally, showing them a

recruitment video, or both. If the individual expressed continued interest, an appointment for face to face screening and enrollment, if eligible, was made.

## **Sample**

The parent study screened a sample of 65 older adult (> 60 years), immediate family caregivers of an individual who received hospice care prior to death. Of these, 54 were eligible and enrolled into the study. Twenty-nine participants completed the interview component of the parent study with audio recordings and transcriptions on file.

## ***Inclusion Criteria***

Inclusion criteria for the parent study were as follows: age 60 years or older; previous primary caregiver of immediate family member who died after enrollment in hospice with the death occurring at least 12 months prior to enrollment; current symptoms indicative of proposed diagnostic criteria for complicated grief disorder (Shear et al., 2011); current score of  $\geq 25$  on the 19-item Inventory of Complicated Grief; current symptoms indicative of significant psychological trauma, as documented by score  $\geq 33$  on the 20-item DSM-5 PTSD checklist (PCL-5) (Weathers et al., 2013) or score of 5 or higher on the PDSQ PTSD subscale; and denial of suicidal ideation or intent, with no evidence of psychotic behavior.

## ***Exclusion Criteria***

Exclusion criteria for the parent study were currently engaged in another psychotherapy regimen, another Accelerated Resolution Therapy, or eye movement therapy such as eye movement desensitization and reprocessing; have a major psychiatric disorder (e.g., bipolar

disorder) deemed likely to interfere with treatment delivery; or have current substance abuse dependence (alcohol and/or drug) treatment anticipated to interfere with treatment delivery.

The sample for this sub-analysis consisted of all participants who completed the interview process during the 8-week, post-completion session for Aims #1 and #3 and provided scores for quality of life at baseline and 8-weeks post completion of therapy time points for Aims #2 and #3. No additional inclusion or exclusion criteria were applied for this sub-analysis.

## **Instruments**

A qualitative semi-structured interview guide and CDC HRQOL-14 instrument (Healthy Days Module) was used for this study. In addition, demographic and clinical characteristics were analyzed from the investigator-developed Demographics Form and Charlson Comorbidity Index. These are described below.

### ***Qualitative - Interview Guide***

During the 8-week post-treatment session, interested participants were interviewed using a semi-structured interview guide which asked them to report on their pre-Accelerated Resolution Therapy expectations; post-therapy experience and feedback; their meaning of quality of life; effect of grief on day to day life, sleep, appetite, and getting out with friends, as well as, change after Accelerated Resolution Therapy; how they and the deceased handled routines and tasks; and intensive care unit stay and experience, if appropriate. Any interview-related observations were documented in field notes. The question related to their understanding of quality of life in the setting of complicated grief was developed specifically for this sub-analysis. See Appendix A.



### ***Quantitative - CDC HRQOL-14***

In 1988, the CDC's aging studies unit was charged with developing and validating brief health-related quality of life measure for older adult populations (Moriarty, Zack, and Kobau, 2003). The complete 14-item health-related quality of life measure consists of three core modules: a 4-item Healthy Days Module, a 5-item Activity Limitations Module, and a 5-item Symptom Module (Centers for Disease Control and Prevention, 2018). The CDC HRQOL-14 purports to measure an individual's or group's perceived physical and mental health (healthy days and activity limitations) over the past 30 days. Items include pain, depression, anxiety, sleeplessness, vitality, and any current activity limitations (Centers for Disease Control and Prevention, 2018). Measures are continuous, cardinal, and bounded (Moriarty et al., 2003) and scoring is a mix of ordinal (poor to excellent), ratio (e.g., enter number of days), and nominal (yes/no) formats (Waltz et al., 2017). There are no summary scores for the total CDC HRQOL-14 or for its three subscales as originally developed (Moriarty et al., 2003). The instrument can be used in whole or in part.

The CDC HRQOL-14 is in the public domain, has been validated in a wide range of community dwelling adults, and is used to assess changes in health-related quality of life in response to treatment (Centers for Disease Control and Prevention, 2000). Associations between CDC HRQOL-14 and the SF-36 were reported as consistent and with evidence of comparable known groups validity with SF-36 appearing superior for chronic disease (SF-36 physical component summary  $R^2$  range 0.38 to 0.60,  $p < 0.001$ ;  $R^2$  range mental component summary 0.52 to 0.67,  $p < 0.001$ ) (Newschaffer, 1998). In a study of participants with arthritis 9 items of the CDC HRQOL loaded primarily onto 1 factor explaining 57% item variance. After rotation a 2-factor interpretation, all loadings were found to be greater than 0.70 (Mielenz et al., 2006). The

CDC HRQOL prediction of SF-36 physical component summary of the SF-36 was 73% ( $R^2 = .73$ ) when general health was included in the CDC HRQOL score and 65% ( $R^2 = .65$ ) when general health was removed. The relative contribution in predicting mental component summary was lower at 56% ( $R^2 = .56$ ) when general health was included and removed (Mielenz et al., 2006).

Evidence of retest reliability was excellent (0.75 or higher) for health and healthy days measures, and moderate (0.58 to 0.71) for other measures. Reliability was lower for older adults (Andresen et al., 2003). Other examples of populations studied include rheumatic disease (Currey et al., 2003); cardiac drug use in older adults (Dominick et al., 1999), diabetes (Gold et al., 2001), adolescents (Coker et al., 2000), and the elderly (Gold et al., 2000). See Appendix B.

### ***Demographics Form***

The investigator-developed Demographics Form captured the following information: age, gender, marital status, income, educational level, race, ethnicity, employment status, number of hospitalizations since loss, number of visits to health care provider since loss, and hospice diagnosis of care recipient who passed away. See Appendix C.

### ***Charlson Comorbidity Index***

The Charlson Comorbidity Index assesses comorbidity levels by taking into account both the number and severity of 19 pre-defined comorbid conditions (Charlson et al., 1987). The instrument can be used to provide a count and weighted score of comorbidities which can be used to predict function and mortality. For the purposes of this study, the number of comorbidities was included in the descriptive analysis of clinical characteristics. See Appendix D.

## **Procedures**

### ***Regulatory Approval***

This study, added into the original University of South Florida Institutional Review Board (IRB) proposal, has received IRB approval (#Pro00032358). See Appendix E.

### ***Data Collection***

Data collection for the quantitative instruments occurred at screening/enrollment, at the end of the 4-week wait list period (control group), weekly during the intervention period (up to four sessions), and at 8-week post-treatment follow-up. Data collection via qualitative interview occurred after the 8-week post-treatment follow-up measurement for interested participants. Instruments and their respective data collection time points are reported elsewhere (Buck et al., 2020).

## **Data Analysis Plan for Specific Aims**

### ***Aim #1***

The first aim of this proposed study was to qualitatively describe self-reported quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy as measured by transcription and coding of semi-structured interviews.

Interview data was collected 8-weeks post-treatment completion. A qualitative thematic analysis was the selected approach for analyzing the semi-structured interviews (Nowell et al., 2017; Vaismoradi et al., 2013). The thematic analysis consisted of six steps (see Box 1).

## Box 1

### *Steps to a Thematic Analysis*

1. Data familiarization
2. Code generation
3. Theme search
4. Theme review
5. Themes defined and named
6. Dissemination

The first step was to become familiar with the data (Braun & Clarke, 2006). Interviews ( $n = 29$ ) were digitally recorded and transcribed verbatim and then checked for accuracy by members of the study team. Removing all identifying personal information for the transcripts prior to team members' review and coding is an ethical consideration essential for data analysis and was performed (Creswell & Poth, 2018). The next step involved generating initial codes (Braun & Clarke, 2006; Vaismoradi et al., 2013). Prior to this step, the student's advisor arranged for a qualitative analysis and coding workshop for the three study team members to provide an initial knowledge base. Regular meetings were held for the three members of the study team involved in the thematic analysis. Team members reviewed interviews as a group, solo, and in pairs. All transcripts were read, re-read, and coded by the team members using an investigator-developed codebook (see Appendix F) and Atlas.ti 6 (Frieze, 2011) for organizing the data. Team members recorded initial impressions and highlighted words or phrases for preliminary code development. As the meetings progress, codes were combined to the minimum number possible for final presentation. The investigator-defined codebook began as a provisional template of a few predefined codes to help initiate the coding process (Fereday & Muir-Cochrane, 2006; Nowell et al., 2017) and was updated with each meeting. The provisional

codebook included physical, mental, and social support domains of quality of life. Each included a label for the quality of life domain, definition, examples of what is included and excluded, and an example of a quote. The next three steps involved searching for themes, reviewing the themes, and defining and naming themes (Braun & Clarke, 2006; Vaismoradi et al., 2013) during regularly held meetings. Revisiting the data, as needed, allowed the study team to reflect and interact with the data (Nowell et al., 2017). Any discrepancies and redundancy of the codes were discussed until consensus was reached (Nowell et al., 2017). This coding process was an essential component of qualitative data and helped the research team make sense of the data and use of a codebook helped ensure inter-rater reliability (Creswell & Poth, 2018). A visualization of the final codes was created. Lastly, a written report was produced that includes extracted examples and final analysis in chapter four and five of this dissertation (Braun & Clarke, 2006; Vaismoradi et al., 2013).

**Trustworthiness.** Using this six-step method (Braun & Clarke, 2006) consistently among the three team members, eliminating discrepancies, and describing a logical, and clearly documented process helped assure trustworthiness (Nowell et al., 2017). Researcher triangulation, using three different team members with the same technique to reach consensus for intercoder agreement, and accurate transcriptions, helped to control reliability and validity (Creswell & Poth, 2018; Harvey, 2014; Polit & Beck, 2017). Audit files, transcripts, and field notes are stored for potential future audit trails and also contributed to the trustworthiness and validity of the data (Nowell et al., 2017; Polit & Beck, 2017; Whittemore et al., 2001). Ensuring confidentiality of participants and presenting multiple quotes for each theme within the final dissemination methods were performed for ethical purposes (Creswell & Poth, 2018).

## *Aim #2*

The second aim of this study was to quantitatively examine change over time in the quality of life of older adults with complicated grief pre-, post-, and eight weeks after Accelerated Resolution Therapy as measured by the CDC HRQOL Healthy Days Module. The Healthy Days Module (questions #1-4 of the current CDC HRQOL-14) was designed for initial use for population health surveillance and has been used in national and international studies since 1993 (Centers for Disease Control and Prevention, 2018). Higher scores indicate poorer quality of life. The questions are:

1. Would you say that in general, your health was poor, fair, good, very good, or excellent? (1= excellent to 5 = poor)
2. How many days during the past 30 days was your physical health not good? (0 to 30)
3. How many days during the past 30 days was your mental health not good? (0 to 30)
4. During past 30 days, how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? (0 to 30)

The Healthy Days Module was selected for this study as it is appropriate for use with relatively healthy older adults, whereas the other two modules contain more patient- and symptom-focused questions.

A quantitative analysis of the responses provided to questions in the Healthy Days Module (Questions #1-4) (appendix B) was conducted for enrolled and treated participants ( $n = 54$ ) who completed at least two time points of data collection. As the quality of life measure was administered to the majority of study participants at baseline, before each individual Accelerated

Resolution Therapy session (typically 4 sessions received) as well at 2-month follow-up. Data was analyzed using IBM® SPSS® 25 (Armonk, NY).

A principal component analysis (PCA) was conducted to determine if there was one or more than one component that best describes the underlying relationships among the variables (Pallant, 2016) in the organization of the instrument. A PCA was used to identify linear components and how variables contributed to a component (Field, 2013). Prior to performing the PCA, the suitability of data for factor analysis was assessed using a correlation matrix ( $r = 0.3$  and above), Kaiser-Meyer-Olkin value (above 0.6), and Bartlett's Test of Sphericity for statistical significance ( $p < 0.05$ ). Eigenvalues of 1.0 or more were retained for further investigation. Lastly, the scree plot was examined to confirm if the point of inflexion (or elbow) matches the number of components to be extracted (Field, 2013).

Univariate and bivariate statistical analyses were conducted for all demographic and clinical characteristics and the Healthy Days Module. A missing value analysis along with counts and frequencies for these four questions, split by visit number, was conducted. This missing value analysis was performed to help determine if the number of missing or unknown responses provided an adequate sample for analysis or if the sample size should be reduced. For example, consideration was given to retain participants for analysis that provided numeric scores for quality of life questions at baseline and 8-weeks post-completion of therapy. Mean scores over time for the four quality of life questions were explored (Field, 2013; Pallant, 2016). A determination was made if these four questions were to be retained and aggregated for further analysis.

Next, paired t-tests and repeated measures analysis of variance (RMANOVA) were conducted on the individual questions or aggregate responses. Paired t-tests were conducted to

determine if there is a statistically significant difference in the mean scores at 1) baseline to end of treatment (4-weeks for immediate treatment arm; 8-weeks for wait list control arm), 2) baseline to 8-weeks post completion of therapy, and 3) end of treatment to 8-weeks post completion of therapy. A RMANOVA with Bonferroni correction to adjust for multiple comparisons, was conducted to compare all the participants in one test, leaving the significance level at 0.05 and avoiding Type I error as compared to the paired t-tests (Pallant, 2016). This analysis determined if there was a significant difference among the scores for the three time periods.

An unconditional means model was conducted to determine if there is systematic variation in the quality of life outcome, calculate the intraclass correlation which compares the relative magnitude of these variances, and evaluate the fit of subsequent models. An unconditional growth model was then conducted to examine within-persons and between-persons residual variances and covariance between the intercepts and slopes. Lastly, a multilevel linear model was fitted to the data to test for a significant change in quality of life over the course of the Accelerated Resolution Therapy intervention (TIME) and if there was a significant effect of the intervention (Pallant, 2016). Two levels (1 = participant, 2 = group) were integrated in the model to examine within-person and between-person effects. The main independent variables of interest were time and group as the aim of the study is to determine if quality of life improved over time for older adults with complicated grief receiving Accelerated Resolution Therapy and if this varies by group (immediate treatment versus wait list control). Time and group variables were placed in the model in this order and one at a time; however, all variables were tested for predictive ability and to explain the variance of the model. Assumptions for statistical tests were checked.



### ***Aim #3***

Lastly, the third aim was to understand changes in quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy by integrating the qualitative and quantitative data.

This sub-analysis drew upon a pragmatic philosophical approach connecting the constructivist view for qualitative research and the postpositivist views for quantitative research underlining a pluralistic emphasis on what works and real-world practice (Creswell & Plano Clark, 2018; NIH Office of Behavioral and Social Sciences, 2018). The qualitative codes and quantitative data of older adults with complicated grief treated with Accelerated Resolution Therapy (Aim #1 and #2) were integrated employing an informational matrix using Microsoft® Excel to compare and contrast the codes and data. This triangulation method (Creswell & Plano Clark, 2018) aided the investigation of the phenomenon of quality of life from multiple perspectives of older adults experiencing complicated grief by seeking the union, validation, and agreement of the results (Schoonenboom & Burke Johnson, 2017). Only participants who completed the interview (Aim #1) and provided a numeric quality of life scores for baseline and post 8-weeks completion of treatment (Aim #2) were used for this integration ( $n = 21$ ) thus avoiding the threat to sample integration (NIH Office of Behavioral and Social Sciences, 2018).

Four basic steps described for implementing a convergent design and triangulation to assess convergence and mutual corroboration (Creswell & Plano Clark, 2018) were used for this sub-analysis. The first step included designing and collecting both the qualitative and quantitative data, completed in the parent study, followed by step 2, analyzing the data separately (Creswell & Plano Clark, 2018). These have been discussed in Aim #1 and Aim #2. The third step began the process for merging the two sets of data for the purposes of comparing,

contrasting, and/or synthesizing. This included creating a display or a comparison discussion (i.e., informational matrix) and transforming one type of results into the other type of data (e.g., turn number of deaths into dichotomy category of single versus multiple) (Creswell & Plano Clark, 2018). Points of integration occurred during the early stage of the research process with the addition of the semi-structured interview and continued during this merge and analysis phase (Schoonenboom & Burke Johnson, 2017).

Integration in this convergent design consisted of the intent to match the results by comparing them in a side-by-side information matrix, in order to identify points of convergence or divergence (Creswell & Plano Clark, 2018). First, select caregiver characteristics, single versus multiple deaths, number of comorbidities, and relationship role, were integrated and compared to qualitative themes. Then, caregiver characteristics were integrated and compared to with quantitative data which consisted of aggregate quality of life scores 8-weeks post completion of therapy and change in scores from baseline to post completion of therapy. A cut point of 14 or more has been used to indicate unhealthy days (Centers for Disease Control and Prevention, 1998; Cook et al., 1998; Moriarty et al., 2003). For the three aggregate quality of life scores, a cut point of 42 was chosen to represent poor quality of life. Lastly, the full integration and comparison of caregiver characterizes, qualitative themes, and quantitative scores were interpreted. A summary and plan for dissemination or future research (step 4) is provided (Creswell & Plano Clark, 2018).

### ***Demographic and Clinical Characteristics***

Descriptive statistics were conducted for all the demographic and clinical characteristics and included frequency and percentage for categorical variables and mean and standard deviation for continuous variables (see Appendix C). Data was also split by group (immediate treatment

and wait list control) and descriptive statistics conducted again. Independent t-tests were conducted for the continuous variables and chi-square analysis for the categorical variables by group. Correlations were conducted to explore the relationship among the continuous variables. Data was analyzed using IBM® SPSS® 25 (Armonk, NY).

### **Limitations and Assumptions**

The proposed study was limited by its sub-analysis design as data was obtained from the larger parent study. The larger study noted the majority was female and Caucasian thus rendering it unfeasible to generalize treatment response by gender and race (Buck et al., 2020). In addition, the parent study also noted limitations due to symptoms of complicated grief for inclusion criteria were via self-report and follow-up results at 8-weeks post completion to treatment cannot address long-term sustainability (Buck et al., 2020). Additionally, missing data was expected and was addressed with statistical analyses. Data collection took place at one hospice center via referrals by their hospice counselor. An additional limitation was the level of expertise of the study team members involved in the qualitative analysis (Creswell & Plano Clark, 2018). To address this limitation, a one-day workshop on qualitative research including coding was arranged by student's advisor and attended by the coding team members.

Assumptions can be made as to the strength of the randomized control design of the parent study and its consistency with use of manualized intervention and clinical interventionists (Buck et al., 2020). Integration of the qualitative and quantitative data within this study can be complementary to each other, especially with the aim to gain a more complete understanding of changes in quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy.

## **Summary**

The sub-analysis described, examined, and integrated data on quality of life for older adult caregivers with complicated grief receiving Accelerated Resolution Therapy. A qualitative analysis of the interview data obtained at 8-weeks post completion of therapy consisted of coding for common themes. A quantitative analysis was conducted for the Health Days Measures, questions #1-4 of the CDC HRQOL-14 instrument. Lastly, data was integrated for a mixed methods approach to investigate the phenomena of quality of life for older adult caregivers with complicated grief receiving Accelerated Resolution Therapy.

## **CHAPTER FOUR:**

### **RESULTS**

This chapter presents the data analysis results for the three aims of this study. First, the final thematic analysis of the semi-structured interviews for Aim #1 are presented. Next, Aim #2 results are provided and consist of a quantitative analysis of the CDC HRQOL Healthy Days Module. Lastly, results for Aim #3 are presented as an integration of the qualitative and quantitative data with select caregiver characteristics. Descriptive statistics for demographics and clinical characteristics are included with each analysis.

#### **Aim #1: Semi-structured Interviews**

The first aim was to qualitatively describe self-reported quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy as measured by transcription and coding of semi-structured interviews. Thirty-one semi-structured interviews were conducted in the parent study (Buck et al., 2020). Two interviews did not have saved digital recordings and were excluded from this analysis leaving a sample size of 29. Recorded interviews totaled 308:23 minutes and consisted of 69,148 transcribed words. The question asked during the interviews (Appendix A) used for this analysis is “When someone asks you about your “quality of life” what do YOU think they mean?”

### ***Demographic and Clinical Characteristics***

Sample demographic and clinical characteristics for the 29 participants were examined and are displayed in Table 1. The majority was female (82.8%,  $n = 24$ ), widowed (69.0%,  $n = 20$ ), White (96.6%,  $n = 28$ ), non-Hispanic/Latino (89.3%,  $n = 26$ ), educated with bachelor or graduate degree (41.4%,  $n = 12$ ), and had a mean age of 68 years ( $SD = 7.23$ ). The majority reported no hospitalizations (75.0%,  $n = 21$ ) and had greater than three visits to their provider/physician (89.7%,  $n = 26$ ) since the death of their family member. The average number of comorbidities was 1.17 ( $SD = 1.17$ ). In keeping with the hospice recruitment site (MacKenzie et al., 2015; National Hospice and Palliative Care Organization, 2020) cancer was the most common diagnosis of the deceased family member (39.1%,  $n = 9$ ).

### ***Bivariate Analyses***

Bivariate analysis found that age and the number of comorbidities were not correlated. There were no statistically significant differences found between the Intervention Group and the Control Group for any of these demographic or clinical variables.

### ***Thematic Analysis***

Four themes describing or elaborating on features of quality of life were identified, three were intrapersonal (Mental Function, Self-management, and Physical Function) and the fourth interpersonal (Social Support). Table 2 lists the themes in order of frequency counts (Sandelowski, 2001) along with sub-themes, as appropriate, and an example. The themes are discussed in this same order.

**Table 1***Demographic and Clinical Characteristics Comparing Groups with Test Statistics*

Variable	All participants mean $\pm$ SD <i>n</i> (%)	Immediate Treatment Group mean $\pm$ SD <i>n</i> (%)	Wait List Control Group mean $\pm$ SD <i>n</i> (%)	Test Statistic
	N = 29	n = 20	n = 9	
Age	68.0 $\pm$ 7.23	68.0 $\pm$ 7.06	68.0 $\pm$ 8.03	$t = 0.017$ , $df = 27$
Biological Sex				$\chi^2 = 2.368$ , $df = 1$
Male	5 (17.2)	2 (10.0)	3 (33.3)	
Female	24 (82.8)	18 (90.0)	6 (66.7)	
Marital status				$\chi^2 = 3.926$ , $df = 2$
Married/partnered	3 (10.3)	1 (5.0)	2 (22.2)	
Divorced	6 (20.7)	3 (15.0)	3 (33.3)	
Widowed	20 (69.0)	16 (80.0)	4 (44.4)	
Annual Income				$\chi^2 = 4.159$ , $df = 4$
Less than \$25,000	12 (41.4)	10 (50.0)	2 (22.2)	
\$25,000 - \$49,999	10 (34.5)	6 (30.0)	4 (44.4)	
\$50,000 - \$74,999	4 (13.8)	3 (15.0)	1 (11.1)	
\$75,000 or greater	2 (6.9)	1 (5.0)	1 (11.1)	
Unknown	1 (3.4)	---	1 (11.1)	
Educational Level				$\chi^2 = 3.859$ , $df = 4$
$\leq$ High School	7 (24.1)	3 (15.0)	4 (44.4)	
Some college/tech	8 (27.6)	6 (30.0)	2 (22.2)	
Associate	2 (6.9)	2 (10.0)	---	
Bachelor	6 (20.7)	5 (25.0)	1 (11.1)	
Graduate	6 (20.7)	4 (20.0)	2 (22.2)	
Race				$\chi^2 = 0.466$ , $df = 1$
White	28 (96.6)	19 (95.0)	9 (100.0)	
Other	1 (3.4)	1 (5.0)	---	
Hispanic Ethnicity (yes)	3 (10.3)	2 (10.0)	1 (11.1)	$\chi^2 = 0.008$ , $df = 1$
Employment	Missing $n = 1$	Missing $n = 1$		$\chi^2 = 7.409$ , $df = 4$
Full Time	3 (10.7)	1 (5.3)	2 (22.2)	
Part Time	1 (3.6)	---	1 (11.1)	
Retired	19 (67.9)	15 (78.9)	4 (44.4)	
Disabled	3 (10.7)	1 (5.3)	2 (22.2)	
Other	2 (7.1)	2 (10.5)	---	
Number comorbidities	1.17 $\pm$ 1.17	1.30 $\pm$ 1.22	0.89 $\pm$ 1.05	$t = 0.874$ , $df = 27$
Hospitalizations*	Missing $n = 1$		Missing $n = 1$	$\chi^2 = 3.453$ , $df = 2$
0	21 (75.0)	16 (80.0)	5 (62.5)	
2	2 (7.1)	2 (10.0)	---	
$\geq 3$	5 (17.9)	2 (10.0)	3 (37.5)	
Physician/provider visits*				$\chi^2 = 1.985$ , $df = 1$
2	3 (10.3)	1 (5.0)	2 (22.2)	
$\geq 3$	26 (89.7)	19 (95.0)	7 (77.8)	
Deceased's diagnosis	Missing $n = 6$	Missing $n = 3$	Missing $n = 3$	$\chi^2 = 3.433$ , $df = 6$
Cancer	9 (39.1)	7 (41.2)	2 (33.3)	
Dementia/Alzheimer's	4 (17.4)	3 (17.6)	1 (16.7)	
Stroke	4 (17.4)	2 (11.8)	2 (33.3)	
Liver +/- kidney failure	3 (13.0)	2 (11.8)	1 (16.7)	
Respiratory	2 (8.7)	2 (11.8)	---	
Brain stem injury	1 (4.3)	1 (5.9)	---	

Note: Percentages may not add up to 100% due to rounding/missing data. All test statistics are non-significant.

\*Number of times since death of care recipient.

**Table 2***Quality of Life Themes and Sub-themes Extracted from Semi-structured Interviews*

Theme	Sub-themes	Frequency	Example of Quote
Mental Function	Mental Health	11	Health of my mind state
	Joy	7	Enjoying life to the fullest
	Happiness	6	My sense of happiness
Self-management	Self-efficacy	9	Have plans for the future
	Self-agency	7	Able to do what I can, what I want to do.
Social Support		8	Being able to communicate
Physical Function		7	Healthy life

When describing quality of life, Mental Function was the most frequently endorsed theme. This is understandable as the former caregivers were being treated by psychotherapists for complicated grief which is an affective state. Mental/psychological quality of life domain refers to the mind, and can include level of satisfaction with life, contentment, and happiness (Centers for Disease Control and Prevention, 2019) and not feeling worried or anxious, sad or depressed, lonely or isolated, or troubled by past experiences (van Leeuwen et al., 2019). Participants' comments were grouped within the three closely interwoven sub-themes of describing quality of life as involving mental health, joy, and happiness. One participant [1046] described quality of life as *“are you depressed, are you moving forward, how are you feeling about yourself?”* Joy and happiness were expressed with comments such as *“enjoy being alive”* [1031], *“enjoying life to the fullest potential”* [1048], and *“being happy”* [1016]. One participant [1049] summed these up as quality of life is *“being able to experience feelings of joy, being able to experience feelings of happiness and I’m talking about the kind of happiness that comes from*



*deep within your soul, not just a, not just a superficial happiness, but something that really emanates from your soul and fills you.”*

The second most frequent theme was Self-management, consisting of self-efficacy (perceived ability) and self-agency (actual ability) sub-themes. Examples include quality of life as *“being able to do things for yourself, being able to follow your dreams”* [1017] and *“accomplishing things you need to for yourself”* [1057], respectively. Included within this theme was having a sense of financial security noted by two participants, for example, quality of life was described as having enough resources *“to pay bills”* [1022] and know how to handle new situations. For example, one participant elaborated that her husband did the household repairs and now is faced with learning how to call a plumber.

Next in frequency of endorsement is Social Support, the one interpersonal theme, which was found to be centered on quality of life being comprised of companionship and being able to communicate. The social domain encompasses a sense of belonging and inclusion, relationships, support, and participation (Waite, 2018). Examples include the negative case of quality of life was poor when *“I was alone. I was very lonely about it, you know. So that really bothered me a lot”* [1018] and the positive care of quality of life *“Being around people and having people in your life that love you and care about you. As well as having people in your life that you love and care about. Um for me, those are the things that have always defined quality”* [1049]. Social support’s function in quality of life included being involved, such as *“being productive, being part of the community, being helpful to others”* and *“If I am getting involved in things”* [1029].

Physical Function was the last theme identified and the least endorsed. The physical domain pertains to the body, generally in respect to a level of feeling healthy and full of energy (Centers for Disease Control and Prevention, 2019) and not limited by one’s health (van

Leeuwen et al., 2019). This theme was comprised of less detailed responses and included quality of life as “*Being able to do things you want or can*” [1016, 1022] and “*health*” [1038, 1052, 1059] feelings of “*healthy life*” [1056]. Two participants described quality of life as being “*well-rounded*” (mental health, physical health, and social health) [1038] while another used the term “*a balanced life*” of friends/family, work balance, activity balance and health [1052].

An across case analysis resulted in identifying that most participants ( $n = 13$ , 44.8%) described quality of life as unidimensional and this was true for both males ( $n = 3$ , 60%) and females ( $n = 10$ , 41.7%). The balance of participants endorsed two themes ( $n = 10$ ; 34.5%). None of the informants endorsed all four themes. These four qualities of life themes or domains, extracted from the structured interviews of former caregivers with complicated grief, are depicted in Figure 2.

**Figure 2**

*Quality of Life Domains Extracted from Semi-structured Interviews*



## **Aim #2: CDC HRQOL-14**

The second aim of this dissertation was to quantitatively examine changes in quality of life of older adults with complicated grief pre-, post-, and eight weeks after Accelerated Resolution Therapy as measured by the CDC HRQOL-14, Health Days Module. The accompanying hypothesis proposed was that older adults experiencing complicated grief will report improved quality of life with completion of Accelerated Resolution Therapy. This analysis began with an examination of The Healthy Days Module, which consists of four questions:

1. Would you say that in general, your health was poor, fair, good, very good, or excellent? (1= excellent to 5 = poor)
2. How many days during the past 30 days was your physical health not good? (0 to 30)
3. How many days during the past 30 days was your mental health not good? (0 to 30)
4. During past 30 days, how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? (0 to 30)

### ***Healthy Days Module***

Prior to conducting the PCA of the 4-item Health Days Module assumptions were tested and found that the Kaiser-Meyer-Olkin value was .73, exceeding the recommendation of .6 (Kaiser, 1974) and the Bartlett's Test of Sphericity (Bartlett, 1954) was statistically significant, supporting the factorability of the correlation matrix. The PCA indicated the presence of one component with eigenvalue greater than 1, explaining 62.8 % of the variance (Table 3). This eigenvalue (2.511) was more than three times that of the second component. An inspection of the scree plot (Figure 3) also revealed a clear break after the first component. Using Catell's scree test (Catell, 1966), a decision was made to retain the one component for further analysis. All the

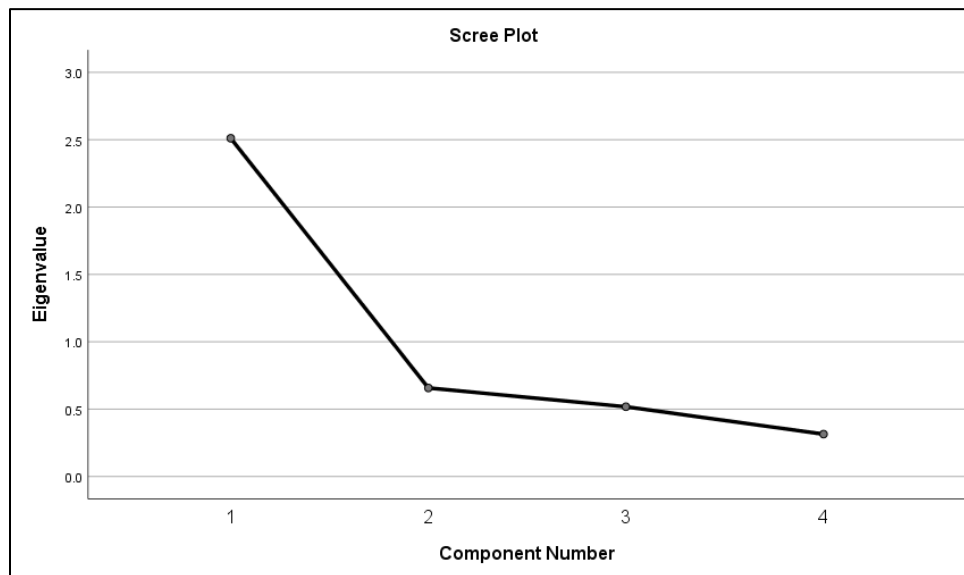
unrotated factor loadings for the questions were positive and ranged from .748 to .852. The results of this analysis support the use of these four items of the Healthy Days Module as one scale in this sample as suggested by the authors (Centers for Disease Control and Prevention, 2018).

**Table 3**

<i>Eigenvalues and Variance Explained</i>		
Component	Eigenvalue	Total Variance
1	2.511	62.77
2	.657	16.43
3	.518	12.04
4	.314	7.86

**Figure 3**

*Scree Plot*



Mean scores for the questions were explored and a lack of variability was noted for the first question pertaining to general health (range 2.29 to 3.35) and was removed from further analysis. Next, missing values were evaluated to determine the number of participants who provided both a baseline and 8-weeks post completion of therapy scores which were needed to ascertain if quality of life improved over time. Half of the participants ( $n = 27$ ) provided data for these time points and were retained for further analysis. When completers vs. non-completers were analyzed no statistically significant differences in salient variables such as age and baseline CG were found. The only statistically significant difference found was that non-completers were more likely to be found in the wait list group (7 completers vs. 15 non-completers,  $p = 0.027$ ). The remaining three questions focusing on physical health, and mental health, and their impact on usual activities contained the same scale and were combined providing an aggregate score (range 0 to 90) (Moriarty et al., 2003) for baseline, end of treatment, and 8-weeks post completion of therapy time points for each of the 27 participants (20 Treatment Group, 7 Control Group).

### ***Demographic and Clinical Characteristics***

In this sample of 27 participants, the majority were female (85.2%,  $n = 23$ ), widowed (59.3%,  $n = 16$ ), White (96.3%,  $n = 26$ ), non-Hispanic/Latino (89.0%,  $n = 24$ ), educated with bachelor or graduate degree (40.7%,  $n = 11$ ), retired (61.5%,  $n = 16$ ), and had a mean age of 66 years ( $SD = 6.60$ ) and 1.2 ( $SD = 1.42$ ) comorbidities. The immediate Treatment Group had, on average, more than double the number of comorbidities (1.45,  $SD = 1.54$ ) as compared to the wait list Control Group (0.57,  $SD = 0.79$ ). The majority reported no hospitalizations (74.1%,  $n = 20$ ) and had greater than three visits to their provider/physician (85.2%,  $n = 23$ ) since the death of their care recipient. Sixteen participants reported the cause of death of their care recipient. In

keeping with the hospice recruitment site (MacKenzie et al., 2015; National Hospice and Palliative Care Organization, 2020), cancer was the most common diagnosis (25.9%,  $n = 7$ ). On average for the total sample (immediate Treatment and wait list Control Groups), there was an improvement (lower scores indicate improved quality of life) in the aggregate quality of life scores from baseline (38.85,  $SD = 26.20$ ) to end of treatment (26.92,  $SD = 22.91$ ) with relative stability of the scores at 8-weeks post completion of therapy ( $21.26 \pm 23.71$ ) for the participants. There was a statistically significant difference for level of employment between the groups ( $p < 0.05$ ) with the immediate Treatment Group having the majority (15, 78.9%) of retired participants than the Control Group (1, 14.3%). No other statistically significant differences were found between the immediate Treatment Group and the wait list Control Group on any other demographic or clinical variable. Tables 4 and 5 present the descriptive analyses for demographic and clinical characteristics, respectively, for these 27 participants.

Total quality of life scores over time are depicted in Figure 4 and represent wide variation among the participants suggesting responses to changes in quality of life are individualized. Figure 5 represents variation by group and suggests improvement over time with treatment for both groups.

### ***Bivariate Relationships between Continuous Variables***

When examined, a strong, positive correlation was found between quality of life scores at baseline and quality of life at the end of treatment ( $r = .62$ ,  $n = 26$ ,  $p < 0.01$ ) and quality of life at 8-weeks post completion of therapy ( $r = .63$ ,  $n = 27$ ,  $p < 0.01$ ) with quality of life scores improving over time. Quality of life at the end of treatment also had a strong, positive correlation with quality of life at 8-weeks post completion of therapy ( $r = .51$ ,  $n = 26$ ,  $p < 0.01$ ) and number of comorbidities ( $r = .65$ ,  $n = 26$ ,  $p < 0.01$ ). Lastly the number of comorbidities was also

positively correlated to age ( $r = .39, n = 27, p < 0.05$ ) and quality of life at 8-weeks post completion of therapy ( $r = .46, n = 27, p < 0.05$ ). Higher number of comorbidities were positively associated with increased age and improved quality of life after treatment for complicated grief. See Table 6.

**Table 4**

*Demographic Characteristics Comparing Groups with Test Statistics*

Variable	All participants	Immediate Treatment Group	Wait List Control Group	Test Statistic
	mean $\pm$ SD	mean $\pm$ SD	mean $\pm$ SD	
	$n$ (%)	$n$ (%)	$n$ (%)	
	N = 27	n = 20	n = 7	
Age	66.1 $\pm$ 6.60	67.0 $\pm$ 6.95	63.6 $\pm$ 5.13	$t = 1.173, df = 25$
Biological Sex				$\chi^2 = 0.002, df = 1$
Male	4 (14.8)	3 (15.0)	1 (14.3)	
Female	23 (85.2)	17 (85.0)	6 (85.7)	
Marital status				$\chi^2 = 5.390, df = 3$
Married/partnered	5 (18.5)	2 (10.0)	3 (42.9)	
Divorced	5 (18.5)	3 (15.0)	2 (28.6)	
Widowed	16 (59.3)	14 (70.0)	2 (28.6)	
Single/never married	1 (3.7)	1 (5.0)	---	
Annual Income				$\chi^2 = 3.318, df = 3$
Less than \$25,000	11 (40.7)	10 (50.0)	1 (14.3)	
\$25,001 - \$49,999	9 (33.3)	5 (25.0)	4 (57.1)	
\$50,000 - \$74,999	4 (14.8)	3 (15.0)	1 (14.3)	
\$75,000 or greater	3 (11.1)	2 (10.0)	1 (14.3)	
Educational Level				$\chi^2 = 0.902, df = 4$
$\leq$ High School	5 (18.5)	3 (15.0)	2 (28.6)	
Some college/tech	7 (25.9)	5 (25.0)	2 (28.6)	
Associate degree	4 (14.8)	3 (15.0)	1 (14.3)	
Bachelor's degree	5 (18.5)	4 (20.0)	1 (14.3)	
Graduate degree	6 (22.2)	5 (25.0)	1 (14.3)	
Race				$\chi^2 = 0.363, df = 1$
White	26 (96.3)	19 (95.0)	7 (100.0)	
Other	1 (3.7)	1 (5.0)	---	
Hispanic Ethnicity-Yes	3 (11.1)	3 (15.0)	---	$\chi^2 = 1.181, df = 1$
Employment	Missing $n = 1$	Missing $n = 1$		$\chi^2 = 11.493, df = 4^*$
Full Time	3 (11.5)	1 (5.3)	2 (28.6)	
Part Time	2 (7.7)	1 (5.3)	1 (14.3)	
Retired	16 (61.5)	15 (78.9)	1 (14.3)	
Disabled	4 (15.4)	1 (5.3)	3 (42.9)	
Other	1 (3.8)	1 (5.3)	---	

Note: Percentages may not add up to 100% due to rounding/missing data.

\* $p < 0.05$ ; all other test statistics are non-significant.

**Table 5***Clinical Characteristics Comparing Groups with Test Statistics*

Variable	All participants mean $\pm$ SD <i>n</i> (%)	Immediate Treatment Group mean $\pm$ SD <i>n</i> (%)	Wait List Control Group mean $\pm$ SD <i>n</i> (%)	Test Statistic
	<i>N</i> = 27	<i>n</i> = 20	<i>n</i> = 7	
Number comorbidities	1.22 $\pm$ 1.42	1.45 $\pm$ 1.54	0.57 $\pm$ 0.79	$t = 1.434, df = 25$
Hospitalizations <sup>a</sup>				$\chi^2 = 6.432, df = 3$
None	20 (74.1)	16 (80.0)	4 (57.1)	
One	1 (3.7)	1 (5.0)	---	
Two	2 (7.4)	2 (10.0)	---	
$\geq$ Three	4 (14.8)	1 (5.0)	3 (42.9)	
Physician/provider visits <sup>a</sup>				$\chi^2 = 4.021, df = 3$
None	1 (3.7)	1 (5.0)	---	
One	1 (3.7)	---	1 (14.3)	
Two	2 (2.4)	1 (5.0)	1 (14.3)	
$\geq$ Three	23 (85.2)	18 (90.0)	5 (71.4)	
Deceased's diagnosis	Missing <i>n</i> = 11	Missing <i>n</i> = 9	Missing <i>n</i> = 2	$\chi^2 = 7.941, df = 6$
Cancer	7 (25.9)	6 (30.0)	1 (14.3)	
Dementia/Alzheimer's	3 (11.1)	1 (5.0)	2 (28.6)	
Liver +/- kidney failure	2 (7.4)	1 (5.0)	1 (14.3)	
Respiratory	2 (7.4)	2 (10.0)	---	
Brain stem injury	1 (3.7)	1 (5.0)	---	
Stroke	1 (3.7)	---	1 (14.3)	
Quality of life scores <sup>b</sup>				
Baseline	38.85 $\pm$ 26.20	32.80 $\pm$ 21.94	56.14 $\pm$ 31.29	$t = 2.169, df = 25$
End of treatment	26.92 $\pm$ 22.91	26.16 $\pm$ 24.74	29.00 $\pm$ 18.55	$t = 0.275, df = 24$
8-weeks post completion	21.26 $\pm$ 23.71	21.40 $\pm$ 24.01	20.86 $\pm$ 24.70	$t = 0.051, df = 25$

Note: Percentages may not add up to 100% due to rounding/missing data. All test statistics are non-significant.

<sup>a</sup>Number of times since death of care recipient.

<sup>b</sup>Aggregate scores for questions #2-4 of CDC HRQOL-14, Healthy Days Measure. Lower scores indicate better quality of life.

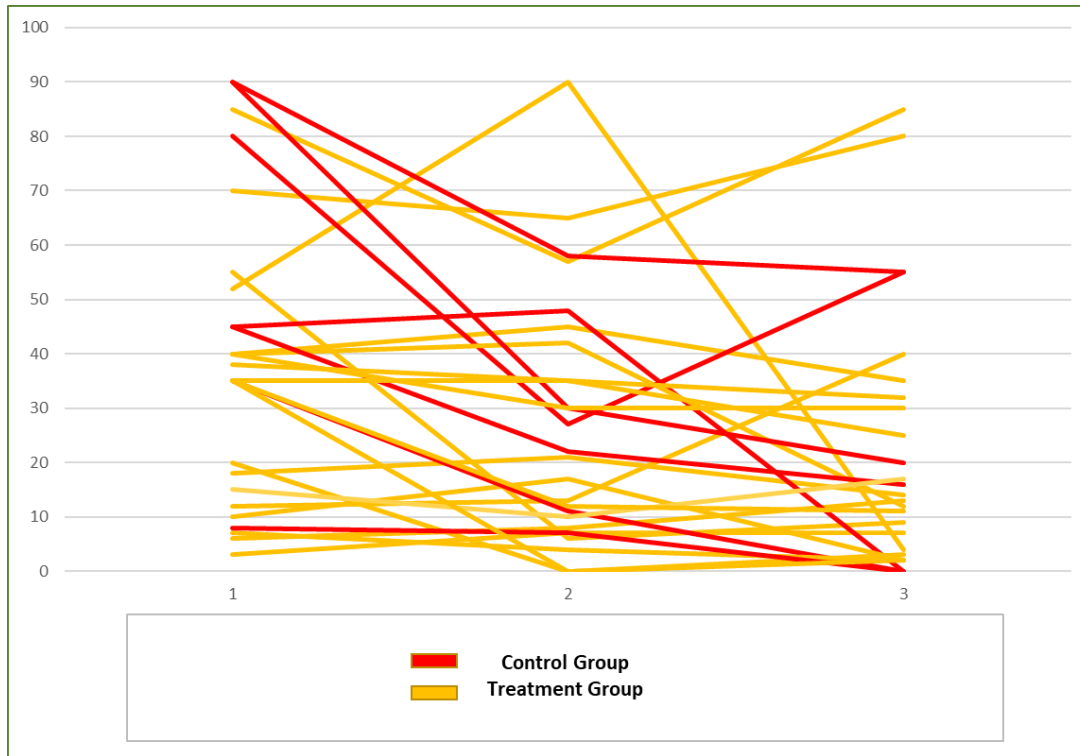
***Paired t-tests and RMANOVA***

There was a statistically significant decrease (improvement) in the means of the aggregate quality of life scores for all participants from Time 1: baseline ( $M = 38.81$ ,  $SD = 26.72$ ) to Time 2: end of treatment ( $M = 26.92$ ,  $SD = 22.91$ ),  $t(25) = 2.77$ ,  $p = 0.01$  (two-tailed) when examined using paired samples t-tests indicating an improvement in quality of life. The mean decrease in scores was 11.89 with a 95% confidence interval ranging from 3.06 to 20.71.



**Figure 4**

*Quality of Life Over Time by Participants (N =27)*



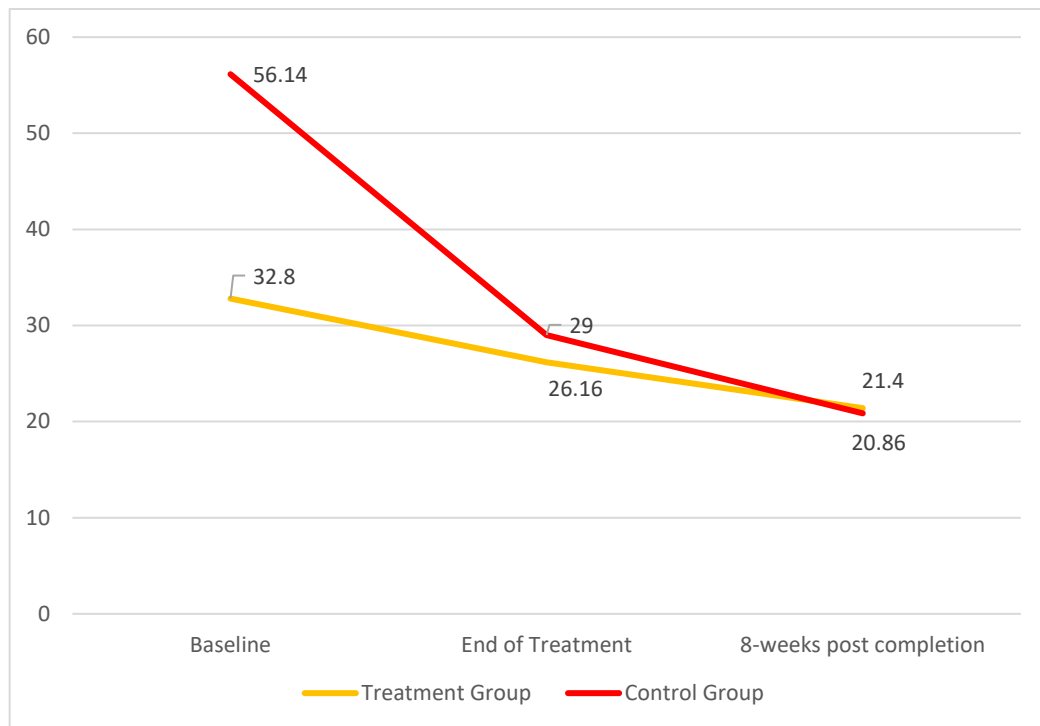
*Note:* Time 1 (baseline): The Control Group is delayed four weeks prior to starting treatment. Time 2: End of treatment for all participants. Time 3: 8-weeks post completion of therapy for all participants.

Downward trending indicates improvement in quality of life scores.

The eta square statistic (.23) indicated a small effect size. There was also a statistically significant decrease from Time 1 ( $M = 38.85$ ,  $SD = 26.20$ ) to Time 3: 8-weeks post completion of therapy ( $M = 21.26$ ,  $SD = 23.71$ ),  $t(26) = 4.21$ ,  $p < 0.001$ ). The mean decrease in the aggregate quality of life scores was 17.59 with a 95% confidence interval ranging from 9.00 to 26.18. The eta square statistic (.41) indicated a small to medium effect size. There was no statistically significant difference found between Time 2 ( $M = 26.92$ ,  $SD = 22.91$ ) and Time 3 ( $M = 21.88$ ,  $SD = 23.95$ ),  $t(25) = 1.11$ . Results indicated that the baseline quality of life scores improved to

**Figure 5**

*Quality of Life Over Time by Group*



*Note:* Downward trending indicates improvement in quality of life scores.

the end of treatment and from baseline to the 8-weeks post completion of therapy time point for the participants. Quality of life scores were maintained from the end of treatment to 8-weeks post completion of therapy time points. Based on the paired t-tests results the hypotheses that older adults experiencing complicated grief will report improved quality of life with Accelerated Resolution Therapy was supported.

Per the analytic plan, an RMANOVA was then conducted to compare aggregate quality of life scores at Time 1 (baseline), Time 2 (end of treatment), and Time 3 (8-weeks post completion of therapy). There was a statistically significant effect for time, Wilks' Lambda = .596,  $F(2, 24) = 8.12$ ,  $p = 0.002$ , multivariate partial eta squared (.40). Despite the small sample size this suggested a very large effect size (Cohen, 1988) with time explaining a bigger

proportion of the variance not attributed to other variables. One participant did not provide a score for Time 2 and the analysis was reduced to a sample size of 26. The means and standard deviations are presented in Table 7.

Next, a RMANOVA was repeated with participants grouped by treatment ( $n = 20$ ) and wait list control ( $n = 7$ ). There was a statistically significant effect by group over time, Wilks' Lambda = .410,  $F(2, 23) = 16.58$ ,  $p < 0.001$ , multivariate partial eta squared (.59) suggested, again, a very large effect size (Cohen, 1988). Similar to the results of the paired t-tests, statistically significant differences at the  $p < 0.05$  level were found between mean scores of Time 1 (44.28, SD = 5.52) and Time 2 (27.58, SD = 5.16) ( $p = 0.003$ ) and Time 1 and Time 3 (21.56, SD = 5.40) ( $p < 0.001$ ) but not Time 2 and Time 3 suggesting that total quality of life scores improved immediately after Accelerated Resolution Therapy and remained stable until at least Time 3. Based on the RMANOVA results the hypotheses that older adults experiencing complicated grief will report improved quality of life with Accelerated Resolution Therapy was supported.

**Table 6**

*Pearson Correlations Among Continuous Variables*

	1	2	3	4	5
1. Number of Comorbidities	--				
2. Age	.39*	--			
3. QOL Baseline	.33	.92	--		
4. QOL End of Treatment	.65**	.11	.62**	--	
5. QOL 8-weeks Post Treatment	.46*	-.04	.63**	.51**	--

Abbreviations: QOL, quality of life.

\*  $p < 0.05$ , \*\*  $p < 0.01$  (two-tailed).

**Table 7***Descriptive Statistics for Total Quality of Life Scores: Time 1, Time 2, & Time 3*

Time Period	N	Mean	Standard Deviation
Time 1 (Baseline)	26	38.81	26.72
Time 2 (End of Treatment)	26	26.92	22.91
Time 3 (8-weeks post Treatment)	26	21.88	23.95

***Multilevel Linear Model***

The sample size of 27 itself precluded the use of more than the indicators of time and randomization group and thus fitting a more complex model. All predictors were tested individually in single predictor models and, apart from time and group were not found to be statistically significant. It was noted that one participant [ID 1004] had a maximum peak (score 90) at the end of treatment (up from a baseline score of 52 and then to an ending score of 4 at 8-weeks post completion). To determine if this participant represented an outlier or had too much influence on the model, two models were fitted, with and without this participant, as a form of sensitivity analysis. First, the unconditional means model fit the data (-2 Log Likelihood = 686.551, Akaike's Information Criterion = 692.551) and indicated that the intervention group was statistically significant ( $\beta = 28.22$ ,  $t = 7.101$ ,  $p < 0.001$ ) with a 28.22 difference based on the variance of the intercepts. Intraclass correlation indicated 45% of the total variation in total quality of life scores can be attributed to differences between participants. An unconditional growth model without participant 1004, revealed a slightly tighter fit (-2 Log Likelihood = 669.960 and Akaike's Information Criterion = 681.960). There was a significant difference in the -2 Log Likelihood ( $\Delta X^2(1) = 16.59$ ,  $p < 0.001$ ). Time was statistically significant ( $\beta = -8.21$ ,  $t = 4.02$ ,  $p < 0.001$ ) and, as such, that for each period of data collection there was an 8.21 negative difference (improvement) in quality of life scores. Total variation within-persons was statistically

significant ( $\beta = 429.861$ ,  $p = 0.008$ ). The between-persons variance ( $\beta = 27.08$ ) and the covariance between the intercepts and slopes ( $\beta = -51.30$ ) were not statistically significant. Time was entered first into the model and explained 7.8% of the variance in quality of life. The slope of the growth curve for aggregate quality life scores over time was statistically significant ( $p = 0.014$ ), indicating that quality of life improved over time. Group (i.e., treatment and control) was then added to the model. Group was a statistically significant predictor ( $p = 0.013$ ) and explained 11.0% of the variance. A potential interaction between time and group was tested, but, given the structure of the data, with all participants receiving the intervention after a wait list, it was best to not include an interaction. The multilevel linear model also supported the hypotheses that older adults experiencing complicated grief will report improved quality of life with completion of Accelerated Resolution Therapy.

### **Aim # 3 Mixed Methods Analysis**

The final aim of this study was to understand changes in quality of life of older adults with complicated grief treated with Accelerated Resolution Therapy by integrating the qualitative and quantitative data. There were 21 participants common to both the previous aims, and thus, included in this integration analysis.

#### ***Demographic and Clinical Characteristics***

In this sample of 21 participants, the majority were female (85.7%,  $n = 18$ ), widowed (66.7%,  $n = 14$ ), White (95.2%,  $n = 20$ ), non-Hispanic/Latino (90.5%,  $n = 19$ ), educated with bachelor or graduate degree (47.6%,  $n = 10$ ), retired (78.6%,  $n = 11$ ), and had a mean age of 66 years ( $SD = 7.13$ ) and 1.2 ( $SD + 1.25$ ) comorbidities. The immediate Treatment Group had, on average, more than double the number of comorbidities (1.40,  $SD = 1.35$ ) as compared to the

**Table 8***Demographic Characteristics Comparing Groups with Test Statistics*

Variable	All participants	Immediate Treatment Group	Wait List Control Group	Test Statistic
	mean $\pm$ SD <i>n</i> (%)	mean $\pm$ SD <i>n</i> (%)	mean $\pm$ SD <i>n</i> (%)	
	<i>N</i> = 21	<i>n</i> = 15	<i>n</i> = 6	
Age	66.0 $\pm$ 7.13	66.9 $\pm$ 7.63	63.7 $\pm$ 5.61	$t = 0.945, df = 19$
Biological Sex				$\chi^2 = 0.039, df = 1$
Male	3 (14.3)	2 (13.3)	1 (16.7)	
Female	18 (85.7)	13 (86.7)	5 (83.3)	
Marital status				$\chi^2 = 4.433, df = 2$
Married/partnered	3 (14.3)	1 (6.7)	2 (33.3)	
Divorced	4 (19.0)	2 (13.3)	2 (33.3)	
Widowed	14 (66.7)	12 (80.0)	2 (33.3)	
Annual Income				$\chi^2 = 2.188, df = 3$
Less than \$25,000	8 (38.1)	7 (46.7)	1 (16.7)	
\$25,001 - \$49,999	7 (33.3)	4 (26.7)	3 (50.0)	
\$50,000 - \$74,999	4 (19.0)	3 (20.0)	1 (16.7)	
\$75,000 or greater	2 (9.5)	1 (6.7)	1 (16.7)	
Educational Level				$\chi^2 = 2.380, df = 4$
$\leq$ High School	4 (19.0)	2 (13.3)	2 (33.3)	
Some college/tech	5 (23.8)	3 (20.0)	2 (33.3)	
Associate degree	2 (9.5)	2 (13.3)	---	
Bachelor's degree	5 (23.8)	4 (26.7)	1 (16.7)	
Graduate degree	5 (23.8)	4 (26.7)	1 (16.7)	
Race				$\chi^2 = 0.420, df = 1$
White	20 (95.2)	14 (93.3)	6 (100.0)	
Other	1 (4.8)	1 (6.7)	---	
Hispanic Ethnicity-Yes	2 (9.5)	2 (13.3)	---	$\chi^2 = 0.884, df = 1$
Employment	Missing <i>n</i> = 1	Missing <i>n</i> = 1		$\chi^2 = 9.286, df = 4$
Full Time	1 (7.1)	1 (5.3)	2 (33.3)	
Part Time	---	1 (5.3)	1 (16.7)	
Retired	11(78.6)	15 (78.9)	1 (16.7)	
Disabled	1 (7.1)	1 (5.3)	2 (33.3)	
Other	1 (7.1)	1 (5.3)	---	

*Note:* Percentages may not add up to 100% due to rounding/missing data. All test statistics are non-significant.

wait list Control Group (0.67, SD = 0.82). The majority reported no hospitalizations (71.4%, *n* = 15) and had greater than three visits to their provider/physician (90.5%, *n* = 19) since the death of their care recipient. Fifteen participants reported the cause of death of their care recipient. In keeping with the hospice recruitment site (MacKenzie et al., 2015; National Hospice and Palliative Care Organization, 2020), cancer was the most common diagnosis (33.3%, *n* = 7). On average for the total sample (immediate Treatment and wait list Control), there was an

improvement in the total quality of life scores from baseline (39.05, SD = 24.71) to end of treatment (24.10, SD = 18.85) with a relative stability of the scores at 8-weeks post-completion of therapy ( $19.10 \pm 21.57$ ) for the participants. No statistically significant differences were found between the immediate Treatment Group and the wait list Control Group on any other demographic or clinical variables therefore the data was aggregated for subsequent analyses. Tables 8 and 9 present the descriptive analyses for demographic and clinical characteristics, respectively, for these 21 participants.

**Table 9**

*Clinical Characteristics Comparing Groups with Test Statistics*

Variable	All participants mean $\pm$ SD <i>n</i> (%)	Immediate Treatment Group mean $\pm$ SD <i>n</i> (%)	Wait List Control Group mean $\pm$ SD <i>n</i> (%)	Test Statistic
	N = 21	<i>n</i> = 15	<i>n</i> = 6	
Number comorbidities	1.19 $\pm$ 1.25	1.40 $\pm$ 1.35	0.67 $\pm$ 0.82	$t = 1.230, df = 19$
Hospitalizations <sup>a</sup>				$\chi^2 = 5.565, df = 2$
None	15 (71.4)	12 (80.0)	3 (50.0)	
Two	2 (9.5)	2 (13.3)	---	
$\geq$ Three	4 (19.0)	1 (6.7)	3 (50.0)	
Physician/provider visits <sup>a</sup>				$\chi^2 = 0.497, df = 1$
Two	2 (9.5)	1 (6.7)	1 (16.7)	
$\geq$ Three	19 (90.5)	14 (93.3)	5 (83.3)	
Deceased's diagnosis	Missing <i>n</i> = 6	Missing <i>n</i> = 4	Missing <i>n</i> = 2	$\chi^2 = 5.367, df = 6$
Cancer	7 (33.3)	6 (40.0)	1 (16.7)	
Dementia/Alzheimer's	2 (9.5)	1 (6.7)	1 (16.7)	
Liver +/- kidney failure	2 (9.5)	1 (6.7)	1 (16.7)	
Respiratory	2 (9.5)	2 (13.3)	---	
Brain stem injury	1 (4.8)	1 (6.7)	---	
Stroke	1 (4.8)	---	1 (16.7)	
Quality of life scores <sup>b</sup>				
Baseline	39.05 $\pm$ 24.71	33.80 $\pm$ 19.91	52.17 $\pm$ 32.28	$t = 1.598, df = 19$
End of treatment	24.10 $\pm$ 18.85	21.86 $\pm$ 18.51	29.33 $\pm$ 20.29	$t = 0.805, df = 18$
8-weeks post completion	19.10 $\pm$ 21.57	20.67 $\pm$ 22.16	15.17 $\pm$ 21.45	$t = 0.518, df = 19$

*Note:* Percentages may not add up to 100% due to rounding/missing data. All test statistics are non-significant.

<sup>a</sup>Number of times since death of care recipient.

<sup>b</sup>Aggregate scores for questions #2-4 of CDC HRQOL-14, Healthy Days Measure. Lower scores indicate better quality of life.

### ***Bivariate Relationships between Continuous Variables***

When examined, a strong, positive correlation was found between quality of life scores at baseline and quality of life scores at the end of treatment ( $r = .67, n = 20, p < 0.01$ ) and quality of life scores at 8-weeks post-completion of therapy ( $r = .58, n = 21, p < 0.01$ ) with quality of life scores improving over time. Quality of life at the end of treatment also had a strong, positive correlation with quality of life at 8-weeks post completion of therapy ( $r = .68, n = 20, p < 0.01$ ). Lastly the number of comorbidities was also positively correlated with quality of life at 8-weeks post completion of therapy ( $r = .54, n = 21, p < 0.05$ ). See Table 10.

**Table 10**

#### ***Pearson Correlations Among Continuous Variables***

	1	2	3	4	5
1. Age	--				
2. Number of comorbidities	.280	--			
3. QOL Baseline	-.12	.22	--		
4. QOL End of Treatment	-.15	.43	.67**	--	
5. QOL 8-weeks Post Treatment	-.11	-.54*	.58**	.68**	--

Abbreviations: QOL, quality of life.

\*  $p < 0.05$ , \*\*  $p < 0.01$  (two-tailed).

### ***Data Integration***

The informational matrix (see Table 11) consisted of select characteristics of the participants that may affect quality of life (determined by the literature review), qualitative themes and sub-themes identified in the qualitative analysis, and quality of life scores at completion of the study (8-weeks post-completion of therapy) and change in quality of life scores from baseline to end of study identified in the quantitative analysis. Concordance between



the qualitative and quantitative data was moderate. This was ascertained by examining similar constructs found in both types of data. There were 17 participants that endorsed the Mental Function theme. Twelve (71%) scored poorly at baseline (e.g., range 15 to 30 out of 30) for the *Mental Health over past 30 days* question. Of the six participants that endorsed the Physical Function theme, 50% scored poorly for the instrument's *physical health over past 3 days* question at baseline (range 15 to 30 out of 30). The differences in concordance may reflect the sample size and difficulty for this sample in using the instrument. See limitations in Chapter 5.

**Table 11**

*Informational Matrix Components*

Participants	Number of comorbidities	Single vs. multiple deaths	Relationship	Theme 1. Mental Function	Theme 2. Self-management	Theme 3. Social Support	Theme 4. Physical Function	Post-completion QOL score	Change in score: First to last

The characteristics of the 21 caregivers with complete data from Aims #1 and #2 revealed that the majority ( $n = 14$ , 66.7%) had experienced multiple deaths, were spouses ( $n = 13$ , 61.9%), and were relatively healthy with 8 (38.1%) reporting one comorbidity and 7 (33.3%) reporting no comorbidities. See Table 12. The quality of life theme most frequently endorsed was Mental Function, followed by Self-Management, Social Support and then Physical Function in descending order of frequency. Table 13 lists the frequency for the themes and sub-themes identified for these 21 participants. Most participants ( $n = 10$ , 47.6%) described quality of life as unidimensional and this was true for both males ( $n = 2$ , 66.7%) and females ( $n = 8$ , 44.4%). This was followed by two themes as described by 7 (33.3%) of the participants. None of the informants endorsed all four themes. Post-completion quality of life scores ranged from 0 to 85, with the majority (14, 66.7%) scoring 30 or less, indicating fair to good quality of life. Eight

(38.1%) participants experienced a relatively minor drop in quality of life scores of 10 points or less and six (28.6%) experienced a larger drop in the range of 35 to 70 points.

The modest sample size of 21 former caregivers with quantitative data may have limited finding meaningful comparisons and contrasts among the data; however, at this early stage of examination the sample size was deemed sufficient to generate hypotheses for future exploration. The role of single or multiple deaths and the relationship with complicated grief and quality of life was highlighted in previous analyses and so was examined more indepth in this aim. As noted previously, overall, these former caregivers, whether they had experienced a single death or multiple deaths, endorsed the Mental Function theme the most frequently, 71.4% and 85.7%, respectively. The only difference of note was that of the seven former caregivers that reported a single death, five were spouses.

**Table 12**

*Caregiver Characteristics in Informational Matrix (N = 21)*

Variable	n (%)
Deaths Experienced by Caregiver	
Single	7 (33.3)
Multiple	14 (66.7)
Relationship of Caregiver	
Spouse	13 (61.9)
Parent	4 (19.0)
Child	3 (14.3)
Sibling	1 (4.8)
Number of Comorbidities of Caregiver	
0	7 (33.3)
1	8 (38.1)
2	3 (14.3)
3	1 (4.8)
4	2 (9.5)

**Table 13***Quality of Life Themes and Sub-themes in Informational Matrix (N=21)*

Theme	Sub-themes	Frequency
Mental Function	Mental Health	11
	Joy	6
	Happiness	3
Self-management	Self-efficacy	5
	Self-agency	4
Social Support		7
Physical Function		6

***Caregivers' Characteristics Examined with Qualitative Data***

First, the differences that the caregiver characteristics (number of deaths, relationship of caregiver to patient, number of comorbidities) made in the qualitative data are reported. Both groups (single and multiple deaths) endorsed the Mental Function theme the most and the Self-management theme equally (29%). Former caregivers who experienced a single death endorsed the Social Support (43%) and Physical Function (43%) themes at a higher rate than those who experienced multiple deaths (28% and 21% respectively). This may suggest that a lack of a history of prior deaths may highlight the need for a support system or emphasize its loss along with a reflection on one's own health. Both groups (single and multiple deaths) had three participants that endorsed Physical Function which also may stress the importance of reflecting on one's own health in the context of complicated grief or that the caregiver's health was affected by the death. Parents and spouses (including all three males) endorsed the Mental Function theme the most frequently, highlighting the context of which the study was conducted. Only females ( $n = 6$ ) endorsed the sub-theme Joy and ( $n = 7$ ) the Social Support theme and five

of the six who endorsed Physical Function were also females. Taken together, role and gender was found to play a role in perception of meaningful quality of life themes. No patterns were found for number of comorbidities and qualitative data.

### ***Qualitative Data Examined with Caregiver's Characteristics***

Second, when qualitative data provided the analytic anchor for caregiver characteristics, it was noted that the Self-management theme was endorsed six times of which five (83.3%) were spouses. Only spouses endorsed the sub-theme self-agency ( $n = 4$ , 100%) and the majority of participants who endorsed the sub-theme self-efficacy were spouses ( $n = 4$ , 80%). This may suggest that in terms of roles spouses may view their perceived and actual abilities more important than other non-marriage relationships. Of these five, two participants in this study had described finances (Self-management) when asked about the meaning of quality of life and both were wives. This suggests lost of income on the part of the husband as a result of death impacted their perceived quality of life.

### ***Caregivers' Characteristics Examined with Quantitative Data***

Third, the differences that the caregiver characteristics (number of deaths, relationship of caregiver to patient, number of comorbidities) made in the quantitative data will be reviewed. Four participants were atypical in that their quality of life scores remained poor or actually increased (signifying poorer quality of life) at the end of the study. Two participants at the completion of the study, 8-weeks post-completion of therapy, continued to score poorly for quality of life despite intervention for their complicated grief. These two participants reported poor quality of life at the end of therapy with scores of 55 and 85 (diagnostic cutpoint = 42). The former had also reported the suicide of her son within two months of the current study which was

in addition to the loss for which she was receiving hospice counseling. Multiple deaths over a shortened time span may require more sessions to resolve complicated grief. The latter had no change in score from baseline to end of study and had endorsed three of the four themes. Both participants were females and endorsed the Mental Function and Social Support themes. The two other atypical participants had an increase in quality of life scores from baseline to the end of the study, although neither scored poorly at these timepoints. These two endorsed the Physical Function theme and experienced a single death. No other patterns with the caregiver characteristics were found. These atypical cases suggest that a more tailored approach or dose would be beneficial for individuals experiencing complicated grief and that the responses are individualized.

### ***Full Integration of Data Results***

Lastly, when reviewing the caregiver characteristics with the qualitative themes and sub-themes and quantitative quality of life end of study scores and change in scores two interesting findings arose which provide a richer understanding of the changes in quality of life of older adults with complicated grief were noted. First, only four participants (19%) endorsed three quality of life themes. These participants all had reported at least one comorbidity, all endorsed the Mental Function theme followed by 75% endorsing Self-management and Social Support themes. Half reported a decreased (improvement) in quality of life scores over the study period ; however, one reported poor quality of life (score 85) and two fair quality of life (35 and 40) at the end of the study. This suggests that mild chronic illness (having at least comorbidity) may lead to a richer description of quality of life indicating perhaps a greater appreciation of the life that remains. For example, dealing with impairments of the illness or medication side effects can provide a broader context for reflection on the meaning of quality of life. Second, the six

participants that reported a greater decrease (improvement) in quality of life scores (range of improvement 33 to 70 points) reported multiple deaths and endorsed the Mental Function (66.7%) the most frequently. This suggests that the past experience with death may play a role in the responsiveness to treatment or that the lifting of a greater death burden results in improvement of mental health and therefore quality of life.

## **CHAPTER 5**

### **DISCUSSION, IMPLICATIONS AND CONCLUSION**

This final chapter presents a brief synthesis of the results from this dissertation study of quality of life of older adults with complicated grief with discussion of the findings, implications for nursing and research, and a conclusion. Briefly, the purpose of the current mixed methods study was to describe quality of life of older adults with complicated grief via the analyses and then integration of qualitative and quantitative data. This convergent design provided for a more complete understanding of quality of life for older adults experiencing complicated grief (Creswell & Plano Clark, 2018; Schoonenboom & Burke Johnson, 2017).

The data was integrated for further exploration to determine the intersection of caregiver characteristics, quality of life themes and sub-themes, and quantitative scores at the end of study and change in scores over the course of the study.

#### **Discussion**

##### ***Aim #1: Qualitative Description of Quality of Life of Older Adults with Complicated Grief***

Four main themes (domains) for quality of life emerged from the thematic analysis: Mental Function, Self-management, Social Support, and Physical Function. Most participants endorsed only one theme suggesting a unidimensional understanding of quality of life while other informants endorsed multiple themes suggesting a more expansive conceptualization.

These domains are consistent for those reported for older adults in previous studies (Baernholdt et al., 2012; van Leeuwen et al., 2019) and as described by the World Health Organization (2019) and Centers for Disease Control and Prevention (2018) and will be discussed in greater detail below.

In three comparable studies with community-dwelling, older adults (Baernholdt et al., 2012; Henchoz et al., 2015; Levasseur et al., 2009) which included a total of 6,229 participants, three (Baernholdt et al., 2012; Levasseur et al., 2009) to seven (Levasseur et al., 2009) quality of life domains were explicated. These domains were categorized as encompassing internal (cognitive, affective) or external (social, environmental) domains. Internal domains included physical and mental health and emotional wellbeing (Baernholdt et al., 2012; Henchoz et al., 2015; Levasseur et al., 2009), feeling of safety (Henchoz et al., 2015), and autonomy (Henchoz et al., 2015). External domains included social functioning (Baernholdt et al., 2012; Henchoz et al., 2015) and material resources (Henchoz et al., 2015). In keeping with its larger dataset, a recent thematic analysis of 48 qualitative studies ( $n = > 3,400$  older adults living at home, 11 Western countries) categorized nine quality of life domains: autonomy, role and activity, health perception, relationships, attitude and adaptation, emotional comfort, spirituality, home and neighborhood, and financial security (van Leeuwen et al., 2019). The authors emphasized that the domains are interwoven, dynamic, influence one another, and do not present a clear hierarchal order.

Table 14 presents an across case comparison of identified themes from this dissertation to these studies. While nomenclature varied among the quality of life studies of community-dwelling, older adults, groupings were made based on similarities of descriptions; however, overlap was noted. Quality of life was relatively stable in this study despite complicated grief.



Thus, the domains noted in the comparable studies are similar to the ones found in this study; however, what this study adds to this previous work is the exploration of quality of life for older adults in the context of complicated grief. This similarity suggests that there are state qualities to our perceptions of quality of life that grief may blunt but does not extinguish.

**Table 14**

*Comparison of Quality of Life Themes Across Studies with Dissertation*

Dissertation N=29	Levasseur et al., 2009 N=18	Baernholdt et al., 2012 N=911	Henchoz et al., 2015 N= 5,300	van Leeuwen et al., 2019 N=48 qualitative studies
Mental Function	Personal Factors	Physical and Mental Health  Emotional Wellbeing	Esteem and Recognition	Emotional Comfort  Spirituality  Attitude and Adaptation
Self-management			Autonomy	Autonomy  Role and Activity  Financial Security
Social Support	Social Participation	Social Functioning	Social and Cultural Life  Close Entourage	Relationships  Attitude and Adaptation
Physical Function	Personal Factors	Physical and Mental Health	Health and Mobility	Health Perception  Attitude and Adaptation
	Environmental Factors		Feeling of Safety  Material Resources	Home and Neighborhood

As noted in the previous paragraph, quality of life is described in the literature as multidimensional, individualized, and contextual (Baernholdt et al., 2012; Centers for Disease

Control and Prevention, 2018; Mandzuk & McMillan, 2005; Pinto et al., 2017; Rondon Garcia & Ramirez Navarro, 2018; Schalock et al., 2016; World Health Organization, 2021). Therefore, in this study, it was not unexpected that Mental Function was the most frequently endorsed quality of life theme. The interviews were conducted with former family caregivers in the context of complicated grief, a mental health condition, and after receiving Accelerated Resolution Therapy, an evidence-based mental health psychotherapy. Previously frailty has been associated with poorer quality of life in older adults (Crocker et al., 2019). In this study, the sample was relatively healthy with an average of only 1.2 comorbidities and this may explain why Physical Function theme was endorsed the least.

### ***Aim #2 Quantitative Examination of Quality of Life of Older Adults with Complicated Grief***

The quantitative findings from this study support the hypothesis that older adults experiencing complicated grief will report improved quality of life with the completion of Accelerated Resolution Therapy. Quality of life scores decreased (improved) over time from baseline to 8-weeks post-completion and this was statistically significant. Given that these participants were at least 12 months post-death without improvement in their complicated grief prior to the intervention suggests that any improvements were not a function of time, but rather an effect of the intervention. Both time (baseline, end of wait list, with therapy session, and post-completion) and group (immediate Treatment and wait list Control) contributed to the model suggesting that Accelerated Resolution Therapy had a positive effect on participants' quality of life.

Accelerated Resolution Therapy has been successfully used in numerous studies to treat trauma-based conditions such as PTSD and sexual assault (Kip et al., 2016; Kip & Diamond, 2018; Kip et al., 2015; Kip, Rosenzweig, et al., 2013). Only one previous study measured and

found an improvement in quality of life using the SF-36 in participants with PTSD when treated with Accelerated Resolution Therapy (Kip et al., 2016). However, multiple studies have examined associations between complicated grief and poorer quality of life in military service members and veterans (Charney et al., 2018), bereaved caregivers (Boelen & Prigerson, 2007; Breen et al., 2020; Utz et al., 2012; Wenn et al., 2019), and general population of older adults (Newson et al., 2011). To date, this is the first study to use Accelerated Resolution Therapy to treat complicated grief (Buck et al., 2020) and this dissertation presented the data for quality of life in this population. Results suggest that Accelerated Resolution Therapy may improve quality of life along with complicated grief for bereaved family caregivers. Whether reducing complicated grief is the mechanism through which ART improves quality of life needs further examination.

While clear treatment guidelines for complicated grief are lacking (Nakajima, 2018) there are currently other treatment options. For example, Complicated Grief Treatment (Shear et al., 2005) is the most widely implemented evidence-based therapy; however it is provided over a 16-week period and can be costly (Nakajima, 2018; Shear et al., 2014; Tofthagen et al., 2017). In a recent review of the literature of complicated grief (Mason et al., 2020), only one study out of 32 examined quality of life (Lichtenthal et al., 2011); however, it did not include a treatment intervention. In this study, Lichtenthal and colleagues examined bereaved cancer caregivers and use of mental health services and found a significant association between complicated grief and poorer quality of life using the SF-36 (Lichtenthal et al., 2011). So, while the literature is scanty in this area it underscores the importance of this dissertation in filling the gap. Results suggests that Accelerated Resolution Therapy, given in four brief sessions for complicated grief with similar results (Buck et al., 2020) to the more expensive, intensive 16-week Complicated Grief

Treatment, and can potentially improve quality of life in a shorter period of time as well. The lack of studies examining complicated grief and quality of life calls for research including further exploration of quality of life domains such as found in this study.

### ***Aim #3 Integration of Data to Understand Quality of Life of Older Adults with Complicated Grief***

The integration of the qualitative and quantitative data identified potential linkages among the caregivers' characteristics, qualitative themes and sub-themes, final aggregate quality of life scores and change in quality of life scores from baseline to end of study. Of greatest interest were the two participants who scored poorly for quality of life at the end of the study. One of whom reported the additional loss, due to suicide, of a son two months prior to starting the study and the other participant who reported no change from baseline. These two participants present a cautionary tale for the need to develop an understanding in dose response for Accelerated Resolution Therapy that requires greater examination. What is known about these participants is that both also scored poorly (scores of 90 and 85, maximum 90) at baseline and at 8-weeks post-intervention (55 and 85, respectively), were female, and endorsed Mental Function and Social Support as quality of life themes. In addition, while the Charlson Comorbidity Index was used to determine the number of comorbidities for these two participants it does not include psychiatric conditions that may one at risk for complicated grief (Allen et al., 2013; Marques et al., 2013; Shear et al., 2013; Sung et al., 2011). Thus, pre-existing psychiatric disorders, such as anxiety disorders, may have been unaccounted for in the data. Taken together this suggests that for some participants more than four therapy sessions with Accelerated Resolution Therapy may be needed, especially with baseline scores indicating very poor quality of life.

A second interesting finding of the data integration was that while no participants endorsed all four themes nearly one-fifth endorsed three themes. These four participants endorsing three themes had at least one comorbidity. Comorbidities, known to diminish one's perception of quality of life and are linked to a decline in physical status and increased disability and associated health care costs (Makovski et al., 2019; Marengoni et al., 2011; Whitson & Boyd, 2020) may have led to a richer understanding and therefore description of quality of life during the interview. These four participants all endorsed Mental Function and 75% endorsed Self-management and Social support; however, Physical Function was the least endorsed. This can be explained by the consideration of quality of life as multidimensional, individualized, and contextual (Baernholdt et al., 2012; Centers for Disease Control and Prevention, 2018; Mandzuk & McMillan, 2005; Pinto et al., 2017; Rondon Garcia & Ramirez Navarro, 2018; World Health Organization, 2021). Endorsing multiple themes highlights the multidimensionality of quality of life while differences in endorsements supports the subjective, individualized nature of this concept. As stated previously, the study was conducted with former family caregivers in the context of complicated grief, a mental health condition, and that they were relatively healthy with an average of only 1.2 comorbidities. This may help to explain why the Physical Function theme was endorsed the least in this group.

Lastly, other lesser but still interesting findings from when the caregiver characteristics and quantitative data were examined found that participants ( $n = 6$ ) that reported the greatest improvement in quality of life scores (35 to 70 points), all had experienced multiple deaths, a known risk factor for complicated grief (Delaney et al., 2017; Shear, 2012) and may suggest that past experiences with death may improve the responsiveness to treatment. Finally, the majority ( $n = 19$ , 90.5%) reported fair to good quality of life scores at the end of this study suggesting that

Accelerated Resolution Therapy may be an effective treatment for improving quality of life for those suffering with complicated grief demonstrating the negative linear relationship described in Chapter 2.

## **Limitations**

The larger study, and this sub-analysis, noted the majority of caregivers in the sample were female and Caucasian thus rendering it impossible to generalize treatment response by gender and race (Buck et al., 2020). In addition, the parent study also noted limitations due to symptoms of complicated grief for inclusion criteria were via self-report, and follow-up results at 8-weeks post completion to treatment cannot address long-term sustainability (Buck et al., 2020). Data collection took place at one hospice center via referrals by their hospice counselor potentially impacting the generalizability. For these three analyses, the samples sizes were small, also limiting generalizability.

A second major limitation relates to the instrument used to measure quality of life. While the CDC HRQOL-14 is a well-established instrument with significant psychometric work, it was designed for epidemiological populations studies for health surveillance and identifying disparities among sub-populations (Centers for Disease Control and Prevention, 2018; Moriarty et al., 2003). In this study it was used for a sample of former family caregivers completing hospice counseling. This may have resulted in incongruities and lack of responses. Missing data was expected, and the analytic plan addressed this missingness. However, ultimately half the sample was eliminated due to missing values. This may have been a function of confusion and burden as participants had multiple instruments to complete at each study visit. Secondly, The CDC HRQOL-14 was used more frequently as intended (weekly during the intervention vs. monthly) in this study. Originally this instrument was developed for telephone surveys and the

option “I don’t know” was not presented. These weekly, paper-based instruments offered this option, “I don’t know” and may have also contributed to some missing values.

### **Implications for Nursing**

The findings of this study suggest that Accelerated Resolution Therapy can improve quality of life for former caregivers with complicated grief. Findings reinforce the need for nursing assessments of quality of life in the context of complicated grief and on an individualized basis. Nursing plays a vital role in collaboration with other disciplines to put in place appropriate referrals such as to social work, psychology, and hospice counseling. It is recommended that education on complicated grief and quality of life are essential for nurses and other interdisciplinary team members throughout caregiver-caregiving experience and post-death to prepare them for this important role.

Patients’ responses to the questionnaires and interviews in this study also highlighted the multidimensional aspects of quality of life and this can provide insight into the role of providing individualized patient- and family-centered care. The ontology of nursing science is that it has a discipline-specific knowledge base focusing on the human health and wellbeing/wellbecoming (Barrett, 2017). Nursing science with its discipline-specific knowledge generated from theory and research focuses on the human-environment health and healing through caring (Turkel et al., 2018) with the human as the most central concept (Gustafsson, 2006). While little is known about quality of life for those suffering with complicated grief, this ontology of nursing science presents a foundation for nurses and nursing scientists to pursue research endeavors with this focus on the human, their health, and their well-being in the grieving process.

## **Implications for Research**

This study highlighted the need for additional research to explore more fully the effect of complicated grief on quality of life. Findings from the quantitative analysis suggest a need to evaluate valid and reliable quality of life measures for this population that are easy to use and less likely to result in missing data. The CDC HRQOL-14 instrument may have led to confusion and participant burden resulting in missing data, considerations not to be taken lightly.

Future research with larger, more diverse samples is warranted (National Institutes of Health, 2020). The caregiver characteristics in this study are similar to a study of informal hospice caregivers in that the majority were White (93.6%) females (73%) (Washington et al., 2015). National hospice data also revealed that the majority of Medicare hospice patients are White (82.0%) and female (55.1%) (National Hospice and Palliative Care Organization, 2020); however, the majority of care recipients in this study were males. Overcoming implicit biases and barriers to palliative care and referrals (Curseen, 2019; Hawley, 2017) and ensuring a diverse sampling that represents the population of interest can lead to more generalizable findings.

Additional data collection timepoints post-intervention may be warranted to examine sustainment of improved quality of life scores. Other related research may include developing and testing a screening instrument for complicated grief for potential early identification for caregivers at-risk and monitoring along with assessments tool for quality of life to guide patient and family referrals. Further research with Accelerated Resolution Therapy for complicated grief, as noted in the parent study (Buck et al., 2020) is also warranted to present a more time efficient and effective treatment for complicated grief and to determine dosing recommendations.

Lastly, due to the current historical context of living during a pandemic with mandated social distancing, and families restricted from visiting dying family members, studies addressing



the impact of unexpected deaths, multiple deaths, unattended deaths, and lack of typical grief mitigating practices such as funerals on the risk, duration, and presentation of complicated grief may be warranted. The COVID-19 crisis has already resulted in a large death toll and it is estimated that the number of sufferers of complicated grief may equal the number of COVID-19 deaths (Gesi et al., 2020).

Some potential hypotheses to consider testing in future research are:

1. Participants with poor quality of life at baseline will require more therapy sessions than those with good scores at baseline.
2. Early identification for caregivers at risk for complicated grief with subsequent early intervention will decrease the incidence of complicated grief, the duration of the symptoms, and the number of treatments needed for relief.
3. Complicated grief symptoms during a worldwide pandemic would have a greater impact on quality of life than prior to the pandemic.

## **Conclusion**

To address the overall aim of this dissertation, quality of life themes and subthemes were identified via semi-structured interviews, improvement in quality of life as measured by the CDC HRQOL-14 was found, and linkages between caregivers' characteristics, themes and subthemes, and quality of life scores and change in scores were explored. While the results of this study contribute to the body of knowledge related to older adults, caregiving, complicated grief, mind-body therapies, and quality of life, the sample size was modest, warranting further study. This study found that former family caregivers with complicated grief who received Accelerated

Resolution Therapy reported improved quality of life and provides preliminary data supporting further research on the effect of treatment on complicated grief and quality of life.

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## **APPENDICES**

## **Appendix A: Interview Guide**

### **Opening statement to use with all participants:**

I am interested in learning more about your thoughts about your Accelerated Resolution Therapy (“ART”) experience both during and after your ART sessions. Your feedback is valuable and might help us offer ART to others who need support with their grief process. This interview is not a counseling session. I am not a trained counselor. What this interview will do is give you a chance to tell us about “your story” with ART. There are no “right” or “wrong” responses – just your story.

### **Interview questions:**

Before you went through ART what did you expect would happen?

What was your experience with ART?

I’m going to ask a couple of different questions now.

When someone asks you about your “quality of life” what do YOU think they mean?

What effect has your grief had on your day to day life?

On your sleep?

*Has there been any change in your sleep patterns since ART and if so, how did it change?*

On your appetite?

On your getting out and around with friends?

How did these change after ART?

How would you describe how you and your [care partner] handled routine, daily tasks together? It could be working on taxes OR it could be taking care medications or diet. Did you work together, did one or the other take the lead, or did you just fight.

Did [the person whose death you have been working on] require admission to an intensive care unit during a hospitalization and you spent at least 24 hours as a visitor.

Can you tell me about that person’s experience (for example, were they on a ventilator, were they confused?)

Can you tell me about your experience (for example, what was stressful, were you able to sleep?)

How did this ICU experience effect you?

I'd just like to ask a final question: Is there anything that you would like to tell me about your experience with ART that we haven't talked about yet?

## Appendix B: CDC HRQOL-14

**Instructions:** Please answer each question listed below.

1. Would you say that in general, your health is: (Check one response)
  - a. \_\_\_\_\_ Excellent
  - b. \_\_\_\_\_ Very good
  - c. \_\_\_\_\_ Good
  - d. \_\_\_\_\_ Fair
  - e. \_\_\_\_\_ Poor
  - f. \_\_\_\_\_ Don't know/not sure
2. Now thinking about your **physical health**, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
  - a. \_\_\_\_\_ Number of days
  - b. \_\_\_\_\_ None
  - c. \_\_\_\_\_ Don't know/not sure
3. Now thinking about your **mental health**, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
  - a. \_\_\_\_\_ Number of days
  - b. \_\_\_\_\_ None
  - c. \_\_\_\_\_ Don't know/not sure
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?
  - a. \_\_\_\_\_ Number of days
  - b. \_\_\_\_\_ None
  - c. \_\_\_\_\_ Don't know/not sure

**The next questions are about physical, mental, or emotional problems or limitations you may have in your daily life.**

5. Are you LIMITED in any way in any activities because of any impairment or health problem?
  - a. \_\_\_\_\_ Yes – *Continue to Question 6*
  - b. \_\_\_\_\_ No – *Skip to Question 10*
  - c. \_\_\_\_\_ Don't know/not sure – *Skip to Question 10*



6. What is the MAJOR impairment or health problem that limits your activities? (**check only one**)

- a. \_\_\_\_\_ Arthritis/rheumatism
- b. \_\_\_\_\_ Back or neck problem
- c. \_\_\_\_\_ Fractures, bone/joint injury
- d. \_\_\_\_\_ Walking problem
- e. \_\_\_\_\_ Lung/breathing problem
- f. \_\_\_\_\_ Hearing problem
- g. \_\_\_\_\_ Eye/vision problem
- h. \_\_\_\_\_ Heart problem
- i. \_\_\_\_\_ Stroke problem
- j. \_\_\_\_\_ Hypertension/high blood pressure
- k. \_\_\_\_\_ Diabetes
- l. \_\_\_\_\_ Cancer
- m. \_\_\_\_\_ Depression/anxiety/emotional problem
- n. \_\_\_\_\_ Other impairment/problem
- o. \_\_\_\_\_ Don't know/Not sure

7. For HOW LONG have your activities been limited because of your major impairment or health problem?

- a. \_\_\_\_\_ Days
- b. \_\_\_\_\_ Weeks
- c. \_\_\_\_\_ Months
- d. \_\_\_\_\_ Years
- e. \_\_\_\_\_ Don't know/Not sure

8. Because of any impairment or health problem, do you need the help of other persons with your PERSONAL CARE needs, such as eating, bathing, dressing, or getting around the house?

- a. \_\_\_\_\_ Yes
- b. \_\_\_\_\_ No
- c. \_\_\_\_\_ Don't know/not sure

9. Because of any impairment or health problem, do you need the help of other persons in handling your ROUTINE needs, such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

- a. \_\_\_\_\_ Yes
- b. \_\_\_\_\_ No
- c. \_\_\_\_\_ Don't know/not sure

10. During the past 30 days, for about how many days did PAIN make it hard for you to do your usual activities, such as self-care, work, or recreation?

- a. \_\_\_\_\_ Number of days
- b. \_\_\_\_\_ None
- c. \_\_\_\_\_ Don't know/Not sure

11. During the past 30 days, for about how many days have you felt SAD, BLUE, or DEPRESSED?

- a. \_\_\_\_\_ Number of days
- b. \_\_\_\_\_ None
- c. \_\_\_\_\_ Don't know/Not sure

12. During the past 30 days, for about how many days have you felt WORRIED, TENSE, or ANXIOUS?

- a. \_\_\_\_\_ Number of days
- b. \_\_\_\_\_ None
- c. \_\_\_\_\_ Don't know/Not sure

13. During the past 30 days, for about how many days have you felt you did NOT get ENOUGH REST or SLEEP?

- a. \_\_\_\_\_ Number of days
- b. \_\_\_\_\_ None
- c. \_\_\_\_\_ Don't know/Not sure

14. During the past 30 days, for about how many days have you felt VERY HEALTHY AND FULL OF ENERGY?

- a. \_\_\_\_\_ Number of days
- b. \_\_\_\_\_ None
- c. \_\_\_\_\_ Don't know/Not sure

## Appendix C: Demographics Form

1. What is your current age in years? \_\_\_\_\_
2. What is your gender?  
\_\_\_\_\_ Male  
\_\_\_\_\_ Female
3. What is your marital status?  
\_\_\_\_\_ Married/partnered  
\_\_\_\_\_ Separated  
\_\_\_\_\_ Divorced  
\_\_\_\_\_ Widowed  
\_\_\_\_\_ Single/Never Married
4. What is your annual household income?  
\_\_\_\_\_ Less than \$25,000/year  
\_\_\_\_\_ \$25,000 - \$49,000/year  
\_\_\_\_\_ \$50,000 - \$74,000/year  
\_\_\_\_\_ More than \$75,000/year  
\_\_\_\_\_ Prefer not to answer
5. Years of formal education completed.  
\_\_\_\_\_ Less than high school/high school  
\_\_\_\_\_ Some college/technical  
\_\_\_\_\_ Associate degree  
\_\_\_\_\_ Bachelors' degree  
\_\_\_\_\_ Graduate degree
6. What is your race? (check all that apply)  
\_\_\_\_\_ American Indian/Alaskan Native  
\_\_\_\_\_ Asian  
\_\_\_\_\_ African American  
\_\_\_\_\_ Native Hawaiian/Pacific Islander  
\_\_\_\_\_ White/Caucasian  
\_\_\_\_\_ Other or unknown
7. Are you of Hispanic ethnicity? \_\_\_\_\_ No \_\_\_\_\_ Yes
8. What is your current employment status?  
\_\_\_\_\_ Full-time employee  
\_\_\_\_\_ Part-time employee  
\_\_\_\_\_ On leave of absence  
\_\_\_\_\_ Retired  
\_\_\_\_\_ Disabled  
\_\_\_\_\_ Other

9. How many times have you been hospitalized since your loved one passed away? ☐ None  
☐ 1 time  
☐ 2 times  
☐ 3 or more times
10. How many times have you visited a physician or health care practitioner since your loved one passed away? ☐ None  
☐ 1 time  
☐ 2 times  
☐ 3 times or more
11. Regarding your loved one who passed away, what was their admission to hospice diagnosis?

## Appendix D: Charlson Comorbidity Index

Please answer the following questions **REGARDING YOURSELF**:

1. Have you ever had a heart attack? .....No Yes
2. Have you ever been treated for heart failure? (You may have been short of breath and the doctor may have told you that you had fluid in your lungs or that your heart was not pumping well.) ..... No Yes
3. Have you had an operation to unclog or bypass the arteries in your legs?..... No Yes
4. Have you had a stroke, cerebrovascular accident, blood clot or bleeding in the brain, or transient ischemic attack (TIA)? ..... No Yes
- 4a. **If yes,** do you have difficulty moving an arm or leg as a result of the stroke or cerebrovascular accident? .....No Yes
5. Do you have asthma? .....No Yes
- 5a. **If yes,** do you take medicines for your asthma (check one)? .....No Yes, only with flare-ups Yes, I take medication regularly, even when I'm not have having an attack
6. Do you have emphysema, chronic bronchitis, or chronic obstructive lung disease? ..... No Yes
- 6a. **If yes,** do you take medicines for your lung disease (check one)?.....No Yes, only with flare-ups Yes, I take medication regularly, even when I'm not have having an attack
7. Do you have stomach ulcers, or peptic ulcer disease? .....No Yes
- 7a. **If yes,** has this condition been diagnosed by endoscopy (where a doctor looks into your stomach through a scope) or an upper GI or barium swallow study (where you swallow chalky dye and then x-rays are taken)?.....No Yes

8. Do you have diabetes (high blood sugar)? (check one)  
 .....No      Yes, treated by      Yes, treated by      Yes, treated by  
                                  modifying my      medications      insulin injections  
                                  diet                                   taken by mouth
- 8a. **If yes**, has the diabetes caused problems with your kidneys? No    Yes
- 8b. **If yes**, has the diabetes caused problems with your eyes,  
 treated by an ophthalmologist .....No    Yes
9. Have you ever had the following problems with your kidneys?
- Poor kidney function (blood tests show high creatinine) .....No    Yes
- Have used hemodialysis or peritoneal dialysis.....No    Yes
- Have received kidney transplantation .....No    Yes
10. Do you have rheumatoid arthritis? .....No    Yes
- 10a. **If yes**, do you take medications for it regularly? .....No    Yes
11. Do you have lupus (systemic lupus erythematosus) .....No    Yes
12. Do you have polymyalgia rheumatica .....No    Yes
13. Do you have any of the following conditions?
- Alzheimer's Disease, or another form of dementia .....No    Yes
- Cirrhosis, or serious liver damage .....No    Yes
- Leukemia or polycythemia vera .....No    Yes
- Lymphoma.....No    Yes
- AIDS.....No    Yes

## Appendix E: IRB Approval Letter



### APPROVAL

March 4, 2020

Harleah Buck  
12901 Bruce B. Downs Blvd. MDC22 Tampa, FL  
33612-4766

Dear Dr. Harleah Buck:

On 3/3/2020, the IRB reviewed and approved the following protocol:

Application Type:	Modification / Update
IRB ID:	Pro00032358_MOD000006
Review Type:	Expedited
Title:	Accelerated Resolution Therapy for Treatment of Complicated Grief in Senior Adults
Funding:	National Institute on Aging
IND, IDE, or HDE:	None
Approved Protocol:	• <a href="#">Protocol 10 clean 2.27.20.docx</a>

The modifications, as described by the study team below, have been approved: Tina Mason,

PhD student and team member will be conducting a pre-planned sub-analysis involving the already collected quality of life data for dissertation under my supervision. The protocol has been updated to reflect this.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely, Shanitra

Butler  
IRB Research Compliance Administrator

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### Institutional Review Boards / Research Integrity & Compliance

FWA No. 00001669

University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813- 974-5638

Page 1 of 1

## Appendix F: Codebook

### Codebook

#### Quality of Life in Senior Adults with Complicated Grief Receiving Accelerated Resolution Therapy

Quality of life, as currently defined, is a subjective statement of how good or bad a person's life is. Health is defined as the general condition of the body or the condition of being sound in body, mind, and spirit usually in the context of thriving and doing well.

#### The question to answer:

To describe how senior adults with complicated grief receiving accelerated resolution therapy define their quality of life.

#### Key aims of study to include in codebook:

The quality of life domains are physical health, mental health, ability to perform usual activities, social support, and spirituality. Includes major impairment and its effect on personal care; routine needs; pain; feeling sad, blue, depressed; feeling worried, tense anxious; rest/sleep; feeling very healthy and full of energy, having available sources of support, and feeling a sense of hope and/or meaning to life.

1. Physical health
  - a. Definition: subjective report on how good or bad one's physical health is; quality or state of being active in usual day-to-day activities
  - b. Includes:
    - i. **Physical** fitness
    - ii. Able to perform activities of daily activities without problems; self-care and personal care needs, such as eating, bathing, dressing, getting around the house
    - iii. Work
    - iv. Recreation
    - v. Feeling rested/enough sleep
    - vi. Full of energy
  - c. Excludes:
    - i. Physical illness
    - ii. Injury
    - iii. Impairment
    - iv. Pain impacting usual activities
    - v. Assistance/help with household chores, doing necessary business, shopping, or getting around for other purposes



- vi. Tired, exhausted
  - d. Example: “Health”
2. Mental health
- a. Definition: the condition of being sound mentally and emotionally; the general condition of one's mental and emotional state
  - b. Includes:
    - i. Adequate adjustment especially as reflected in feeling comfortable about oneself
    - ii. Positive feelings about others
    - iii. Ability to meet the demands of daily life
    - iv. Being/feeling useful
  - c. Excludes:
    - i. Mental illness
    - ii. Stress
    - iii. Sadness, feeling blue, depression
    - iv. Problems with emotions
    - v. Feeling worried, tense, anxious
  - d. Example: “Emotional well-being”, “Healthy state of mind”
3. Social Support (friends and family)
- a. Definition: perceived availability of support, affections, and instrumental aid from significant social partners, including family members, close friends, neighbors, and coworker
  - b. Includes:
    - i. Emotional support (affection, acceptance, or approval)
    - ii. Instrumental support (assistance with self-management or financial support)
    - iii. Informational support (education, advice, information)
    - iv. Affirmation support (validating self-care-related behaviors and efforts)
    - v. Getting out and about, support system.
  - c. Excludes:
    - i. Lack of external support system
    - ii. Unable to maintain social relationships
  - d. Example: “Enjoy being out with friends and getting out for lunch.”
4. Self-agency
- a. Definition: The act or power of making one’s own choices or decisions
  - b. Includes:
    - i. Independence
    - ii. Self-governance
    - iii. Having control over making decisions without undue influence
    - iv. Self-management

- v. Financial means to meet wants and needs
    - vi. Having enough money to cover emergencies and future financial goals
  - c. Excludes:
    - i. Dependence
    - ii. Governed
    - iii. Coercion, pressure, duress, force
    - iv. Unable to afford wants (e.g., personal excursions) or needs (e.g., home expenses)
    - v. High financial burden
  - d. Example: “Doing things for yourself, following your dreams, doing things you are interested in.” “Able to pay bills.”
5. Self-efficacy
- a. Definition: One’s belief in one’s ability to succeed in specific situations or accomplish a task
  - b. Includes:
    - i. Effectiveness
    - ii. Success, successfulness
    - iii. Productiveness
    - iv. Potency, power,
    - v. Value, virtue
  - c. Excludes:
    - i. Inefficacy
    - ii. Unsuccessful
    - iii. Inability, inadequacy
    - iv. Incompetence
  - d. Example: “Being needed by my children.”
6. Happy
- a. Definition: feeling of showing pleasure or contentment
  - b. Includes:
    - i. Contented, content, satisfied
    - ii. Cheerful, merry, merry
    - iii. Carefree, untroubled
  - c. Excludes:
    - i. Sad
    - ii. Unfortunate
  - d. Example: “Being happy”. “Happiness”
7. Joy
- a. Definition: A feeling of great pleasure
  - b. Includes:
    - i. Delight

- ii. Great pleasure
  - iii. Joyfulness, jubilation
  - iv. Triumph
  - v. Rejoicing
- c. Excludes:
  - i. Misery
  - ii. Despair
  - iii. Trial, tribulation
- d. Example: “Experience of joy deep from within the soul”

## **ABOUT THE AUTHOR**

Tina M. Mason has over thirty years of experience as a registered nurse with extensive experience in oncology. Currently, she is a Nurse Researcher at the H. Lee Moffitt Cancer Center in Tampa, FL. Prior to this she was an oncology clinical nurse specialist for 20 years at the same cancer center. She earned her Bachelor of Science in Nursing from Mt. Saint Mary College in 1990, her Master of Science in Nursing in the oncology clinical nurse specialist track from Yale University in 1996, and her post-master's certificate as an Oncology Nurse Practitioner from the University of South Florida in 2003. She holds two advanced practice oncology certifications and is a fellow in the Clinical Nurse Specialist Institute. In April 2021, she was awarded the Oncology Nursing Society's Excellence in Advanced Clinical Practice Award. Her research interests include caregivers, both formal and informal, oncology patient care, and quality of life. Her doctoral degree was partially funded by a scholarship from the Oncology Nursing Society.