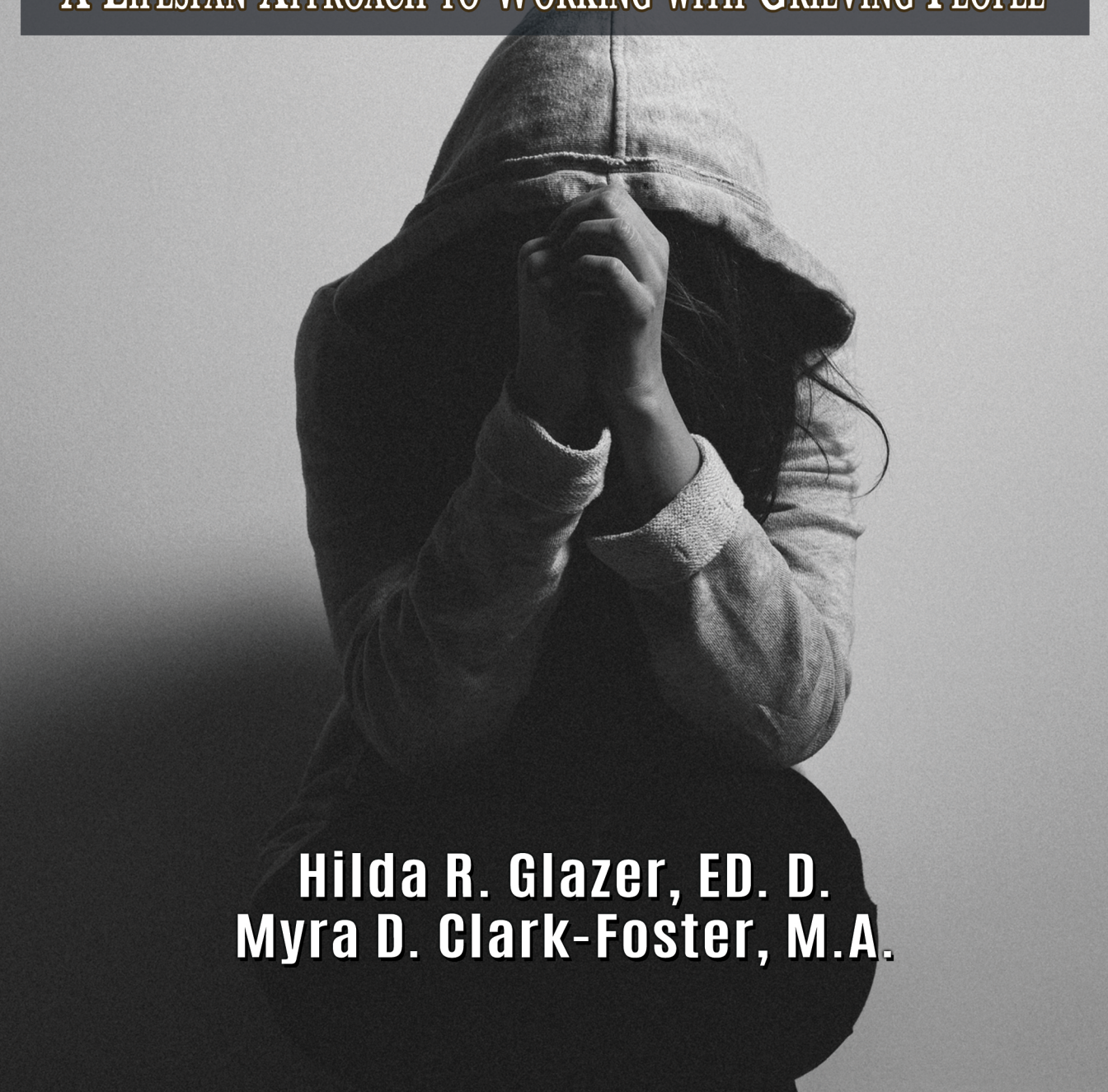
UNDERSTANDING THE JOURNEY

A Lifespan Approach to Working with Grieving People



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FOREWORD

Grieving has no rules, no prescribed course, or expiration date. Family members, well-meaning friends, and even professionals may offer advice after a death, tell you to "Get over it," or "He's in a better place now." I was 27 years old and pregnant with my first child when my husband died. We had dated since high school, and were married for five years. My son was born the following week, and I still, 34 years later, recall the words of others: "At least you have your son to replace him." "You're still young, you can get married again." And, "You'll get over it someday." I didn't want to get over it. He was the love of my life and the father of the son he'd never know. Don't tell me how to feel.

It was very difficult for me to express the feelings of loss, loneliness, and rage. I got through it with the support and process that allowed me to grieve in my own way, at my pace, and just knowing there were families and professionals who would allow it.

The authors of this book, *Understanding the Journey: A Lifespan Approach to Working with Grieving People,* understand that all losses are managed in diverse ways, and grief takes many forms of expression and physical manifestation. They are all experts in the field of Hospice and Palliative Care and have nearly a century of combined clinical experience. I am honored to have worked with many of these professionals over the years, and know their passion, skills, and commitment to aiding or companioning grieving individuals within a culture that can stifle emotional responses. Their ability to create a supportive environment that normalizes the phases of grief guides these expert interventions and support described in the chapters. Through case examples and clinical expertise, the authors describe experiences and share tools to help enhance coping and encourage healing. Their book will be a significant resource to add to any professional's tool kit for grief counseling and support.

In my 35 years of working in health care, and the past 16 in Hospice and Palliative Care, I observe the death-denying culture we have in the United States. Such a culture further complicates responses to death and necessitates ongoing training and mentoring for professionals working with individuals

diagnosed with advanced or terminal illness and their family members and friends after a death. This becomes especially important after a traumatic death and the secondary losses that follow. I have educated many physicians, students, and allied health care professionals over the past 30 years to enhance their patient-centered care, and understanding of palliative care, hospice and related grief responses. The Hospice movement continues to be a change agent, across the continuum of medical care. However, we won't truly validate and normalize grieving until we consistently improve how people leave this life, and do so with the same comfort, love, and support as when they entered this life.

Lori Yosick, MSW, LISW-S, CHPCA
National Director for Community Palliative Care, Trinity Health
And widowed at age 27

INTRODUCTION

This book addresses a need we identified as clinicians while working with grieving families. In our work at hospice, we met multigenerational families from diverse backgrounds. Our goal was to accompany all family members of all ages on their grief journey. We wished for a book that used a lifespan approach and provided practical, evidence-based guidance that we could apply to our work. In addition to the books written by experts in bereavement, we gratefully acknowledge there has been significant research and a variety of books based on that research. But what we wanted was something in addition.

A lifespan approach means that grief is certainly a journey from which none of us ever escapes nor perhaps reached closure. Rest assured, life can be quite good again following the inevitable loss of a precious friend, coworker, spouse, child, pet, or other individual special to us. First, we must choose to live and actively participate in the work of mourning during our grief process. As many have said, the only way out of grief is to go through it—hence the verbiage that grief is a journey.

Grief is often revisited at pivotal points during one's development throughout the lifespan. While the grief may not feel as raw at those times, it will be nonetheless felt as real. We are passionate about the opportunity to share our experiences and the many lessons learned from our clients. These lessons nurtured our passion and stoked the fire in our hearts to be the best clinicians possible. We continue to learn and recognize that we will never arrive at a place of complacency.

We have worked together in bereavement care for over a quarter of a century, and this book honors that time together and the families we have journeyed with during that time. We also hope to honor the compassionate, dedicated, and courageous professionals at Mount Carmel Hospice and Palliative Care in Columbus, Ohio, that we worked with since its founding by Mary Ann Gill, RN, MA, LPCC-S.

Therefore, our book describes the various responses of how we care for these souls based on the nature of their grief. The intent of this book is to take the reader on the grief journey from anticipatory grief, to understand-

ing the basic components of grief and its phases. While undergoing this pathway, the reader will become a participant in the bereaved's travels by also learning about the developmental process for a grieving child.

A chapter dedicated to the self-care by the bereaved and also for the clinician will emphasize how to build resilience. Grief care is exhausting and all who participate must engage in quality-of-life activities and rituals that are personally meaningful to them. Chapters on interventions provide the reader with healing methods to enable the bereaved to identify meaning and purpose for their life that is left.

To accomplish this task, we selected chapter authors who had extensive involvement in various areas of grief practice. We knew these authors would come from a place of commitment regarding importance of their work, and would share their experiences and approaches from their area of competency so that each chapter provides knowledge pertinent to that area of grief.

From our work, we have developed a deep respect for the uniqueness of each person's journey. We recognize that each individual brings to this journey the totality of their experiences and beliefs. We also know that grief is a whole-body experience. Thus, we have included the spiritual, emotional, psychological, and physical aspects of the person's grief while companioning them on their distinctive journey. The objective is to share the experiences and knowledge of our authors to aid you in companioning the grieving family or individual.

We have also included chapters that reflect contemporary issues. The chapters look at grief after death in the military family, deaths due to drug overdoses, and violent death. These are the tragic deaths of our time. We are particularly grateful to those who were willing to describe their experiences, stories, and feelings with us.

Most chapters will include evidence-based research and case studies to support the information presented in that chapter. However, there needs to be more research concerning the value of applying the arts in the grief treatment plan. These are the expressive therapies. The arts might include dance, yoga, and other movements, music, photography as well as drawing, painting, and writing. The arts chapter will address only a portion of the expressive therapies—drawing and painting.

Research in any clinical field is necessarily limited due to the ethics of client privacy. Grief often begins at the diagnosis of an illness and shows up throughout the course of care. For others, grief begins when the death is sudden or unexpected.

It is our hope this book will be used by grief clinicians as well as those clinicians who do not identify grief care as their area of expertise. The book may be particularly helpful to interns and others new to grief work. In addition, families might find the contents of this book to be useful in increasing

their understanding of their own unique process and the clinician's approach in responding to their sacred story.

Reading may raise more questions, and that is good. It may be helpful to keep a journal while reading and seek out resources that can be useful in your quest to evolve into your best. And, when the information recalls a situation of a client or someone else dear to you, remember them with compassion and apply that same compassion to yourself.

Myra D. Clark-Foster
Hilda R. Glazer

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We gratefully acknowledge everything we have learned from the families who attended the Evergreen Program of Mount Carmel Hospice and Palliative Care developed in 1988 after the inception of Mount Carmel Hospice in 1985. We also want to recognize the encouragement and support of our husbands, Howard A. Foster, Jr. and David Stein, Ph.D.

CONTENTS

UNDERSTANDING THE JOURNEY

Chapter 1

THE PHYSICAL ASPECTS OF GRIEF

Walter Ferris

Joe, a 30-year-old, athletic, extremely physically fit, local police officer comes to my office as a new patient complaining of a six-month history of generalized fatigue with difficulty concentrating. He also complains of nausea and abdominal pain. He has no previous history of difficulty with these symptoms. He has been a policeman for six years, loves his work and hopes to become a sergeant soon. He has not changed assignment recently, has no chronic illnesses and has not lost weight. He is meticulously dressed in his uniform. He is quite worried these symptoms may be from an occult cancer or other progressive disease. He denies any symptoms of depression or generalized anxiety stating he continues to perform well in tense, acute situations. As I review his social history and ask about his marital status, he tells me his wife of five years died suddenly in an automobile accident six months ago. Joe was not with her at the time and was notified by one of his partners who was called to the accident scene. Calmly and stoically, Joe tells me he is doing fine and is adjusting to the loss. "Life must go on. What else can you do?" He does not believe his symptoms are related to his wife's death. Several serial visits later, after a thorough physical exam and some simple screening tests, I assure Joe that he does not have cancer. Joe accepts my gentle probing about his relationship with his wife, the events surrounding his wife's death and his functioning since her death. He begins to accept my framing his symptoms as the awful, major shock of his wife's death producing real physical changes in his body, despite his excellent fitness, good health and emotional strength. Joe never talks much about feelings, never cries and always is neatly dressed and "in control." As I follow Joe with less frequent but regular office visits, his symptoms gradually improve, he starts running again and he reminisces more about his wife, once even getting a little "misty eyed."

Although Joe is a policeman whose defense mechanisms of repression and denial serve him well to manage the everyday emotional trauma of his inner-city police work, they do not effectively help him adjust to his wife's sudden death. Unable to openly express his feelings of shock, loss, yearning and loneliness, these feelings emerge as physical symptoms. Yet Joe is one of many of my grieving patients who complain of similar physical symptoms. Even patients who are introspective, who openly express their sadness, pain and loss, and actively pursue the work of mourning, complain of physical symptoms. Bereavement is an all-encompassing experience. No part of a person's being is spared from its life-changing effects, not the emotional, spiritual, relational or physical parts.

Much of the past and current grief literature appropriately focuses mostly on the intense emotional and spiritual challenges of the work of mourning for a grieving person, but only briefly mentions the physical aspects of the grief process. To provide the best, most healing care for those struggling with the grief process, grief counselors, social workers, chaplains, pastors, and medical clinicians need to collaborate as much as possible to provide a systemic approach to grief support, helping their grieving patients manage the challenges mourning brings to their emotional, spiritual, relational and physical beings. While one grief clinician will not likely possess all the skills needed to address these challenges; two or more usually will, with effective, coordinated communication and collaboration. This chapter will address the physical aspects of bereavement and how—by using a practical, collaborative approach—grief clinicians can integrate management of physical symptoms and illness into healing total-grief care.

The myriad emotional, spiritual and relational challenges of bereavement are well described in other chapters in this book. A grieving person must process and adjust to these challenges, revising their internalized representation of the person lost to incorporate the reality of their death and establish a forward-focused life without them; a life that accommodates or integrates grief (Gundel, O'Connor, Littrell, Fort, & Lane, 2003; Shear & Shair, 2005). The bereaved often call this life a "new normal." A grieving person must also process and adjust to the physical challenges of bereavement, learning to accept grief-triggered symptoms as part of their physical adjustment to the loss while not ignoring or misattributing physical symptoms due to new or chronic illness. Spouses or partners must adjust to the loss of physical sexual intimacy and find different healthy ways to express their physical sexuality. They may often need to develop new self-care skills and habits, particularly if the person lost took much of the responsibility for managing the grieving person's diet, activity, medication and/or health care. The physical challenges of establishing a "new normal" can often be as dif-

ficult or even more difficult than the emotional, spiritual and relational challenges of bereavement (Zisook & Shear, 2009; Strada, 2009).

PHYSICAL EFFECTS OF BEREAVEMENT

Even with appropriate spiritual and psychosocial adjustments to loss, the physical effects of bereavement are profound. Although the absolute number of bereaved persons who die is fairly low in the first year, bereavement is associated with an increased risk of death (hazard ratio 1.25), even after controlling for chronic medical conditions, age, sex, smoking status and access to support (Shear, Reynolds, Simon, & Ziso, 2018). Surprisingly the risk is even higher in individuals with no significant comorbid illness (hazard ratio 1.50) (Shah, Carey, Harris, DeWilde, & Cook, 2012). Losing a spouse, child, or sibling are each associated with an increased risk of dying. The risk is even higher when one loses a spouse unexpectedly, more so than when one loses a spouse with known terminal illness. Individuals lose on average 12 percent of residual life expectancy after loss of a spouse (van den Berg, Lindeboom, & Portrait, 2011). The most common causes of bereavement-related deaths are cardiovascular diseases and cancer (Shear et al., 2018).

Cardiovascular Disease

Acute myocardial infarction risk increases immediately after the loss (Carey et al., 2014; Mostofsky et al., 2012). One retrospective study of patients with myocardial infarction (n = 1985) found that within one day of the death of a significant person, the risk of myocardial infarction was 21 times greater than the risk 31 to 180 days after the death. This elevated infarction risk persisted up to 30 days after the onset of bereavement (Mostofsky et al., 2012). Increases in heart rate, systolic blood pressure and cortisol in the first few weeks after bereavement may be the cause of this increased risk (Buckley, McKinley, Tofler, & Bartrop, 2010; Buckley et al., 2011). Acute bereavement can truly result in death from a broken heart. Takotsubo syndrome, an abnormality of cardiac contraction in a person with normal coronary arteries, triggered by the physiologic changes noted above, primarily occurs early in bereavement in older women experiencing a sudden, unexpected loss. Despite life-threatening complications such as sudden congestive heart failure or arrhythmia during the early phase of bereavement, this syndrome usually completely resolves over time (Shinning, Keller, Abegunewardene, Kreitner, & Munzel, 2010).

Cancer

Although cancer incidence does not appear to be increased in bereaved individuals, the rate of dying from cancer is much higher. Multiple studies demonstrate higher rates of cancer-specific death in widows with gastric (Zhou, Yan, & Li, 2016), colon (Li, Gan, Liang, Li, & Cai, 2015), thyroid (Xu et al., 2017; Shi, Qu, Lu, Liao, & Gao, 2016), uterine and vulvar cancers (Lowery et al., 2015; Wu et al., 2018), chondrosarcoma (Gao et al., 2018), renal cell cancer (Li, Zhu, & Qi, 2018), and glioma (Long, Li, Ou, & Li, 2018). Currently, the neurophysiologic mechanisms for this association are not clearly defined.

Immune System

A bereaved person's immune system also becomes depressed during the initial period of mourning. The stress response to grief increases cortisol levels which suppress neutrophil (white blood cell) antibacterial activities leading to an increased frequency and severity of bacterial infections. Another hormone, dehydroepiandrosterone sulfate, DHEAS, counters this suppressive effective of cortisol; but DHEAS levels naturally decrease as one ages. A 70-year-old has a DHEAS level around 10 to 20 percent of the level of a 30-year-old. As a result, elderly individuals have a much higher risk of dying of bacterial infections during the grief process. Unfortunately, grief counselling does not lower this risk (Khanfer, Lord, & Phillips, 2011; Buckley et al., 2012).

Alcohol and Suicide

As noted in other chapters of this book—in bereaved individuals—the risk of alcohol-related deaths and suicide are almost twice the risk in nonbereaved individuals. Several studies report bereavement is associated with suicidal ideation and behavior that is unrelated to preexisting mental illness such as major depression or post-traumatic stress disorder (PTSD) (Shear et al., 2018). A national registry study (n >9000 suicide deaths and 180,000 matched controls) that adjusted the analysis for psychiatric disorders, found the risk of suicide eight times greater among individuals whose spouse died in the prior two years, compared with individuals whose spouse was alive. The risk in males was approximately three times greater than females (van Denderen, de Keijser, Kleen, & Boelen, 2015). Death of a loved one by suicide further increases the risk of suicide in the bereaved. Death of a loved one by homicide or suicide also increases the risk of complicated grief, major depression, PTSD, and substance use disorders in the bereaved. The