DEVASTATING LOSSES

How Parents Cope with the Death of a Child to Suicide or Drugs

William Feigelman  |  John R. Jordan
John L. McIntosh  |  Beverly Feigelman
Advance Praise for *Devastating Losses*

This volume is a pioneering and long overdue work, a study not only of grieving parents who lost children to suicide but also of parents whose children succumbed to drug overdoses. The authors have done a masterful job of blending their quantitative research findings and the anguished voices of parents attending survivor support groups to create a rich and very engaging book. Their scope is huge as they discuss the unique characteristics of traumatic loss, how stigma affects grief and healing, the impact of multiple losses, early and later years after losing a child, the essentials of bereavement support groups (including Internet groups), posttraumatic growth and resilience, gender differences in grieving parents, and how losing a child affects marital function and continuance. Clinicians who read *Devastating Losses* will come away with enhanced empathy, essential new insights, and a skill set that will give sustenance and hope to these shell-shocked yet courageous parents on a bumpy journey of recovery and repair, a journey they never asked for.

—*Michael F. Myers, MD*, professor of clinical psychiatry, SUNY Downstate Medical Center, Brooklyn, New York, and author (with Carla Fine) of *Touched by Suicide: Hope and Healing After Loss*

Taking a journey out of their own heart of darkness, the Feigelmans, along with researchers Jack Jordan and John McIntosh, have blazed a trail of enlightenment for survivors of sudden, traumatic loss and suicide and for those who work with them. This book breaks new ground while establishing pathways yet needing to be mapped in the landscape of surviving. This is much more than an important book; it is an essential book.

—*Lanny Berman, PhD*, executive director, American Association of Suicidology
Devastating Losses: How Parents Cope With the Death of a Child to Suicide or Drugs is an incredibly important book for many reasons. As a carefully conducted study, it helps bridge the gap between research and practice—truly this is research that matters. This research offers powerful information and clinical tools to assist counselors in helping parents deal with the devastating and disenfranchising losses when a child dies due to his or her own self-destructive behaviors. Clinicians, educators, and researchers will need this book.

—Kenneth J. Doka, PhD, professor, The College of New Rochelle, and senior consultant, The Hospice Foundation of America

Devastating Losses is what survivors of suicide have long been waiting for: a compassionate yet scientifically based study on the grief we experience following the loss of a loved one to suicide. The stories, research, and insights in the book helped me personally and will certainly provide comfort and understanding to others as well. By breaking through the stereotypes and stigma surrounding suicide and other sudden and unexpected deaths, the authors open the door for us to begin our healing with both dignity and courage.

—Carla Fine, author of No Time to Say Goodbye: Surviving the Suicide of a Loved One

Grounded equally on solid clinical practice and uniquely relevant research, and tragically leavened by the personal bereavement of two of the book’s authors, Devastating Losses sheds new and compassionate light on the experience of a child’s death due to traumatic causes. Readers will find in these pages the stories of many who have suffered the unspeakable loss of a son or daughter to suicide, drug overdose, or fatal accident and who have struggled with and often surmounted the subsequent symptoms and stigmatization with the help of family, peer support, online communities, and, sometimes, professional help. This book is for all parents who experience the tragedy of sudden bereavement and all those who try to help them, as they reach through suffering to survivorship and from grief to growth in the journey.

—Robert A. Neimeyer, PhD, editor of Techniques of Grief Therapy: Creative Practices for Counseling the Bereaved and Grief and Bereavement in Contemporary Society: Bridging Research and Practice
Devastating Losses
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Devastating Losses
How Parents Cope With the Death of a Child to Suicide or Drugs

William Feigelman, PhD, John R. Jordan, PhD, John L. McIntosh, PhD, and Beverly Feigelman, LCSW

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This book is for Jesse and all other children lost to untimely deaths and their parents who were brought down to the depths of despair. May their parents be able to rekindle hope for a better future and sufficient energy to work with others in society, to diminish the numbers of these deaths, and spare others the agony and grief that they know only too well.
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Foreword

For those who have lost a child to suicide, this book will provide a life ring for their unique journey down this dangerous river of suicide. For the clinician who seeks to be a resource or a guide to those who have begun this journey, it will be a map that can help provide clinical support and understanding necessary for a safer trip. For anyone in a community who wants to be there for those experiencing the bereavement problems associated with a child’s suicide, it may help them keep the survivor inside the boat.

Doctors Feigelman, Jordan, and McIntosh, and Beverly Feigelman have taken us into the most treacherous area of bereavement, the loss of a child to suicide. This reality, which impacts so many parents each year, is the tsunami of grief. It is held up as the worst scenario one might ever experience and the most difficult to bear. The generous work compiled in this text will enable anyone in the community seeking to support someone who has lost a child to suicide to accomplish their goal more readily. It will also allow those who have gotten a call or found their child having taken their life to not feel the void of hope and know that they can survive this loss that so many survivors have experienced. Anyone who reads this book can find ways to contribute support to those who receive the sad news of a suicide loss. Parents who lose a child this way become members of a new community of suicide-survivors and they may need a diverse variety of supports to outlast their grief.

The authors bring not only a wealth of knowledge about research and suicide but for William Feigelman and his wife Beverly, this is also their personal story. Their son Jesse’s suicide has immersed them in this devastating loss and by their sheer will to understand his death by suicide, they have fought to find a safe passage through their own unique streams of grief and have helped others in the process.

This book will ensure that the reader has the information necessary to not only survive but to manage their lives effectively after their loss—with a renewed sense of self. The loss of a child, especially when it follows a suicide death, inevitably requires the mourning parents to re-invent themselves afterwards. This is not an easy journey nor is the outcome guaranteed; however, like most journeys, preparation and knowledge increase the survival rates of those who are cast into the water.

By using the chapters presented as a guide to deepen their knowledge, parent survivors may be able to avoid some of the pitfalls and barriers that most parents who experience the death of a child to suicide often encounter.
There is also important information for those who want to be supportive to the newly bereaved. Because bereavement following suicide is filled with paradoxes (opposites being true) and those who want to provide much needed support may need guidance themselves—the information in this book can improve the bereavement trajectory of the people they wish to support. In many cultures we do not readily accept oppositional viewpoints. We expect behavior to make sense and be logical. This is not what the research has found. Some seemingly logical assumptions about suicide (for example about finding the body) might not impact on the bereaved in the same way or with the same consequences as assumed by those in supportive roles. Therefore, providing support without more insight can be less than helpful and in some cases may create harm. It is clear to those of us who have had the privilege of working with parents who have suffered this grief that many of those who wish to be supportive do not have the tools they need to provide adequate support. A classic example of one of the paradoxes of this bereavement are attempts to encourage the bereaved to talk openly about the death by asking various questions about “why it may have occurred.” Yet, it may be more supportive to a newly bereaved to simply listen to them, similarly offering to do what is helpful (“Just let me know if there is anything I can do”) may not be as valued as doing what is needed (“I have brought groceries and will fix dinner for tonight”) and especially to listen nonjudgmentally to a story that may need to be told over and over again.

The information offered in this book on the initial days after the loss will perhaps help caregivers more than the newly bereaved, as many survivors are so deeply absorbed in their grief and unable to concentrate enough to read or comprehend each section. However, it will be a valuable resource throughout the grief process, which can predictably last and be revisited for a very long time. Recognizing that what is important in the first year may be less important in the second and later postloss years will be essential to reducing expectations about grief. It is for this and many other reasons that this book will be a valued resource for the parents and caregivers to return to re-reading sections throughout their lifelong grief journeys.

More than 40 years ago Dr. Edwin Shneidman suggested that the deceased “hang their psychological skeleton in the survivors emotional closet” (p. x, 1972). For the first time in all the intervening years, these authors have provided the reader a well-researched and informed view of the psychological and emotional closets of suicide-bereaved parents. Their work will provide a much-needed compass for those who are cast into this complex bereavement and help steer them safely from the edge of a very dangerous journey.

If *Devastating Losses* ended here the rewards for its readership would be sufficiently bountiful. But, fortunately for those who explore this volume, the wide-ranging perspectives offered here—across different important, neglected subjects in the bereavement field—provide readers with many new insights about grief and bereavement and about the impact of traumatic losses more
comprehensively. In many ways this is a ground-breaking work. Among the subjects investigated is drug overdose death bereavement, whose mourners may actually outnumber those bereaved-by-suicide, who again, paradoxically, have attracted little attention among bereavement researchers, despite their many unmet needs for bereavement support and services. For the first time we hear from nearly 50 drug-death bereaved parents who report on their postloss travails. Initially, we might have expected these mourners to have experienced more supportive responses from their intimate associates than those bereaved-by-suicide, as their children died “accidental deaths,” much like automobile accident casualties or victims of drownings. Yet, again, paradoxically, the taint of illegal drug use and its associations with mental illness puts a strong negative spin on these deaths, leading some close friends and family members to recoil and avoid the bereaved parents afterwards or to say thoughtless and even blameworthy things about the deceased child and the parental care prior to the death. Thus, bereaved-by-drug-death parents find themselves placed in a similar boat as the bereaved-by-suicide, isolated, stigmatized, and deeply ashamed of their children’s death causes. Like suicide-bereaved parents, many feel reluctant to speak openly about their children’s deaths because of the censure it may evoke and assume a posture antithetical to the development of a sense of psychological wellness.

This book also brings into sharper focus a number of other important neglected topics in the bereavement field. These subjects are occasionally mentioned as important ones for study but little empirical data have been collected on them. The authors explore how bereaved parents that sustain multiple losses (either from the loss of two children or from the loss of a spouse and a child) manage their grief afterwards, compared to the parents who lost a single child; how parents who lost their only child adapt afterwards, compared to parents who still have surviving children. Only-child-bereaved-parents must carve out new types of family forms that make sense to them, without any living children. Another topic taken up here is how traumatic child deaths affect marital integrity and cohesion afterwards. These divergent bereavement subjects intersect and overlap with each other. The authors broad-ranging perspectives are valuable for providing all subgroups of traumatically bereaved parents with the best and most appropriate kinds of help needed. In this way *Devastating Losses* helps both the bereaved and their caregivers, by offering a more complete and detailed understanding of the bereavement process, so essential to promoting a smoother healing after the loss of a child.

Another important shortcoming, and another paradox, in the professional bereavement literature that does not correspond well with bereavement realities is fortunately addressed in this volume. Bereavement scholars stand in almost universal agreement on the point that bereavement will be a lifelong process for the mourner. Yet, few studies have extended beyond the reach of 5 years after the loss. Here, for the first-time, we find solid empirical data from almost 250 suicide-bereaved parents who averaged 10 years
postloss, who provide much informative detail about the longer-range impact of child loss.

This analysis leads us two ways. First, it takes us to the unfortunate conclusion that there will remain a small minority of bereaved parents, who suffer from their suicide-losses of children to such an extent that they will remain permanently hurt psychologically from their losses. Higher rates of reported depression and poor mental health were reported among these 10-years-or-longer postloss survivors than other nonbereaved parents in the general population. For these bereaved parents ready access to professional mental health services will be needed to help them over their lifelong grief adaptation course.

Most longer-term suicide-bereaved, however, will not need such help for their grief-related issues. The majority group of survivors will adapt well after their children’s suicide deaths, finding new life goals, a renewal of their sense of purpose and some new friends in their postloss lives that will be decidedly different from who and how they lived prior to the death. They will experience occasional waves of sadness and yearning for their lost children, especially at holidays and commemorative date times. Yet, with the help from the communities of other survivors and with access to other healing help like professionals, psychics, and clergy, most will manage well. Some will express their new sense of purpose within the bereavement communities, helping the newly bereaved, but many will find other important spiritual or social issues with which to invest themselves beyond the bereavement arena.

Most traumatic-loss bereaved parents start their healing from a perceptual field of feeling utterly vanquished from their losses. Thus, they begin healing facing a challenge that this adaptation may represent the single most imposing trial they have ever assumed in their lives. Yet, as we have heard from so many bereaved parents in this book, and with the profound help they offer each other with their grief and coping struggles, most succeed in finding hope again and are able to move forward, setting new life goals and renewing their sense of purpose. From the many accounts provided by these survivors, we see there are ultimately better days ahead as time after losses passes and a myriad number of small curative social forces bring survivors along on their healing journeys.

Until this book was written many parents had to travel their healing journeys without much assurance that they could survive this trip, believing they were engaged in a mostly singular effort to heal on their own. Now, parents who read this text will know that what they thought was uncommon and rare, may not have been so unusual when contrasted against the responses given by other survivors. They will also see, in sharp relief from other survivors’ responses, the uniqueness of their own losses. Thus, each healing journey will differ and not everything experienced will be the same for some, as it may be for others on this same journey.
Foreword

It is sometimes said that each death has a life of its own, i.e. its distinctive characteristics. Traumatically bereaved parents are especially vulnerable after the death of a child. They often question their judgement and decision-making abilities. Well intentioned, but perhaps less well-informed, friends and family members may advise them, “Isn’t it time you gave away your son’s clothing now?” and the bereaved parent will wonder whether they should be doing this. Yet, within the bereavement community, and in close association with many other similar mourners, survivors learn there is no timetable for “letting go” of things. Bereaved parents learn they must follow the needs for their own self-care first. Thus, they learn that the uniqueness of their losses will be as complex as the relationships they had with the children they lost. Seeing their distinctiveness, against the contrasting responses of bereaved others, helps survivors from falling prey to feelings of isolation in grief. This, in turn, helps promote more self-confidence, better decision-making abilities, and psychological health; it may also aid survivors from ultimately becoming additional casualties to depression, high-risk and self-destructive behavior patterns and even their own suicides. Thus, what these authors have gathered in this important research effort are the voices of those who have been on this journey and have survived. Other survivors who have found their voices are often the best resource to those who are now starting their own journeys to survive the traumatic death of a child.

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REFERENCE
Acknowledgments

Many hands and hearts went into this book. We are so grateful to the many bereaved parents, nearly a thousand in total, who generously gave their time to answer our very demanding 27-page survey or who participated in interviews. We are so thankful for the enthusiastic support we received from so many, who wrote in additional comments or added important qualifiers to further clarify their survey answers. Some even went to the trouble of including additional typed pages and stapled these to their surveys to fully explain why they answered particular questions in given ways. We were also greatly helped by the postloss memoirs that eight respondents generously offered to help us more fully understand the nature of their healing journeys. These demonstrations of enthusiastic interest and support from our respondents helped to sustain us during this long and sometimes arduous intellectual and analytical journey.

In addition, we are keenly appreciative of our many sponsors, people who helped us along the way—some repeatedly, as we sought respondents to complete our surveys. These people showed exceptional support to publicize our study and placed their own credibility on the line to encourage bereaved parents to complete surveys. They helped us find particular types of respondents, such as drug overdose bereaved parents, parents who lost an only child, those who had never used therapies or support groups, and so on. Most of these sponsors came from the ranks of support group facilitators, clinicians, and suicide prevention organization personnel: Karen Anderson, Donna Barnes, Anita Becker, Iris Bolton, Karyl Chastain-Beal, Fred Fox, Gail Fox, Carol Greenberg, Ron Hall, Walter Katz, Marilyn Koenig, Phyllis Kosminsky, Sandy LaCagnina, Ann Marie Mairorana, Karen Marshall, Sherry McGinnis, Melinda Moore, Karen Opp, Jane Quencia, Gloria Schramm, Arthur Silverman, Elaine Stillwell, and Pat Wittberger. Without the repeated help of some of these most generous and committed sponsors, our sample never would have been as large and diverse as it eventually became.

Ana Ruth Colon completed the mammoth enterprise of coding all 575 surveys, reducing each from its original 27 pages into a 3-page form of more than 400 places of bubble-coded markings for scanning. She also diligently transcribed the many comments offered by respondents into machine-readable Excel files for later data analyses. On many occasions, we needed to revisit the original surveys and the accompanying electronic records, and we were always struck by the remarkable correspondence between both, indicating rare coding errors. Bob Reily, of Nassau Community College MIS,
also offered us invaluable help with scanning the code sheets into ASCII data files. Bob’s perseverance and technological know-how enabled us to get accurate records from antiquated scanning equipment that would have been abandoned by any profit-making company but which, unfortunately, was the best available at NCC at that time.

As an early member of our research team, Bernard S. Gorman, professor of psychology at Nassau Community College, offered us valuable help with our project. Helping to design our research instruments, programming the statistical software to compute our numerous scales and measures, he was an invaluable statistical consultant during the formative stages of this project. Gorman also helped to create tables and graphics displaying our findings, assisted greatly in preliminary analyses of early papers, and offered valuable methodological counsel and support during the formative and developmental stages of this work.

We would not have been able to complete the analysis of Internet support groups in Chapter 11 without the very generous help and support of Karyl Chastain-Beal. She encouraged us to complete a survey of the parents of suicide (POS) group membership and helped to facilitate it by continually posting reminders to members about our survey so that within 3 months, 200 members had completed our survey. We are also grateful to Tom Taylor of the Nassau Community College Academic Computing Services for creating our easy-to-take survey on the NCC file server. Both Taylor and Anthony DeLouise helped us to administer this survey with a maximum of ease and efficiency, fully protecting respondents’ confidentiality.

We, our four-author team, assume full responsibility for all errors. For each of us, this project has represented an attempt to advance the knowledge base about how bereaved parents repair their lives after the traumatic loss of a child. Our past experiences have shown us that the information presently available for clinicians and the bereaved themselves is woefully inadequate to the immense challenge presented by a traumatic loss of a child to any bereaved parent. Survivors and clinicians alike deserve a broader perspective and more comprehensive information than what is currently available. None of us were paid to do this work; yet, each of us felt a sense of urgency to provide richer, more detailed, and evidence-based information for all concerned parties—the bereaved, their friends and families, and clinicians/caregivers and researchers—who are concerned with a suicide or a drug overdose death. It is in this spirit of fostering the development of a more solid base of social science knowledge about this important but neglected group of bereaved persons that we offer the present work.
Theoretical Issues Guiding This Study and How the Data Were Collected

THE PLAN OF THIS BOOK

This chapter focuses on the theoretical issues guiding this research and explains how the data were collected. In this first chapter we set the stage for our remaining analyses, which focus on how parents cope and repair their lives after the traumatic death of a child.

Part I, which includes Chapters 2 through 5, focuses on the nature of the trauma that parents experienced. In each of these chapters we investigate how a different kind of traumatic death or the distinct circumstances of the death can bring about differences in outcomes for parent survivors, leaving some with greater grief difficulties, complicated grief, posttraumatic stress, and mental health problems compared to other child-loss survivors. Chapter 2 covers suicide stigmatization, widely discussed as an obstacle in any survivor’s healing course, as survivors struggle with their loss being discredited in the eyes of some (or many) of their socially significant others. In Chapter 2 we investigate the pervasiveness of stigmatization as it affects suicide survivors, wherein particular significant others are likely to stigmatize the survivor and whether this shunning has a measurable impact on a survivor’s healing processes, grieving, and mental health problems. In Chapter 2 we also compare whether suicide survivors experience more stigma than other child-loss survivors. Chapter 3 investigates the bereavement difficulties of parents who experienced the loss of children from drug overdoses and other drug-related deaths. We compare this group of parents to suicide survivors and parents sustaining losses of a child from other causes of death. In Chapter 3 we gauge
the pervasiveness of drug overdose deaths compared to other deaths of young adults. We also compare and contrast the stigmatization experienced by these parents and examine whether they confront any greater or different challenges of stigmatization compared to other parents experiencing traumatic and non-traumatic losses of children. Chapter 4 delves into some of the additional death circumstances surrounding a suicide that may have an impact on bereavement—for example, whether the bereaved parents found the body, had a history of prior suicide attempt experiences with their child before suicide completion, or had a close or conflicted relationship with their child before the death—and how these experiences may be associated with different bereavement outcomes. In Chapter 4 we also evaluate how time after the loss is associated with reductions in a suicide survivor’s grief difficulties. Chapter 5 explores another poorly understood bereavement phenomenon: parents who sustain the loss of their only child and the question of whether they experience any different or greater bereavement difficulties compared to bereaved parents with surviving children. In addition, we also explore whether parents who sustained multiple death losses in their families (e.g., the death of two children or of a parent and a child, closely following each other) experience any greater or different bereavement problems compared to parents who lost one child.

In Part II we investigate the different kinds of help-seeking resources survivors use along their healing journeys as they cope with their grief and try to advance to a new normal after the death of a child. Recognizing the profoundly disturbing pain of early loss, we devote Chapter 6 to the help-seeking behaviors survivors usually pursue in their first years after a loss. Early grief often brings survivors to a desperate quest to seek help from a wide variety of sources: grief counselors, support groups, pastoral counselors, psychics, and so on, or sometimes several different support groups or counselors are visited at the same time. In Chapter 6 we examine survivors’ usage patterns during these early difficult years and the resources perceived as most and least helpful to them. In Chapter 7 we turn our attention to the later years after loss, another poorly researched and understood subject, when most survivors accept their grief as an enduring feature of their lives. Most available studies cover bereavement adaptations taking place within the first 5 years after the death. In Chapter 7 we focus on bereaved parents who averaged 10 postloss years. In later years after loss, we find survivors usually narrow their help-seeking to fewer resources and diminish their attachment to any single resource. In Chapter 7, we also pose the question whether longer term child-loss survivors experience more enduring mental health problems when compared with their peers in the population at large who have not experienced child losses. Chapter 8 takes us to a close-up look at peer support groups for suicide survivors, one of the most popular arenas where survivors seek grief help after a suicide loss. Chapter 8 takes an overview of the many psychosocial needs of survivors addressed in peer support groups, examining the many benefits survivors experience through participation in such groups. In Chapter 9 we identify the
characteristics of those survivors for whom these groups offer little grief help, and we also explore the transition process and the social characteristics of those survivors who are more likely to rely on these groups. In Chapter 9 we also explore support group termination and how, as the time after a loss passes, many survivors outgrow these groups and withdraw from them, whereas a smaller number of survivors assume positions of support group leadership. Chapter 9 also delves into the qualities of support group leadership and other group features that promote beneficial group functioning. Chapter 10 focuses on the posttraumatic growth that many survivors experience years after their loss. Our findings suggest that posttraumatic growth is associated with better mental health for survivors. In Chapter 10 we identify those social characteristics associated with the development of survivors’ posttraumatic growth. Chapter 11, the last chapter in this section, examines a relatively new resource for survivors: participation in Internet support groups. In Chapter 11 we contrast the social and loss-related differences between those seeking grief help from other survivors in online groups with others who seek grief help exclusively in face-to-face groups or from other sources. This analysis generally shows that Internet support group affiliates devote much more time to their groups than members of face-to-face groups. In addition, Internet affiliates have usually experienced greater stigmatization, grief, and other mental health difficulties than face-to-face members. Thus, Internet support groups appear to offer these survivors valuable help that is not readily available to them elsewhere.

In Part III we investigate the impact of a child’s traumatic death on married couples. Chapter 12 explores how men and women deal differently with grief after the loss of a child and how this may affect spousal relationships afterward. In Chapter 12 we explore the differences between men and women regarding grief difficulties, complicated grief, posttraumatic stress disorder (PTSD), and mental health problems after losing a child. We also explore gender differences in seeking grief help and support. This analysis of gender differences sets the stage for the next chapter, Chapter 13, where we examine spousal relationships after the traumatic loss of a child. We explore whether the loss brings a married couple closer together or drives a wedge between them. In Chapter 13 we also investigate those shared social characteristics that may have an impact on marital discord (or harmony) after the loss.

In Part IV, our final chapter, entitled “Where Do We Go From Here?” we suggest directions for future research based on our current findings. In Chapter 14 we also sum up the important practical implications of this study as it suggests better ways for survivors to cope with loss and to advance their healing afterward.

THEORETICAL ISSUES GUIDING THIS RESEARCH

If there were an array of questions propelling us forward with this inquiry, it was to investigate whether parents sustaining the traumatic death of a child stand at a higher risk of premature mortality and whether they are more likely
to have any greater mental health, grief, and other problems than other child-
loss survivors.

With our heavy reliance on our bereaved parent survey and interview
data, we knew we would be unable to say very much from these sources about
the premature mortality of parents who lost children to traumatic deaths. Yet,
this is a question that often arises in the mind of a bereaved parent: Are they at
risk for dying prematurely? We, therefore, felt it necessary to review the avail-
able literature on this important question.

First, we should clarify our terms of what may constitute “a traumatic
death” of a child. Arguably, it might be advanced that any death of a child
is a traumatic one because it goes against the natural order of life where par-
ents ordinarily expect to predecease their children. Yet, when a child dies after
repeated unsuccessful surgeries to treat a faulty heart valve or a progressive
decline in functionality associated with an aggressive cancer, an inoperable
brain tumor, an acute asthmatic attack, or diabetic complications, such cases
usually offer parents advanced warnings of their child’s mortality risks. In
many of these cases, parents may have had long and painful histories of wit-
tnessing declines in their child’s health, as he or she may have been shuttled
from home to hospital (or to hospice care) and to eventual death. Probably a
substantial portion of child deaths recorded on death certificates as attribut-
able to natural causes could be termed less traumatic deaths, where parents
had varying degrees of awareness of their child’s fragile health and dimin-
ished ability to survive. Of course, some natural deaths leave parents totally
surprised and unprepared for the fatality, such as a single lethal attack from a
brain aneurysm.

In this research traumatic deaths are defined as those listed on death certifi-
cates occurring with varying degrees of suddenness and violence. Sudden, un-
expected, and violent deaths bring about more traumas. The standardized U.S.
death certificate lists five different death cause classifications: natural causes,
accidental deaths (such as automobile accident deaths, drownings, poison-
ings, etc.), homicides, suicides, and deaths under ambiguous circumstances
(“undetermined” deaths; Hetzel, 1997). It is our assumption throughout this
study that most parents accept the definition of their child’s death designated
by their local medical examiner or coroner. They may not share this informa-
tion fully and correctly with everyone they know, but they will usually share it
accurately with many, if not most, of their socially significant others.

Let us take a look at the frequency of individuals who experience traum-
atic and natural deaths among the U.S. population who are likely to have
living parents. We computed these numbers from the Web-based Injury Sta-
tistics Query and Reporting System (WISQARS) website, maintained by the
Centers for Disease Control and Prevention. The WISQARS database enables
users to investigate deaths occurring in 2008. If we look at the deaths of people
surviving the first year of life and dying by age 50 (and thus likely to have
living parents), we see almost as many traumatic deaths cases ($N = 97,457$)
as those dying from natural causes ($N = 106,477$; Centers for Disease Control
and Prevention, 2011). Thus, there are substantial numbers, probably close to 200,000 parents every year who will be added to the ranks of traumatic death survivors, having lost one or more of their children to a suicide \(N = 21,652\), homicide \(N = 14,988\), or an accidental death \(N = 60,817\), dying within the age range of 1 to 50 years. These numbers quickly mount to the millions as the total of youth and adult child deaths accumulate over the years.

When we began this inquiry into traumatic child death bereavement, with our somewhat less conventional method of gathering a sample primarily from the ranks of various general bereavement support groups and from the rosters of survivor of suicide (SOS) support groups, we expected to draw in at least some bereaved parents who had lost children to homicides. We expected this for several reasons. One of our principal resources for our respondents was The Compassionate Friends, a general bereavement group with many local chapters explicitly offering grief support to parents sustaining losses of a child to homicide (www.compassionatefriends.org). Given the relatively high frequency of U.S. homicides among the young, we anticipated some of these parents would inevitably become respondents in our sample. In addition, drawing upon (SOS) support groups, we anticipated some numbers of parents who had experienced a murder/suicide death of a child to inevitably join our sample. Given the extensive media coverage of murder/suicide cases, we thought (SOS) groups would attract at least some of these bereaved parents to seek grief help.

Yet, oddly, as our sample rose to more than 500 cases, only four parents who had lost a child to a homicide were included, and we did not encounter a single parent from a murder/suicide case. Despite its frequent media coverage, we discovered the reality of murder/suicide is exceedingly rare. As suicides themselves are relatively uncommon events in the United States, with an annual rate of approximately 11 per 100,000 persons, the murder/suicide rate is especially rare, with a rate of 0.2 to 0.3 per 100,000 or about 1,000 to 1,500 cases yearly (Marzuk, Tardiff, & Hirsch, 1992). Had we extended our recruitment efforts of traumatic loss survivors to the dedicated support groups serving the bereavement needs of parents sustaining homicide losses of children, such as the U.S. Parents of Murdered Children (www.pomc.com) or Loved Ones Left After Murder in Great Britain (www.lolam.org), we would have been able to recruit potential respondents from these organizations. However, because of the small number of homicide survivors who became part of our sample, it was not possible to provide any useful information about this important subgroup.

Let us now return to the important questions stimulating this inquiry. What does the previous research tell us about whether parent survivors from all child deaths stand at a higher risk for their own premature mortalities (compared to nonbereaved parents)? Do parents of traumatic death losses have higher mortality than people whose children died from nontraumatic causes? Only three previous studies were found that attempted to answer these questions. One early study of child loss conducted with a British sample of more than 900 cases found excess mortality for bereaved parent survivors compared
to their nonbereaved peers (Rees & Lutkins, 1967). However, these results contrast sharply with an Israeli study that found no differences in mortality between bereaved and nonbereaved parents (Levav, Friedlander, Kark, & Peritz, 1988). More recently, a Danish study (Li, Precht, Mortensen, & Olsen, 2003) based on a national registry matched a sample of more than 21,000 bereaved parents against a control group of more than 29,000 nonbereaved peers and found the following: “(T)he death of a child is associated with an increased mortality from both natural and unnatural causes in mothers, and an early increased mortality from unnatural causes in fathers” (p. 363). Thus, these results are mixed and do not help us arrive at any firm conclusion regarding whether any premature death of a child is associated with a diminished life expectancy and whether a traumatic death of a child has any special significance in this respect. Thus, these important questions remain unresolved and deserve further exploration in future research.

**STUDYING A MORE APPROACHABLE QUESTION**

A more approachable question for us to consider is whether parents experiencing traumatic deaths of children stand at higher risk for grief and other mental health difficulties as compared to others sustaining nontraumatic losses of children. Up to this time, those wishing to review this issue within the context of drug overdose deaths and drug-related deaths have not been able to find much guidance from previous research. The question has never been considered explicitly within this population. Now, if one wishes to approach this question in relation to suicide bereavement, there are at least some opportunities to gain an overview of how suicide survivors compare against other groups of survivors. However, one will need to be especially cautious before making any inferences from this research record because of the many differences between previous suicide bereavement studies. Past studies have yielded many diverging findings and all these are perfectly understandable, considering the many studies being completed at different times and focusing on diverging objectives, having differing samples, sampling methods, control populations, and loss relationships, and using differing measurements, along with the existence of very few longitudinal studies.

In an ambitious synthesis of many of the diverse research findings on suicide bereavement, Sveen and Walby (2008) were able to extrapolate several convergent themes from this confusion. Scouring all similar studies cited in MEDLINE from over a 60-year period and from an even longer period from psycINFO and applying minimalist criteria for inclusion (studies had to include suicide survivors, include another bereaved group as controls, be quantitative, and be published), they found 43 studies to fit their criteria. Their assessment of overall findings showed no significant differences between suicide survivors and people bereaved by other causes of death in terms of general mental health, depression, PTSD symptoms, anxiety, and suicidal behavior.
Chapter 1  Theoretical Issues Guiding This Study

The comparisons on overall levels of grief were less clear. When measures developed specifically regarding suicide bereavement were included, the suicide survivors reported higher levels of rejection, shame, stigma, and a need for concealing the cause of death than controls.

As helpful as Sveen and Walby’s (2008) results may be in summarizing overall patterns, they do not reduce the confusion when we examine a particular type of loss relationship, such as the loss of a child. Of the 43 studies fitting their minimalist criteria, only seven explicitly focused on parents sustaining the suicide death of a child. One of these seven focused on family functioning and did not deal explicitly with grief and mental health issues. Six others of the seven studies of parental suicide bereavement drew comparisons to other traumatic child-loss populations, such as to parents bereaved by homicide and accidental deaths. We would consider both of these bereaved parent populations as traumatic death survivors. Thus, only one previous study (Miles & Demi, 1991–1992) explicitly compared parent suicide survivors ($N = 62$) to natural death survivors ($N = 38$) and found higher guilt among the suicide survivors compared to their natural death–surviving counterparts. Throughout our investigation we will use all available previous bereavement studies to help us better illuminate how our specific findings may mesh with the past research record.

What is striking about the Sveen and Walby (2008) work is the relative paucity of studies collected from their extensive online searches. Only 69 studies were uncovered that had any potential for inclusion in their review, of which 43 were chosen when selection criteria were met. Previous research offers a meager number of studies—seven in all—that have dealt with the matter of parental suicide bereavement, a matter that affects some 40,000 to 60,000 surviving parents each year based on the yearly suicide frequencies among decedents who might be imagined to have living parents. This says a great deal about the virtual neglect of suicide survivors by behavioral scientists in their choice of participants. It is no small wonder that in 2003, the National Institute of Mental Health (NIMH) sponsored a special conference among suicidologists to help stimulate more research on suicide bereavement (National Institute of Mental Health [NIMH], 2003).

Suicide survivors appear to be a greatly neglected population in the field of suicidology. Sometime ago, Edwin Shneidman estimated six survivors for every case of suicide (Shneidman, 1969), which probably was a drastic undercounting of survivors because a more recent random-digit-dial phone survey implied approximately 13 million Americans knowing someone who took his or her life in the past year, of whom 2.2 million knew an immediate family member or other relative who had taken his or her life (Crosby & Sacks, 2002). Research has also documented that suicide survivors have a higher risk of self-harm and suicide compared to the nonbereaved (Agerbo, 2003; Mościcki, 1995; Runeberg & Asberg, 2003). Yet, despite their demonstrated greater risk of self-harm, relatively little research has been conducted with this population.
If one were to undertake a similar literature review of all studies of people dying by suicide compared to people dying by other causes of death over a 60-year period (much like the review Sveen & Walby, [2008] conducted—but on suicide directly) one would uncover many times more studies on this topic than the paltry number of 69 found on suicide bereavement. Any cursory examination of the journals devoted to suicidology shows that the bulk of the work generated has been devoted to suicide explicitly, with very few articles focused on bereavement after suicide.

Drug overdose bereavement, another substantial problem affecting hundreds of thousands of new mourners each year and rivaling suicide as a frequent cause of death among youth, is another greatly neglected subject. We made exhaustive online searches on MEDLINE and psycINFO and were able to find only two previous studies on drug overdose bereavement. Both studies were preliminary studies, undertaken on small samples, completed outside the United States: one, a Brazilian study based on six cases (da Silva, Noto, & Formigoni, 2007) and the other, a British study based on four cases (Guy, 2004). This very meager previous research record contrasts very sharply with the hundreds of epidemiological studies of overdose drug decedents themselves, examining the diverging combinations of drugs consumed, differing locales where the deaths occurred, treatment exposures, social characteristics and life histories of the decedents, and so on. Somehow, bereaved families sustaining the loss of family members to drug overdose appears to have failed to attract the interest of researchers. Why behavioral scientists have ignored these risk populations is an interesting and important question to which we will return at a later point in this introduction. Readers less interested in the details of how the data were collected, characteristics of survey sample, measurements, and additional data sources may wish to scan over or skip this next section and go to the final part: “Thoughts on the Difficulties of Doing Traumatic-Loss Research.”

**STUDY METHODS, SAMPLE CHARACTERISTICS, AND MEASUREMENTS**

**Quantitative Data Sources and Methods**

Before seeking to distribute our survey among different groups of bereaved parents, the study protocol was reviewed and approved by the Nassau Community College Institutional Review Board. Each respondent received a mailed survey kit consisting of a cover letter outlining the overall goals of the research, a consent form, a survey form, and a postpaid return mail envelope.

As we began this study, we sought to gain a large and diverse sample of parents who lost children to traumatic and nontraumatic death causes. We also sought to better represent survivors in the community at large who used peer support groups. Suicide survivors were an important targeted population for our research, and we sought to better represent survivors participating in peer support (SOS) groups. Thus far, only one survey research study
has been conducted specifically with this population (Callahan, 2000). With the listings of support groups from the American Association of Suicidology (AAS) and the American Foundation of Suicide Prevention (AFSP), we attempted to include support group members from most regions of the country. Several facilitators were initially contacted and were asked either to furnish their membership lists or to publicize information about the study at meetings, in their newsletters, or on their electronic list serves. Typically, support group facilitators posted announcements in their newsletters calling for volunteers to participate in a confidential and anonymous survey of parent survivors. Volunteers were directed to contact the first author who was identified as both a sociologist and a survivor of his son’s suicide.

In seeking contrast populations for the parent suicide survivors investigated here, we sought to include parents who lost children to other sudden death causes, such as automobile accidents, drug overdoses, accidental drownings, homicides, and so on. We also sought to include cases of child death from natural causes, such as brain aneurysms, cancers, heart disease, AIDS/HIV, and so on. To represent these additional groups of other traumatic and natural death cases, we also made contacts with chapters of The Compassionate Friends groups from where we acquired not only cases of parents losing children from other-than-suicide-death causes but also additional parent suicide survivors. The Compassionate Friends groups, existing throughout the nation, are general bereavement support groups open to parent survivors of all types of child deaths.

We also sought to include traumatic loss survivors using Internet-based support groups. Two such suicide survivor groups were contacted and gained respondents: The Parents of Suicide Support Group (www.parentsofsuicide.com) and the Parents Grieving Children of Suicide Group, which presently no longer functions. We also contacted and gained respondents from two Internet support groups serving survivors of drug overdose deaths: Angels of Addiction, Inc. (www.groww.org/Branches/angelsofaddiction.htm) and Grief Recovery After a Substance Abuse Passing Group (widely known as GRASP; www.grasphelp.org). The present survey is the first ever to investigate survivor support affiliates using the Internet.

The following newsletters and list servers played crucial roles in circulating information about our survey: the SPAN USA list server, the Friends For Survival Inc. Newsletter, and the “Surviving Suicide” newsletter published by AAS. These outlets reached large audiences of survivors and clinicians. In addition, several bereavement counselors and psychologists also asked to distribute copies of the survey among their patients. Also, many survivors who learned of the study by word of mouth spontaneously offered names of additional respondents who they thought would want to complete the survey.

By drawing our sample primarily from the ranks of those with past or present affiliations to support groups, there may be bias overrepresenting survivors with more mental health difficulties. This possibility has been advanced in two earlier analyses (Levy & Derby, 1992; Stroebe & Stroebe,
1989–1990). We sought to correct this possible bias in the following manner. Almost every respondent was asked, in the course of our data collection, to furnish their e-mail addresses, and close to 400 e-mail addresses were collected from this solicitation. Using a “snowball” technique, toward the end of the data collection period, all respondents were sent an e-mail asking if they knew of another child-loss survivor who, to the best of their knowledge, had neither used support groups nor had seen professional mental health or bereavement counselors. They were asked to contact this person, and upon obtaining that person’s permission, they, in turn, would be sent survey kits. Eight more survivors became survey respondents from these additional recruitment efforts. When these respondents were added to the numbers that we obtained from the marital pairs subsample (to be described in the next few pages) and from those who learned about our study because they were newsletter subscribers, the data collection eventually included 37 respondents who reported never participating in a peer support group or having any form of postloss professional counseling. Bereaved parents who never had peer support group contact or professional help have rarely been studied previously. In Chapter 6 we investigate the distinctive characteristics of this lesser known bereaved parent population.

We also encouraged respondents to have their spouses or partners complete surveys. The cover letter accompanying every survey stated that if any respondent wished to have an additional survey mailed to his or her home for a spouse or partner, we would gladly send one. Of all respondents to the first wave of data collection (N = 540), 60% (n = 327) reported being married at the time of the survey. Only a small percentage of that number, less than 15% (n = 45), elected to receive a second survey for a spouse; and of these, only two spouses who had requested second surveys did not complete them. It is possible that the imposing length of our survey instrument (see Appendix) led some to feel their responses were already covered by their partners’ responses. In other cases, a parent’s grief problems may have diminished his or her ability to complete the survey. Yet, we were still able to gain completed surveys from 13% of all married respondents, which represented a total of 43 cases of marital pairs whose responses were later analyzed both separately and comparatively. Comparative evaluations were made both between the husbands and wives in our survivor sample and between our sample’s marital pairs and nonbereaved husbands and wives from the Wisconsin National Survey of Families and Households (NSFH) Study (Bumpass & Sweet, 2001). Four marital cohesion questions were selected from the NSFH surveys and were administered to our respondents for comparative purposes.

Quantitative surveys were collected at two separate time intervals. The first, extended from March 2006 to September 2007. During this early phase, 754 surveys were sent out and 540 surveys were returned, yielding a response rate of 72%. We thought this was a more than satisfactory return rate, considering the difficulty of conducting surveys on grief issues and considering the length of the research instrument, a 27-page mailed survey form. Typically
in mailed questionnaire surveys, responses rates fall below the 60% mark (Hopkins & Gullickson, 1992; Kaplowitz, Hadlock, & Levine, 2004; Smith, 1995). Although we never planned it this way, from the outpouring of cooperation received from survivors, our study \( N = 462 \) became the largest sample of suicide survivors ever collected.

Within the first data collection wave, there were also 24 natural death survivors, 11 drug overdose death survivors, and 43 other parents who lost children from all other traumatic death causes, such as vehicular accidents, drownings, homicides, military casualties, and ambiguous deaths. As we also sought to further investigate drug overdose bereavement, it became clear that we had insufficient numbers for any preliminary analysis of this important bereavement subgroup. Starting again in March 2009 and extending until September 2009, we contacted three different chapters of The Compassionate Friends groups in the New York metropolitan area to find additional respondents who had lost children to drug overdose or to drug-related deaths. We also made contact at this time with the two Internet support groups serving the drug overdose death bereaved: Angels of Addiction and GRASP. At that time, 42 potential respondents names were given to us, 35 of whom completed surveys, yielding an 83% response rate for this subgroup.

Characteristics of the Sample

Our final sample included 575 respondents. Females outnumbered males by a huge margin, 85% to 15%. By age, 74% of respondents were between the ages of 46 and 65 years; 18% were 66 years or older; and 8% were 45 years of age or younger. The sample also overrepresented upper-status respondents: 34% had household incomes of $90,000 or higher; 43% had incomes between $40,000 and $90,000; and 23% with incomes below $40,000. In addition, 53% of our respondents reported having managerial or professional occupations; 41% reported completing 4 or more years of college; 42% reported some college; and 17% had high school degrees or less schooling. Religious affiliations included 35% Protestant, 26% Catholic, and 11% Jewish, 18% affiliated to other faiths, and 9% with no religious affiliation. The sample was predominately White and native born with 94% of respondents U.S. born, 95% White, and 5% from all other races. Respondents came from every state in the United States, and seven were from Canada.

Of the 575 cases, survivors of suicide outnumbered all others at 80% (462 cases); there were 46 cases of overdose drug death survivors, 24 natural death survivors, 34 other traumatic death survivors such as drownings and auto accidents, 4 homicide deaths, and 5 cases where it was reported that a child had died under ambiguous circumstances. Based on all the information provided, two of the five ambiguous death cases were subsequently reclassified as drug overdose cases, and the three remaining cases were incorporated into the other traumatic, mostly accidental death, survivors group. For 10%, their loss had been sustained within the past 12 months, 39% between 1 and
4 years ago, 35% between 4 and 10 years ago, and the balance, 16%, more than 10 years ago. A total of 18 respondents reported experiencing multiple untimely death losses of either two children to suicide, the loss of a child and a partner to suicide, or some other combination of accidental and/or natural death losses of nuclear family members occurring close each other. Decedents ranged narrowly in age, with 7% being 15 years or younger, 30% between 16 and 21 years, 36% between 22 and 28 years, 18% between 29 and 35 years, and 9% older than 36 years. Clearly, adolescent and young adult deaths predominated in our sample, with over 80% of respondents \((n = 478)\) reporting the loss of a son or daughter between the ages 16 and 35 years.

**Measurements**

To measure grief difficulties we used an abbreviated version of The Grief Experience Questionnaire (GEQ; Barrett & Scott, 1989). The original GEQ scale consisted of 55 items. Following the lead of Bailley, Dunham, and Kral (2000) who performed a factor analysis of the scale and identified eight distinct factors within it, we selected the two highest factor-loaded items for each of the eight factors to form our 16-item abbreviated scale. Our abbreviated scale yielded an internal consistency (Cronbach’s alpha) coefficient of .87. The brief GEQ scale was answered by 522 respondents, yielding a mean of 39.1 \((SD = 11.5)\) with scores that ranged from a low of 16 to a high of 80. Although we had no way of verifying how closely this abbreviated scale correlated with the full 55-item scale, we did find it correlated highly with other grief problems indicators that were also administered to our respondents: the Impact of Events Scale (Horowitz, Wilner, & Alvarez, 1979) and the Complicated Grief scale (Prigerson, 2002). The correlations between the abbreviated GEQ scale were .77 with the Complicated Grief scale and .69 with the Impact of Events Scale. The Complicated Grief scale was answered by 541 respondents, yielding a mean of 27.9 \((SD = 8.9)\), with scores ranging from 11 to 51. The Impact of Events Scales, a measure of PTSD, was completed by 522 respondents showing a mean score of 33.3 \((SD = 8.9)\) and a range of 14 to 56.

We used the same single-item depression screening question that was asked in the 1998 Midlife Development survey (Wethington, Kessler, & Brim, 1998): “During the past year, was there ever a time when you felt sad, blue, or depressed for 2 weeks or more in a row?” with possible answers of “yes,” “no,” or “not depressed because of taking antidepressant medication.” We found that overall depression was widely reported by our respondents, with 67% reporting current depression. In comparison with the same question, only 32% of a nationally representative sample of middle-aged adult women and only 17% of men reported depression. In our sample, the comparable depression rates by gender were 70% for women and 52% for men.

This 1998 Midlife Development survey also included an eight-item measure of depression that we administered to our respondents. It was based on responses to the previous screening question: “During the past year, was there
ever a time when you felt sad, blue, or depressed for 2 weeks or more in a row?" Those answering affirmatively were asked seven additional questions. 

1. During this period, did you lose interest in most things?
2. Did you feel more tired or low on energy than is usual for you?
3. Did you lose your appetite?
4. Did you have more trouble concentrating than usual?
5. Did you feel down on yourself or worthless?
6. Did you think a lot about death—either your own or someone else’s or death in general—during this time?
7. Did you have any sleep disturbances?

An 8-point scale (no = 0; yes = 1) was created for responses to these eight questions. In our sample, the alpha coefficient for the scale was .92. The depression scale was completed by 506 respondents with a mean of 4.34 (SD = 3.1), with scores ranging from 0 to 8.

We also created an index of personal psychological problems by combining several questions that had been asked in the Midlife Development survey. The survey asked respondents to self-rate their mental or emotional health: “How about your mental or emotional health? Is it poor, fair, good, very good, or excellent?” Then, we also counted the previously mentioned depression screening question. Survey respondents were also asked to count the number of days in the past 30-day period when they were unable to go to work or had to cut back normal household activities because of mental health difficulties. In addition, they were also asked a life satisfaction question: “At present, how satisfied are you with your life—a lot, somewhat, a little, or not at all/none at all?” We administered these same questions to our respondents and found responses associated with one another that had correlation coefficients ranging from .20 to .52. Summing together responses of (a) poor or fair mental health reports, (b) self-reported depression, (c) one or more days lost to work or housework during the past 30-day period, and (d) life satisfaction reports of little or none at all, we placed respondents along a continuum from 0 to 4 on our mental health problems scale, which yielded a Chronbach’s alpha of .70. The total score of our respondents on the personal psychological problems scale was 1.6 out of a possible 4 (SD = 1.3, N = 556). For the national sample, midlife survey women older than 46 years (and thus representing over 75% of our survey respondents), the reported mean was only 0.5 (n = 1,051).

Respondent suicidality was measured by three items. (These same items have appeared in the National Survey of Drug Use and Health [2010] and various other general mental health surveys.) The first item assessed suicidal thoughts, “How often during the past 12 months did you think about taking your own life?” Respondents could answer from 1 to 5: almost never or never, rarely, occasionally, frequently, or very frequently. Respondents reported rare-to-occasional suicide thoughts, with a mean of 1.8 (SD = 1.1) among the
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567 respondents that answered this question. The second item assessed suicide plans. Respondents were asked, “Had you made any specific plan for suicide during the past 12 months?” Of our respondents, 10% \((n = 59)\) reported making a suicide plan during the year prior to the survey. The third item assessed suicide attempts and nine respondents (1.6%) answered affirmatively to the query: “Had you made any suicide attempts during the previous 12 months?”

To assess positive growth after the loss, we also included the 7 items that had the highest factor loadings from a 12-item set of personal growth questions that formed part of the Hogan Grief Reaction Checklist (HGRC; Hogan, Greenfield, & Schmidt, 2001). The included items were “I have learned to cope better with life; I feel as though I’m a better person; I have a better outlook on life; I have more compassion for others; I am stronger because of the grief I have experienced; I care more deeply for others; I am a more forgiving person.” These 7 items yielded an alpha coefficient of .91 among the 536 respondents that offered useable responses to this abbreviated personal growth scale where responses ranged from a low of 7 to a high of 35, with a mean of 24.0 \((SD = 7.1)\).

Another important measure, our stigmatization scale, which appears throughout many of our analyses, is described in detail in the next chapter.

Additional Qualitative Data Sources

Besides the previously described survey administered to the largest number of our respondents \((N = 575)\), two supplemental surveys were also collected during the course of this investigation. As we examined survivors’ attachments to Internet support groups, we developed an online survey that we administered to 200 Internet support group members who belonged to an online parent (SOS) support group. More details on how this survey was conducted and our findings will be found in Chapter 11. For Chapter 9, devoted to transitioning and use of peer support groups, we collected 24 additional follow-up interviews by telephone with survivors who had withdrawn from peer support groups.

In addition to numerical survey materials, this study is also based on several different qualitative data sources. Our survey included several open-ended questions where respondents could offer more information on the nature of their particular bereavement experiences, in addition to the previously mentioned scales. For example, respondents were asked to enumerate any troublesome stigmatizing situations encountered or any particular socially supportive (or hindering) experiences that advanced or retarded their recoveries. In addition, many respondents offered lengthy comments and qualifications to survey questions. From among our respondents, eight had written memoirs or pamphlets detailing their loss and healing journeys since the death of their children and supplied these materials to us. We examined and analyzed all this information and, wherever relevant, cross-checked it with the survey data findings.
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We also collected participant observation data from more than 200 other survivors, from monthly peer support meetings of suicide survivors, and from various survivor healing conferences over an 8-year period. Because the first and fourth authors were survivors of their son’s suicide, they were able to regularly attend monthly meetings of a peer-led, (SOS) support group for over 5 years—from 2002 to 2007. Findings based on this field observation experience are described in detail in Chapter 8. Both investigators provided a cross-check on one another, making sure observations were accurately recorded. All names and personally identifying information about these respondents were changed to protect respondent confidentiality. Wherever necessary, nonessential details of observations and persons were changed to safeguard each participant’s privacy and confidentiality.

Additional participant observations were also collected over a 3-year period when the first and fourth authors led their own support group situated close to a large metropolitan center. Whereas most participants in the first support group were aware they were being studied (and the majority had offered signed consent forms before completing their surveys), few participants in the second group were aware that observations were being collected on them at the group’s meetings. The researchers identified their research objectives and obtained respondents’ permissions for study participation among all individuals who gave interviews. Again, in the second group, all names of individual informants have been changed, and nonessential details of the observations and the persons have been changed to safeguard each participant’s privacy and confidentiality.

THOUGHTS ON THE DIFFICULTIES OF DOING TRAUMATIC-LOSS RESEARCH

If any answer can be found to the question why so little research has been conducted among traumatic loss survivors and the suicide bereaved in particular, it leads back to the widely held belief that survivors are an especially vulnerable population, easily hurt by any questioning that would take them back to reviewing their loss experiences. In one early discussion of the capacity of bereaved individuals to offer informed consent to participate in research, Macklin (1978), a bioethicist, questioned whether any bereaved individual can offer their informed consent to participate in research given their trying personal circumstances. More recently, Wortman and Silver (1989) framed this question somewhat differently, suggesting that “normal” grieving may present few difficulties for bereavement survey research participation. Yet, the authors claimed some survivors may have difficulties freely making consent decisions when they have lost close relatives, such as a spouse or a child, or in cases of traumatic deaths when the death occurred under violent circumstances.

Beliefs claiming that suicide survivors may be unable to freely offer their consent to participate in research have a wide currency among behavioral science professionals and clinicians. At a 2003 conference sponsored by NIMH...
dedicated to expanding the knowledge base of suicide bereavement, experts in the field concluded that one of the important methodological and ethical challenges in doing survivor research includes the potential risk of retraumatization (NIMH, 2003). With pervasive fears of harming survivors by doing survivor research, researchers have often encountered difficulties in gaining approvals to do survivor studies by institutional review boards (IRBs) at universities, hospitals, and other research institutions (Ceci, Peters, & Plotkin, 1985). Recently, an incident was reported to us of two very experienced and respected researchers in the suicidology field who were turned down in their initial application to administer pencil-and-paper tests (consisting of established grief problems measures) to groups of suicide survivors by a university human subjects review board. The board rendering this decision was at one of the larger research universities in the country, regularly reviewing hundreds of similar behavioral science proposals yearly (although not often with survivor populations). The board claimed that answering these grief experience questions would be too upsetting for these very fragile respondents.

In another case, taking place at another large research university, a graduate student completing doctoral studies was initially denied IRB approval to do a survey research of suicide survivors. This student/researcher had survived a family member’s suicide and intended to impart this information to potential respondents. The IRB committee initially told this student that it was not proper for her to tell research subjects she was a suicide survivor. By doing so, she would lead some respondents into study participation out of pity for her. She was advised that if she did not disclose her survivor status, she could proceed with the research. The student objected to being considered “pitiable” by the IRB committee and was especially troubled by the restriction being placed on her study that would deny her an important rapport-building opportunity (from appropriate self-disclosure), thereby diminishing the trust and support that would have otherwise been available to her. With help from more experienced suicide bereavement researchers from across the country, she was eventually able to persuade the committee to withdraw its prejudicial procedural requirements. These cases are just two of many in which bereavement researchers may be discouraged or thwarted altogether from doing grief studies, usually without any well-founded empirical justification. At professional conferences, bereavement researchers often swap their hard luck stories of trying to persuade human subjects review boards to accept their survey research proposals.

The accepted protocol for most any survey research is to clearly tell potential respondents they do not need to answer all questions and to skip over all items found as personally troublesome. And if they wish to leave parts of their surveys uncompleted, they are also free to do so. They are also routinely told if any parts of the survey questions are personally upsetting, the researcher will refer them to a professional counseling resource for assistance. Yet, despite these very clear and protective stipulations about research participation (which as we noted are common practice in many investigations), many review
boards still remain skeptical that survivor research can be completed without harmful incidents.

In sharp contrast to these widespread beliefs about reluctant and easily damaged respondents, we found a very keen willingness on the part of our respondents to complete the lengthy 27-page surveys. Although we made only a single follow-up effort to secure cooperation from delaying respondents, in deference to beliefs about respondent fragility, we still obtained a 72% rate of cooperation from the first wave of survivors we approached. Some respondents returned surveys many months later, offering profuse apologies for their delays, stating they had mislaid their forms. We are confident that had we made a subsequent follow-up effort, response rates would have been higher, even closer to the 80% rate, which is considerably higher than that found for most mailed surveys (Kaplowitz et al., 2004). Such a rate would have rivaled those for household interviews (Siemiatycki, 1979; Smith, 1995).

Many of our respondents voluntarily expressed their willingness to be contacted in the future at the end of their surveys. Many commented how thankful they were that this research was being conducted. Some said they felt honored and privileged to be selected as respondents. Many also wrote in or typed long and detailed qualifications to their survey answers. Some also transmitted copies of books, journals, or memoirs they had written since their loss. A few of our more articulate respondents also commented that they found the survey experience to be cathartic. Of course, there were others who refused to complete the surveys. They often sent back notes stating that answering the questions was too painful for them now. Statements of apologies frequently accompanied these survey refusals.

We should also acknowledge that another important element enhancing cooperation with this study was the fact that the principal investigator was himself a survivor of his son’s suicide. Had this fact been withheld, it could be argued that it is doubtful that as many respondents would have been as keenly motivated to complete surveys or available for future assistance. As it was, many respondents expressed condolence wishes to the principal investigator as they returned their surveys. The survivor/researcher also helped to engender trust and a sense of importance about the research enterprise. This sentiment cannot be more vividly documented than by the acts of one especially cooperative respondent who insisted on conveying to the principal investigator her only copies of her son’s last letters, a photo memory book, and newspaper clippings about her son that she insisted must be seen and evaluated by the researchers in completing this study.

The responses to our survey were comparable to those obtained from another survey of child-loss survivors, whose deaths were attributable to three causes: SIDS, suicides, and accidents (Dyregrov, 2004). In this Norwegian study, a subsample of 64 parents from the larger sample of 262 was reinterviewed, and 100% reported their research participation was a positive or very positive experience and none regretted participating. Respondents to this Norwegian
study linked their positive experiences to being allowed to tell their complete stories and to having a hope that telling their stories might help others. Everyone in this smaller group of respondents to the follow-up survey had participated in open-ended interviews, lasting between 1.5 and 4 hours, where respondents had the opportunity to talk about whatever bereavement subjects they wished to of personal importance. Many, approximately three-fourths, reported feeling varying degrees of pain in talking about their traumatic losses; yet, because most felt they would be thinking about their lost children everyday anyway, there were no added dangers from having the research interviews. Many expressed feelings of satisfaction at being able to vent their feelings for the first time, having a sympathetic and supportive listener, and gaining a therapeutic experience from their research participation.

These findings converge closely with several other studies of survivor populations cited by Alicia Skinner Cook (2001): Cook and Bosley (1995), Dyregrov, Dregrov, and Raundalen (2000), Lehman, Ellard, and Wortman (1986), Pennebaker, Barger, and Tiebout (1989), and Pennebaker and O’Heeron (1984). In each of these cases, bereavement research respondents welcomed the opportunity to openly discuss their feelings of loss; it offered grievers an outlet for thoughts and feelings not previously shared with available support systems, and they also felt sharing their sorrows would educate others and promote a better understanding of the impact of death on survivors. Some of this research also suggested that when survivors talk more about the death, this is associated with better long-term health outcomes (Pennebaker et al., 1989).

Dyregrov (2004), reviewing several similar studies, concluded

a growing body of research has started to point out that research participation may even serve the interests of the participants and not only those of the researchers. Instead of causing distress, research may be educational, enriching, therapeutic, or empowering for vulnerable populations. (p. 392)

Talking about their bereavement experiences is believed to help people heal and find meaning to their loss and recovery (Neimeyer, 2000; Neimeyer, 2001; Steeves, Kahn, Ropka, & Wise, 2001). This is especially true in cases of traumatic deaths where respondents find fewer opportunities to openly discuss their losses among most significant others. In the next chapter, we will be examining how stigmatization associated with suicide and other traumatic deaths complicates survivors’ grief experiences.

Based on the previously mentioned findings, although most survivors will probably find bereavement research to be personally beneficial, some may not. It is possible that a small number of cases of highly troubled psychiatrically impaired survivors may find that the opportunities to participate in research only exacerbate their psychic difficulties. Yet, the reader is asked to consider the alternatives: ignoring this group of psychologically needy persons altogether or inviting this group to participate in a research task. It seems plausible that by answering survey questions, people will probably gain more
help through the attempts to engage them, rather than by being bypassed altogether. Invitations to participate in research may also help troubled individuals identify their needs for gaining psychological services, if they are not already engaged in receiving this kind of aid.

In this opening chapter we outlined the theoretical directions for this research on bereaved parents suffering from diverging types of child losses. Our consideration embraces child deaths from suicides, drug overdoses, other accidents, and natural causes. We described our large and diverse study group, some of whom had lost children just weeks before we encountered them, whereas others experienced losses more than a decade ago. In our attempt to better illuminate the directions bereaved parents take in attempting to cope with their losses, we employed various quantitative and qualitative methods. Some of our methods included precise written measurements with professionally recognized scales of bereavement and mental health difficulties scales, and others involved the direct observation and interviewing of bereaved parents at their support group meetings, healing conferences, and other gatherings and by examining some of their writings about loss. Hopefully, all this will help to form a clearer picture how bereaved parents restart their lives after loss and how this process changes as bereaved parents move from early grief until later years after loss. In this chapter we also approached the question why previous researchers appear to have paid scant attention to these mourners. It is hoped that in the chapters that follow we will present some new and insightful thinking to help guide future research on this neglected and important subject.

REFERENCES

Devastating Losses


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