Man survives because he cares and is cared for. . . . Civilization is, at least in part, a form of crystallized love.

—William Gaylin

It is said that books in process take on a life of their own—mystified authors following their characters wherever they lead, unsure of where they’re headed until all is revealed on the final pages. But that is supposed to happen only in fiction. Little did I imagine when I began this project that its course would undergo such drastic revision before its end.

This was to be a book about the professional view of “family caregiving”—a continuation and amplification of a theme I had introduced in a 1995 article in Social Work entitled “The Caregiver’s Memoir: A New Look at Family Support.” In that article I argued that the quantitative research that marks the field (centered primarily as it is on the concepts of “stress” and “burden”) fails to capture the complexity of the experience.¹ I suggested that looking backward—after time had distilled the significance of the event—could allow the person who had served as caregiver to uncover the thoughts and feelings that exist below the radar of scientific inquiry. And I cited excerpts from a few published book-length memoirs to prove my point.
It was a topic close to my heart. For thirty years I’d practiced clinical social work with ill and disabled people and their families. As daughter, wife, and mother, I’d been involved in family care myself. All that I’d experienced indicated that caregiving was not an intrusion on family life but an intrinsic part of it, a crucible in which the crux of relationships was revealed; an occasion not only of stress and burden, but of growth, possibility, and meaning. Over time, I’d come to see “independent living” as an oxymoron, and to accept interdependence as the underlying order of life. Every family I’d ever known had at least one story of care inextricably bound to its sense of identity. The years may have obscured or exaggerated the particulars but the essence remained. The depth, shading, and nuance that accompanied these stories were not to be found in the professional literature. Nor were answers to the questions that interested me most: How do family caregivers “keep on keeping on”? How do their views on family and on the meaning of life itself change over the course of caregiving? How can their hard-won wisdom be used to sustain others faced with the same challenges?

Using published memoirs as research texts seemed an obvious way to examine these questions. Authored by sons and daughters, spouses and life partners, parents and children, they provide reflective accounts of the experience of caring for ill and disabled family members. As a caregiver, I’d drawn strength from reading the words of those who had passed that way before me. (In the words of a dearly remembered English professor, they “spoke to my condition.”) As a practitioner, I’d sometimes suggested reading memoirs to my clients. And, in the tradition of Robert Coles (1989), who used fiction to develop the “moral imagination” of medical students, I assigned memoirs to the social work interns in my graduate school classes.

So tethered to the empirical literature was I that it seemed right to devote a major portion of the book to its review and to a discussion of the ways in which memoirs validated or contradicted the dominant paradigm of stress and burden. It seemed at first that an analysis of child-care, peer-care, and parent-care relationships in thirty book-length memoirs would do the job. I had no intention of moving
beyond comparison—much less developing an overarching theory—in the process.

Many of the memoirs I chose to read featured caregiving in the sense that clinicians and researchers use the word: hands-on help with personal and instrumental tasks of daily living undertaken by one family member on behalf of another—usually for a time-limited period—of greater or lesser duration—of illness or disability. For it is generally understood—if not publicly acknowledged—that most of the people occupying hospital beds today will not “get well soon,” as the greeting cards on the bureau command. Nor will they die just yet. They will get a little better and go home, get a lot worse and come back. Good days will follow bad days as energy and spirits wax and wane. Bad news will follow good news as diagnostic tests yield contradictory results and second and third opinions are solicited. And throughout this time—however long it may last—ill and disabled adults will depend on those closest to them for help with tasks they once performed independently. Or, in the case of young children, will require more parental assistance than is usual for their age.

I began to read. Memoirs that centered on the accepted definition of caregiving were most often about the care of individuals with whom the author lived or had daily contact—young children, spouses, or life partners. Cancer, HIV/AIDS, and developmental disabilities were amply represented. Tales of stress and burden, amplified by insights into previously unrecognized facets of the experience—they were exactly what I expected to find.

But what of the ones that did not fit this mold—and there were so many! Memoirs by children, parents, and siblings of adults who were mentally ill, addicted, or trauma survivors. Memoirs in which hands-on care was minimally or never mentioned. When Bad Things Happen to Good People has become a classic since its publication more than twenty years ago. According to the author, Rabbi Harold S. Kushner, the book is a response to personal tragedy: his eldest son’s illness of progeria (rapid aging) and death at the age of fourteen. This experience is a subtext of the book, but actual mentions of the family’s daily struggles are few. Was this a “caregiving memoir”? Julie Hilden knew
that her mother was rapidly succumbing to Alzheimer’s Disease but
did not return home until it was too late to care for her. The title of
her book, *The Bad Daughter*, reflects its content and the depth of her
remorse. Was this a “caregiving memoir”?

Jean Starobinski wrote: “One would hardly have sufficient motive
to write an autobiography had not some radical change occurred in
his life—conversion, entry into a new life, the operation of Grace”
(cited in Olney 1998, 272). Every one of the memoirs I read—even
those in which the author had been estranged from the ailing family
member up to and including the moment of death—attests the truth
of that observation. Given the life-transforming meanings to be found
in these unanticipated memoirs, it was impossible to eliminate them
on the grounds that they didn’t fit into an a priori category.

The memoirs piled up. Each week seemed to bring publication of
another. I passed the thirtieth and didn’t even notice. I held myself to
one rule: to read each in one sitting. If I started at dawn, I would end
by nightfall. If I started in the late afternoon, I’d be up until the next
morning. By employing the “total immersion” technique of language
learning I drove out of my mind all families but the one before me.3

The cumulative effect of so much vicarious grief was immense.
The stories cast a pall over my days and haunted my nights. Although
I had long ago discounted Kübler-Ross’s (1969) “stages” of grief as
unmindful of individual variation, I found myself fitting all too eas-
ily into them. I moved from denial (that this project would not spill
over into my life) to anger (at the cruelty of fate and of people), to
bargaining (just one memoir more and my sample will be complete),
to mourning (recalling, amidst all the sorrow, examples of courage,
even joy), and finally to acceptance (that as they told their individual
stories, I could tell their collective one).

Although I had intended to focus only on care relationships, I
soon found that care situations were just as significant in shaping
the narratives. The stories of caring for a family member with can-
cer were remarkably similar across memoirs of parents, spouses,
and adult children. And the same could be said for mental illness or
HIV/AIDS. Clearly it would not be sufficient to confine my study to
relationships—situations would have to be included. Soon I began
to recognize that each author described a care situation that fit into
one of three narrative forms—the U, the arrow, or the spiral. The U is the illness from which the family member returned, such as when the cancer has been in remission for so long that it is pronounced a cure. The arrow is the progressive illness with a fatal prognosis, such as dementia. The spiral is the situation in which losses are permanent but not life-threatening; such as the disability that is the aftermath of an accident. Unlike the U, where the family member is returned to his former self, or the arrow, where he is on a direct downward course, the spiral denotes a self reconstituted on a lower level of functioning.

Bruner (2002, 66) would not have been surprised at this realization: “all cultures provide presuppositions and perspectives about selfhood, rather like plot summaries or homilies for telling oneself or others about oneself.” Each narrative form was as constricting and as liberating as a Bach fugue. Point and counterpoint. What was lost, what was found. Though surface differences were great, authors were suffering similar losses, creating similar meanings from the experience. I began to realize that identifying common stories was the same as identifying common meanings.

Moving from a consideration of “family caregiving” to one of “family caring,” considering care situations as well as relationships, and concentrating on the “lost and found” made comparison with the empirical literature irrelevant if not impossible. The evaluation of memoir texts involved a different methodology entirely. And here I entered the realm of narrative analysis. The literature was unfamiliar, but the beliefs on which it based was not. I had heard thousands of stories from clients—always aware that they were selected from the many incidents of their lives and shaped in a way they hoped would explain them to themselves and to me. Their stories held many common elements (for example, the difficulties in receiving needed support from others); in short, they reflected cultural conditions inextricably linked to, if not responsible for, their personal troubles.

Still, I had much to learn. Narrative analysts consider memoirs a subset of “life writing,” nonfiction approaches to depicting the human condition that—along with essays, diaries, autobiographies, and biographies—reflect the cultural context of the individual experience. The few analysts who focused on narratives of illness and
disability commingled first-person and caregiver narratives. Their interest in illuminating what G. Thomas Couser (1997, 289) termed the “gratuitous collateral damage” that contributes to the problems of the afflicted in our society has led them to examination of myths, metaphors, stigma, and marginalization—and to an affirmation of the power of the personal voice in bearing witness.

Couser, Anne Hunsaker Hawkins (1993, 1999), and Arthur Frank (1995) broke ground in recognizing the value of memoirs and in limning their cultural significance. They discuss some of the same books I do and come to some of the same conclusions. However, my exclusive emphasis on family care across the lifespan and the way I chose to portray it influenced the books I selected and the lens through which I viewed them.

Deconstructing memoirs to uncover their commonalities is an essential part of narrative analysis. It comes at a price: the unique family constellation, the particularities of each situation, and the power of the authorial voice are lost. Yet how much of what I read could be taken at face value? I accepted a few facts as literally true: that the authors were indeed the persons named on the cover and pictured on the book jacket; that the photographs sprinkled through the text were of their families; that their relatives suffered from the illnesses and disabilities attributed to them; that the care experience they described was the truth as they saw it. The artifices they used to shape a readable narrative—particularly verbatim conversations and omissions—were, finally, not significant.

Leibowitz (1989, 230) wrote: “Moods and events blur, facts are forgotten, misremembered, distorted. Faced with these handicaps, the autobiographer substitutes surmises, daydreams, idealizations, enthusiasms, thematic designs. Through the potent magic of style, the solitary confinement of time and consciousness may be transcended, and autobiography becomes what Edwin Muir called a fable.”

I began to think of memoirs of slavery, the Holocaust, the Depression. A microcosm of the event could be seen in each story, while each story illuminated the whole. Over time, historical data and personal testimony merged in the public consciousness—to create a unified understanding of the event. Clearly, that was my charge—not to question what “really happened” but to draw from its recollection
a collective truth. The challenge was to find a framework that allowed the individual memoirs to breathe; that honored their particularities while recognizing all that was myth, fable, about our shared culture of family care in the first years of the twenty-first century. There was no such framework at hand.

I recalled and reread the following: “Every work of literature has both a situation and a story. The situation is the context or circumstance, sometimes the plot; the story is the emotional experience that preoccupies the writer: the insight, the wisdom, the thing one has come to say” (Gornick 2001, 13). What, exactly, was the thing I had “come to say?” That family care is not limited to time-limited, hands-on activity during a period of illness or disability (as the bulk of professional “family caregiving” literature suggests) but is an integral, ongoing part of family life. That in telling the story of their experience, family members create meanings out of the care they provide. That these individual meanings are constructed at the point where the idiosyncratic history of the family member joins with socially constructed meanings of the situation (illness or disability) and the relationship (parent-child, sibling or life partner, adult child–parent). That meanings refer not only to what was lost but also to what was found. That the memoir—portraying the author’s relation to self and others over time—is a narrative form particularly suited to portraying the fragile, mutable nature of family bonds. And finally, that reading memoirs will enhance the understanding of both the general reader who is dealing with the situation herself and the professionals she turns to for help.

One might wonder, of course, how representative those who write published book-length memoirs of the family-care experience are of the legions who do not. In the statistical sense, not at all. Novelists, journalists, poets, clergy, academics, lawyers, physicians, and public figures—the authors are a cultural elite, possessing educational, social, and financial resources beyond the reach of most of their readers. Yet memoirs do not exist in the realm of science but in the realm of art—and are to be judged by the standards of art. This is not to say that they are all literary masterpieces, but only to say that the truth of their words lies not on the pages of the text but in the way it resonates with its readers. We read the words of a father mourning the death of
his son, a wife who is battling with medical staff over the care of her husband, a daughter who is finding new ways to communicate with a mother beyond speech—and we know them to be true.

One problem: how was I to reflect that truth to those who had not read the books themselves? “It is clear that we do not find stories; we make stories. We retell our respondent’s accounts through our analytic re-descriptions. . . . In this sense the story is always co-authored” (Mishler 1995, 90).

Four decades ago the anthropologist Claude Levi-Strauss (1966) adopted the term “bricolage” to describe how disparate approaches can be pieced together to solve a research problem. Weinstein and Weinstein (1991, 161) further defined this method as an “emergent construction” that can include tools, methods, and techniques tailored to meet the needs of the researcher.

My guiding metaphor was not one of a collagist but of a jeweler, creating settings in which the gems (the authors’ own stories, own words) could be shown to best advantage. I wanted to honor the stories by intruding upon them as little as possible while at the same time stressing their common elements. And so my method of analysis and the outline of this book evolved.

Whatever narrative structure a memoir author chose, it soon became clear to me that each family-care situation, each family-care relationship had its overriding story. Dementia had its own story. Sibling care had its own story. This story transcended the particularities of each family to tell what I came to think of as what Muir would describe as the care “fable” of that particular experience. This had to be broad enough to include all the variations to be found, yet specific enough to mark the experience as different from all others of its class. After identifying the common story, I challenged my own blind spots by trying to prove myself wrong. I looked again at each of the memoirs of the section. Where were the exceptions to the rule? Under what circumstances did the story not hold? It was gratifying when this internal dialectic confirmed my original idea. However, it was more useful when it did not—leading to significant revisions.4

Of all the authors read, about one-third are visited again and again. Prototypical of a care situation or a care relationship and eloquently
written, their words give voice to the experiences of the others. Their memoirs became the source of quotes that drive the story and the case examples that enliven its narrative. Memoirs abound in metaphor and apt turns of phrase. I used these as chapter titles and excerpts that introduced and punctuated each chapter.

Although the memoirs are readily available, it is doubtful that anyone would read them all. So I thought it particularly important to provide ample representation of the work on which my findings are based.

Part I, “Care Situations,” is introduced by a discussion of the cultural context of illness and disability as well as an overview of elements that all care situations share. Four chapters follow this one, each focusing on a commonly occurring family-care situation: cancer, HIV/AIDS, mental illness/chemical dependence, and dementia.

Part II, “Care Relationships,” is introduced by an overview of common thoughts, feelings, and issues arising out of family care juxtaposed against a handful of memoirs of friend care. This is followed by four chapters, each discussing a family relationship: parents caring for ill or disabled children, brothers and sisters caring for siblings, spouses or life partners caring for each other, adult children caring for parents.

Part III, “The Memoirs,” is introduced by a discussion of memoir formats, this is followed by paragraph-long summaries of each memoir in the study. These reflect the unique characteristics of each book. The section concludes with a chart for quick identification of those care situations and family relationships that may be of particular interest to the reader.

An epilogue summarizes the findings of the study. It includes a reflection on the authors’ common journey through the family-care experience by identifying and describing ten steps along the way from loss to renewal, and by discussing the lessons that the authors pass on to their readers. It also considers implications for clinical practice and future research.

Family care is a universal experience, and this book was written for anyone who has cared for, is caring for, or expects to care for a seriously ill or disabled loved one. What professional citations there are
arise from the stories themselves and my attempts to understand them better. In no way intended as a compendium of family care information, this book offers one vision of the experience—and an invitation for others to read the memoirs for themselves.

Gaylin (1976, 13) sees care giving and care receiving as the root of civilization, the intangible quality of love rendered visible in “crystallized” form. Crystal seems to be a solid white block, yet when turned this way and that it reveals a prism. The authors whose memoirs fill these pages have found the prism in the crystal—in the process revealing a rainbow of colors and possibilities.