‘Crystallized Love’

1. Families have always looked after their own. But it was not until the last decades of the twentieth century—when the consequences of medical and technological advances first entered public awareness—that someone who helped an ailing relative was deemed worthy of a title: “family caregiver.” Many illnesses that were previously fatal could now be treated (if not yet cured). Many disabilities that had previously landed their sufferers in institutions were now being managed at home. The elderly were the largest, but by no means the only, age group affected. Developments in pediatric medicine, long-term survivorship with cancer and HIV/AIDS, and improved management of chronic illnesses touched everyone. Few areas of contemporary life received more research, programmatic, or advocacy attention.

Large-scale studies—over a span of four decades—confirmed a few basic truths. Families rarely appealed to outsiders for help until their own resources were exhausted; relatives did not necessarily have to share a household or neighborhood to be caregivers; care passed between the generations throughout the lifespan (moving from older to younger in the early years and reversing in the later years); ethnic and cultural differences influenced many aspects of the process but not the essential nature of the family-caring response. Above all, caring exacted a price from all who provided it. If the financial consequences of providing care to family members could be measured in lost workdays and out-of-pocket expenses, emotional costs were no less evident. “Stress” and “burden” were linked to specific characteristics of caregiver, patient, and illness.

Notes
Needs assessments and service utilization studies investigated the ways in which outside services meshed with the needs of patients and their families. Positive outcomes were rarely recognized. Appearing under the rubric of “adaptation” or “coping,” a few studies addressed the strengths that caregivers employed to meet the challenge. Fewer still identified difficult situations as “hassles” and pleasant ones as “uplifts,” so acknowledging that caregiving need not be an unremitting nightmare. However, their voices were all but drowned out in the dominant paradigm.

2. “Personal tasks of daily living” include assistance with bathing, feeding, toileting, and other intimate activities. “Instrumental tasks” include assistance with marketing, finances, transportation, and other activities that the relative may no longer be able to perform independently.

3. Of the more than one hundred memoirs I eventually read, the subjects of about a dozen did not meet the traditional criteria of “family”: those bound by blood or marriage. Life partners, adopted children, friends—their stories extended and enriched the definition.

4. Each chapter could easily be expanded to fill a book of its own. Viewing the shared story of a particular relationship or situation through a variety of lenses (culture, gender, class, age) would generate useful insights.

5. In selecting the memoirs, I felt there were a few classics of decades past that could not be ignored (for example, John Gunther’s *Death Be Not Proud* and Simone de Beauvoir’s *A Very Easy Death*). Most, however, were published after 1990 and so reflect recent trends in medical, psychiatric, and rehabilitative care. The majority are still in print, and even that aren’t can be accessed through libraries, bookstores, and the Internet.

1. “Introduction: ‘The Flavor of the Name’”

1. Some of the unexpectedness of the family-care experience may have to do with popular culture. The images of family life portrayed in the media rarely reflect the reality of millions of families. And when such a situation is shown—a daughter in a wheelchair after an accident, a husband who is unable to speak clearly after a stroke—the illness or disability is always the main point of the story. Slowly this is changing. (The inclusion of people with visible health problems is evident in some commercials.) But until it becomes commonplace, individuals will continue to be shocked when what is perceived to be a rare situation actually happens to them.

2. Professionals refer to the former as the “formal system” and the latter as the “informal system.” Put another way, there are those who arrive on the scene as a result of the relative’s difficulties and those who were
there before. Sometimes there are crossovers—the doctor or home health aide who becomes “one of the family,” the old friend who happens to be a nurse. However, the primary distinction is that those who are paid to care have assigned tasks.

3. Using a quantitative approach, Biegel, Sales, and Shulz (1991) identified illness- distinct variables in Alzheimer’s Disease, cancer, mental illness, and stroke.

2. “Cancer: Cancer’s Gift”

1. Using cancer as a case in point, Kübler-Ross posited a series of stages through which patients (as well as the bereaved) must pass in dealing with terminal illness. The stages are shock and disbelief, denial, anger, bargaining, sadness, and acceptance.

5. “Mental Illness/Chemical Dependence: ‘Companion Demons’”

1. The 1970s were a time of great change in the way mental health and chemical dependence services were delivered. The efficacy of newly developed psychotropic medications led to the belief that many institutionalized people could be sufficiently stabilized to live on their own. The problem was that community mental health and social services could not keep pace with the number and needs of patients, many of whom were now ricocheting from one bad situation to another. The fact that many of these patients did not see themselves as ill and soon discontinued taking prescribed medications, or began self-medicating with the illegal drugs then flooding the streets, was not anticipated. Nor were the vast challenges they faced in keeping themselves fed, clothed, and housed while struggling with an altered sense of reality. There were also changes in the philosophy of care. Shifting power from institutions to the people they served sounded good. Self-help and rehabilitation programs that focused on personal efficacy and responsibility were seen as more democratic and in keeping with the prevailing Zeitgeist. However, these worthy goals were not backed up with services. The fine line between independence from the system and abandonment by it was—and remains—hard to distinguish.

7. “Child Care: ‘An Unimagined Life’”

1. These and other pioneering parents were very much a product of their time in history—a time when a confluence of biomedical research,
technological advances, and cultural change made it easier for their children to find their places in the world.

8. “Sibling Care: ‘She Was My Parents’ Child, and So Was I’”

1. Perhaps it has been ever thus. Contrast the oft-quoted Biblical question: “Am I my brother’s keeper?” to the commandment “Honor thy father and thy mother.” At least two authors have answered the question in the affirmative, turning the question into a book title: Margaret Moorman in *My Sister’s Keeper* and John Edgar Wideman, writing of a sibling in jail, *Brothers and Keepers* (New York, Vintage Books, 1984).

2. All of the authors who grow up with impaired siblings are faced with cognitively and emotionally disabled brothers and sisters. Most likely the situation would be quite different if their siblings were physically disabled and mentally competent to make decisions for themselves.

10. “Parent Care: ‘The Consummate Act’”

1. There are more memoirs of the parent-care experience than of any other—perhaps because the category includes books that are not specifically written to discuss the experience but inevitably include it (for whatever an author’s purpose in writing an autobiography, the relationship with parents up to their final illness and death is an integral part of the story). Sometimes—as in the case of Phillip Roth or Simone de Beauvoir—the memoir is devoted to the parent, but it is the promise of learning more about the life of the celebrated child that commands initial attention. Sometimes the author has followed in the parent’s literary footsteps: Martin Amis and Kingsley Amis, Christopher Dickey and James Dickey, Susan Cheever and John Cheever, Reeve Lindbergh and Anne Morrow Lindbergh. Part biography of a person the world wants to know more about, part memoir of a child emerging from the shadow of a celebrated parent, these stories of parent care combine many powerful themes.

Most memoirs, however, are written by and about unfamiliar people involved in familiar situations: a parent’s end-of-life struggle with cancer or dementia being the most common.


1. Issues of “reference and temporal order” in the construction and understanding of stories are covered extensively in the literature of life history and narrative.
13. Epilogue

1. This aspect might reflect the demographic profile of the authors, most of whom are privileged by education and income.

2. Lejeune suggests a way to prompt people to tell life stories: “‘Could you talk to me about your given name and your last name? What do they remind you of?’ Experience shows that this is an inexhaustible question, and an absolutely central one. Dear reader, it’s up to you to answer it. What is your name?” (1989, 231).