
Day In, Day Out with Alzheimer's

Stress in Caregiving Relationships



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Relationships

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*In memory of Auntie Olga
and with respect for Auntie Ben,
who cared for each other
throughout their lives,
including dementia at the end.*

*And to Aunt Carol,
who has begun her journey
into the strange world
of dementing illness.*

Preface

An eighty-five-year-old never-married woman, who cared for a sister with Alzheimer's until her death some years ago and who now has no family living nearby, has adjusted cheerfully over the years to giving up driving, walking with a cane, and eventually not being able to walk to the grocery store. Her identity and her daily routine have centered around her little house, her yard, and various cats who have adopted her.

In recent years she has begun to move across that invisible boundary between the eccentricity of someone living alone and the incompetence of someone who cannot manage alone. Her friends and neighbors think she needs to move to a place where she will receive some assistance in daily living, but she has rejected this idea as well as any suggestion of assistance from service agencies. Meanwhile, she has let things burn on the stove, has neglected some bills and repairs, her telephone service has been cut off once, and she has had a fall or two. Most important, her friends are no longer willing to help her in her home or have her ride in their cars, because she has allowed a half dozen untamed cats and their kittens to take over her house, including using her closets and corners as litter boxes; she is oblivious to the odor.

These friends, who have helped her immeasurably over the years, telephone her only living sibling, an eighty-one-year-old sister living 300 miles away. They tell her: "It's time. Something has to be done. She needs help." And so the woman is taken on "a little vacation" and left with the widowed sister, who must break the news: "You're not going back. You need to live somewhere where people can help you now. You have to give up your home." And then these sisters, who have lived apart since they became adults, begin a new relationship at the end of their lives, with one dependent upon the other.

The eighty-five-year-old woman, who has essentially been kidnapped and moved into a group home (albeit a lovely one) after living alone all these years, reflects on her situation with painful resignation: "This is happening because I have lived too long."

The eighty-one-year-old widow, who is taking responsibility for her sister while trying to maintain her own health and independence, is struggling to deal with her sister's uncooperative behavior as well as her own sense of guilt: "She's very unreasonable. I'm wondering if that might be Alzheimer's. I just think she can't help it."

DURING A BOUT with pneumonia in April of 1981, for approximately three minutes, I experienced a memory lapse. Suddenly, without warning, I did not know what day it was, or if a reunion I had looked forward to for months had occurred. Time stopped. I felt very small, lost, falling through some black hole in the universe. My instinctive reaction was to curl up in the fetal position. Fortunately, my husband was there to ask grounding questions, and the moment passed.

Several years later, when I first visited an Alzheimer's day care center, I remembered the incident. I was disturbed

by the seeming insensitivity of some staff to the distressing confusion of their clients. After a period of participant observation, however, I came to understand the daily demands experienced by service providers. It was difficult for staff to remain sensitive to the needs of clients when their own needs as workers often were not met.

I became curious if this center was typical. Was there a general pattern of stress in dementia care? Or was staff stress associated with conditions found in some settings and not others? Just as I asked these questions, the California Department of Aging established eight Alzheimer's day care centers as a model project for dementia care. And so, the seeds of this project were sown. With generous financial support from the Alzheimer's Association and steadfast emotional support from family and friends, I spent three years in the eight centers, immersed in the world of people who live with a dementing illness and people who provide dementia care. I came to understand patterns of stress experienced by both caregivers and care recipients.

I began this project with the usual stereotypes about people with dementia: they are so confused that they cannot make decisions for themselves; the disease causes them to misbehave; they are fading away, no longer the same person. But I came away from this research with considerable evidence that refutes these stereotypes, as well as confirmation of the general principles I teach in a sociology of aging course: that there is tremendous variation in the aging process and considerable potential for change and growth in the later years of life, even for people who live with impairment and disability. I am convinced as a result of this project that these principles of variation and potential apply even to people with dementia. Consequently, I feel a strong sense of responsibility as an advocate, not only for Alzheimer's care providers whose daily work is not well supported, but especially for people with dementia whose daily lives become meaningless in the eyes of others.

I acknowledge that at some point people who have been diagnosed accurately with Alzheimer's disease (or a related

disorder), and who live long enough, will experience deterioration so profound that they will become increasingly confused, lost, and dependent upon others for virtually all of their personal needs and decisions. But these are not the people who still live in the community, including those who participate in Alzheimer's day care. These programs include people "moderately to severely impaired," but even those identified as "severely impaired" (who also fill the halls and day rooms of long-term care facilities) are not without considerable variation and remaining potential. My concern, as a result of this research, is that variation among people with dementia is ignored and their remaining potential is not developed, because of inappropriate treatment by care providers who are simply trying to get through the day, managing stressful working conditions as best they can.

When people are in pain, it is difficult to consider the pain of others. It is easier to rationalize that they are not in pain. I remember being in labor for twenty-eight hours with my first child, fading in and out of a conscious sense of connection with time and the reason for being there, asking for drugs or a C-section despite all of my clearly predetermined, politically correct decisions about "natural childbirth" prior to labor. My main concern was to "stay in control," not "lose it." The attending OB-GYN was a gentle, caring young man who stayed hours longer than his scheduled shift. Sometime during the long night he told me we needed to monitor fetal heart rate during contractions, and he hooked up the equipment. I was aware that this meant screwing electrodes into the baby's head, and I raised a weak objection to the possibility of inflicting pain. But under the circumstances, struggling to "stay in control," I chose to believe the doctor's explanation that "infants don't feel pain, or remember it." This is the same argument that has been used for decades to justify surgery without anesthesia for infants. Recent research has demonstrated, of course, that infants do suffer pain. But it has been convenient to believe otherwise.

Alzheimer's care providers also experience very difficult labor, during which they struggle to "stay in control." And under the circumstances, they choose to believe that exercising control over people with dementia either "doesn't hurt" or "is for their own good." But for the person with a dementing illness, unnecessary and unwanted interventions by caregivers often contribute to the sense of lonely degradation, self-doubt, and incompetence that accompanies the downward slide into Alzheimer's. And sometimes people with dementia express anger and frustration, not only because of the illness but because of the caregivers' attempts to "stay in control," including dismissing their anger as just an expression of the disease.

The central dilemma of Alzheimer's care is that both caregivers and care recipients struggle to "stay in control," to avoid "losing it." In the process, they may have quite different interpretations of the interventions that are necessary and appropriate in the daily lives of people with dementia. What kind of help is helpful? And by whose definition?

While I was writing one draft of this manuscript, my study breaks involved spending time outside my home on a coastal bluff above the Pacific in northern California, watching wildlife or pulling a few weeds. On two occasions I encountered wounded birds and faced the dilemma of whether or not to help. A hummingbird was caught in a maze of cobwebs attached to a window. I knew her constitution required almost constant movement so I worked quickly to remove her from the web with a piece of cardboard. She was motionless during this process, and even when it appeared she was free she remained still, lying on one side on the cardboard, looking up at me. I slid her from the cardboard to my palm, worried that she was too far gone to fly. And then, while I held this uncharacteristically motionless hummingbird in my open palm at eye level, she looked at me once more and flew off, with the reassuringly rapid movement and sound of a healthy hummer.

On another study break, I found a barn swallow fluttering on the ground, lying on her side. I knelt over her and slowly

tried to try to pick her up, but she began flapping her wings wildly, her body landing in a heap with one wing bent, breathing heavily. I went away. Several hours later I returned, and she had moved a few feet, lying at an awkward angle. Again she resisted my efforts to move her, and it seemed she would injure herself more if I persisted in trying to help. And yet it was difficult to let her suffer, knowing that eventually she would die or be killed by a predator.

People in helping professions, as well as family caregivers, face a number of persistent, recurrent dilemmas in deciding about appropriate care for "wounded birds." If the person offers passive cooperation, is it appropriate to "take over"? If the person resists efforts to help, is it appropriate to let them suffer?

During the course of writing this manuscript, I have become a "family caregiver" myself, facing some of these decisions in regard to appropriate care for a relative. The eighty-five-year-old woman in the story at the beginning is my aunt. Her eighty-one-year-old widowed sister is my mother. And I am expected to help, because I "know something about Alzheimer's," which my aunt is now suspected of having. I am not convinced. I do know that she seems to be "functioning better," but less happy, in her new home. I also know that suggestions that she has Alzheimer's are offered when she is considered to be "confused" or "uncooperative," because she does not agree with decisions others have made for her. And whether or not she has "mild dementia" is irrelevant to the larger ethical issue: should people have "taken over" the decision about her living arrangements, even if it was thought to be "for her own good"?

My aunt's experience is similar to that of many individuals I have met in Alzheimer's day care centers, people who have been diagnosed (accurately or not) with Alzheimer's disease or a related disorder, whose expressed concerns and wishes are often dismissed because they "don't know what's good for them." My mother's situation, and that of the staff in my aunt's care home, is similar to the experience of care providers in the day care centers. All caregivers

struggle with the ethical and practical issues of how best to meet the needs of someone who seems unable to live independently. And all caregivers must take care of themselves, as well, if they are to continue to provide care to others.

I feel privileged to have been included as a temporary “insider” in the eight Alzheimer’s day care centers, to be able to understand the daily reality of this work. The directors and staff in the eight facilities were wonderful hosts, and many became special friends over the course of this project. I hope this research will contribute to greater recognition of their work and improvement in their working conditions.

A number of the day-care participants I met have since died or moved into long-term care facilities. A number of the workers and directors have left this field of employment because of the stress associated with the work. Regardless, their experiences have made a lasting contribution to this study. I hope their words will not be forgotten.

Acknowledgments

THIS WORK BEGAN as a graduate research project in the department of sociology at the University of Southern California. As my interests crystallized and I became determined to conduct a multisite field study, the difficulties inherent in such a project would have been insurmountable without a very supportive dissertation committee. I am most grateful to Vern Bengtson, Jon Miller, Andy Scharlach, and Carol Warren, who offered both the intellectual investment and emotional support necessary to complete the research.

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Writing is such a private experience; it is difficult for someone else to understand or value the process or the product as much as the writer does. I must express appreciation to Michael for everything, especially understanding. And to Heather and Lauren for trying to understand, and occasionally even being interested in the research! I hope that what my daughters have seen is some of the excitement of the intellectual journey, more than the destination, and that they remember something more than just the price of the ticket.

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Parts of this book have been published elsewhere. Portions of Chapter 1 may be found in *The Gerontologist* (Lyman, 1989a). Much of Chapter 4 has been published in *The Journal of Aging Studies* (Lyman, 1990). "Facility Design and Staff Stress: A Case Study" (in Chapter 5) has appeared in *The Gerontologist* (Lyman, 1989b).

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