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Challenges of Residential Living in Late Life

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NEGOTIATING A GOOD OLD AGE

Preface

Negotiating a Good Old Age contains material that is critical to all of us, for both individual and institutional reasons. On an existential level, it answers "Where am I going and what will I become?"; on an institutional plane, it addresses the question "What is the emerging shape of long-term care?" Above all, this book covers the meeting ground of these concerns as it describes patterns of interaction between residents, staff, and setting in two homes for the very old, homes that were themselves in the process of change.

These issues gain their urgency from demographic changes that have generated a growing sense that familiar economic forces have slipped out of control. The ensuing uneasiness is expressed by such concerns as the right-to-die movement. Aging individuals look at patients in nursing homes and ask, "Must we live and die like this?" Passive euthanasia draws much of its support from the middle-aged and old. For its part, society examines the bill for long-term care, shakes its head, and says, "We can't afford it."

The attention now focused on issues of aging is but one part of a general concern about being human in a crowded world. Both the corrections and mental health fields deal with some individuals who appear to be unable to use the community alternatives our society is willing to fund. As their absolute numbers grow, increasing interest in settings of close containment will follow. Professionals will be forced to consider how these troublesome or needful people can be handled efficiently when care must be delivered within walls; those who are thoughtful will also begin to think about how individuality can be maintained under such circumstances. As these issues come into focus, we need to learn more about how people negotiate relationships in closed and semiclosed environments.

By describing the experiences of 116 residents in two homes for the aged over a fifteen-year period, this book examines negotiation about status and relationships and how individuals seek to maintain an acceptable self. Far from accepting the "elderly mystique" with its low goals and self-expectations (Cohen, 1988), these residents jousted with peers, attempted to control staff, and tried to make good lives and deaths for themselves in settings that some chose and others did not.

Each home offered two levels of care and control. Most residents liked the boarding units but waged lonely battles to stave off patienthood. In describing similar struggles in a retirement complex, David Morgan (1982) points out that when persons entered they shed their burdens, but when they became patients they lost their independence. Some won their fight to remain boarders to the end; more did not. Like the residents, staff members also aged and left, while the homes themselves changed under the impact of economic, regulatory, and population factors.

The homes were in flux. They were transforming themselves in order to survive. At the study's start, the dichotomy was clear-cut: one home was proprietary, the other sectarian. Each typified its kind. Seventeen years later, the two homes have become more like each other. Both are like small ships tossed on the same sea of regulation that has accomplished some professionalization but has failed to make most facilities for the elderly decent places to live and die.

Background Information

This book is based on a longitudinal study I conducted in the 1970s and 1980s. Instruments measuring social resources, norm conformity, and morale were administered to a cohort of residents in

1973 to 1974 and again to the survivors in 1978, 1979, 1980, 1981, 1982, 1983, and 1984. By the last year, the number of subjects had shrunk from the original 116 to 10. At the present writing, one survivor remains. In-depth interviews centering around the Philadelphia Geriatric Morale Scale provided a rich flow of qualitative data that reflected changes over time. (See Resource A for attrition and Resource B for all of the instruments except the Philadelphia Geriatric Morale Scale, which is available in Lawton's [1973] chapter of a book edited by Brantl and Brown.)

In this book, I use material about residents anecdotally but also follow some persons throughout the narrative in order to illustrate changes in status and in the management of self over time. *Negotiating a Good Old Age* stays with individuals, settings, and staff long enough to find out "how it all came out."

Because of my personal relationship with each of the subjects, a word of explanation is in order. While I was engaged in doctoral studies, I provided social services at Mountainside, a sectarian home for the aged. Theories relating to deviance, control, and social resources came alive as I observed daily exchange in the setting. When I came to do research for my dissertation, I found that these well-educated residents were happier to have me as a researcher than as a social worker: They wanted to contribute to knowledge; they were not sure they needed social services.

To expand my sample into numbers I could work with, I added Countryside, a proprietary facility. I spent several months getting acquainted with its residents before I began administering tests, and from 1973 to 1974, I gathered data. My role at Countryside was purely that of researcher, but again I found myself drawn to the residents and the staff.

Eventually I completed my dissertation and set off for Australia; but I was hooked, and I corresponded with people in the two homes. From afar, I watched the small dramas, the deaths, and the sudden turns of fortune.

When I returned to the United States in 1978, I went back to the homes and administered tests to the survivors. Thereafter, I returned each summer, interviewed those who remained, did in-service training for the staff, and observed the changes in the settings. By 1984, only ten of the original subjects remained. Three were lost to the study and the others were dead, so that year I tested for the last time. In December 1984, the last members of the original cohort at Countryside died and I ceased my visits there, but I continued to go to Mountainside. At this writing, one Mountainside resident from the original group remains in the nursing unit, and we stay in touch. As an old friend might, I have come to feel a sense of personal loss at each resident's passing and also to experience vicarious release when I knew the person was praying for death.

The study's strength lies in its longitudinal perspective. The people, the buildings, and even the neighborhoods change over time. Peer leaders rise and fall and many individuals snatch small victories and die good deaths. Administrators despair but keep going.

The study's limitations have positive features. On the one hand, because it was not tightly planned as a longitudinal study, the point of view shifted to take into account larger structural features: Over time I became aware that the ship was moving as well as its passengers. On the other hand, the instruments were frozen into place, although some might not be chosen today. Because of the age of the residents, time eventually reduced their numbers below statistical convenience. Finally, the two homes were atypical in at least two respects: Neither belonged to one of the big national chains that have come to dominate the long-term care "industry," and most of the residents were middle class. The two homes experienced the constraints of smaller size and state regulation, but their independence of distant management may have made them more responsive to individuals and to intrasystemic pressures. In addition, the absence of the poor and minorities meant that findings were not complicated by the problems of lifetimes of deprivation and struggle. Life had been relatively kind to these people, and what happened to them at Countryside and Mountainside reflected the experience of old age and institutionalization relatively uncontaminated by past or current social injustice.

For Whom Is This Book Intended?

For various readers, the book offers special features and attempts to answer certain questions.

For readers in general, there are the portraits of the residents.

How does one preserve something of one's self when others control so much of one's life at the end, when the biological assault seems so inexorable? What happens when children grow old and friends die? Can others take their place? How, at the end of life, can one live so close to so many others?

For the sociologist, the social psychologist, and the anthropologist, there are the two settings, each offering two levels of care and control, each level with its own roles, statuses, norms, and sanctions and with residents moving between them. Is transfer between boarding and nursing units determined solely by medical criteria? And if not, what other factors enter into the decision? Who is able to fend off transfer, and how? How do different ground rules constrain the individual's ability to bargain for status and to resist demands? When staff's expectations compete with those of peers, which prevail? Do "conformers" conform to everything or do they choose their areas of conformity? What is lost and what is retained when most familiar statuses are stripped away?

For the planner, the applied sociologist, and the administrator, there are the changes over time in the two settings. These homes serve similar clienteles and charge equivalent rates, but only the proprietary home makes a profit. Do nonprofit facilities provide more, or do they operate less efficiently? Do licensing requirements improve care, or do they result chiefly in the paper compliance that is easier to check than is the quality of service delivery? Can nonprofits remain service oriented in a climate of rising costs? How can the demands for affordable care be reconciled with the demands for individualization and self-determination?

For those professionals with patients and clients in old-age settings—physicians, nurses, psychologists, social workers, activities directors, administrators, and board members—there are the day-to-day and year-to-year observations in the two homes. Why does so much friction surround the interaction between staff members and the patient's spouse? Why are so few roommates friends? Why do some residents slip easily into the hierarchies of congregate living and others persistently court rejection? What happens to patient care plans when professionals must depend on paraprofessionals to implement them? Does the patient become their hostage? How can the arrival of a new director of nursing affect the incontinence level?

How do residents shape the behavior of staff? Does the resident's unhappiness over placement necessarily mean that he or she is dissatisfied with the home?

Above all, what happens to the inner self in the course of the moral career, when the challenges of institutional living reach from entry to the door of death? (See Resource C for waystations in the institutional career.)

Finally, for all readers as responsible members of society, there are the profound and sometimes costly changes that have taken place in both settings. How can an appropriate degree of consumer autonomy be engineered into a system already burdened with staff accountability and budgetary and licensing controls? Within the existing constraints, what can be done to support the elderly resident more and make the system better?

In dealing with these issues, *Negotiating a Good Old Age* employs a symbolic interactionist perspective to help the reader understand the interplay between resident and resident and between resident and staff, especially in status negotiation. It draws on the social exchange theory of Blau (1964), Emerson (1962), Rogers (1974), and Dowd (1980); Goffman's (1961) institutional totality; Roth's (1963) concept of the career; Lieberman and Tobin's (1983) work on institutions and identity; Litwak's (1985) exploration of the complementary roles of formal and informal systems; Strauss's (1978) examination of negotiation; and Glaser and Strauss's (1971) work on status passage.

Because of the rapidity of change, journal articles and demographics ground observed shifts within the two homes. Those emerging from the 1985 National Nursing Home survey (National Center for Health Statistics and Hing, Sekscenski, and Strahan, 1989; National Center for Health Statistics and Hing, 1987) are of special importance.

Overview of the Contents

The book describes the efforts of residents to negotiate acceptable selves as they move through the levels of care and the concurrent changes in the two homes themselves. These are discussed in three parts, each with its own introduction.

The first part, "The People, the Places, the Paths," describes the homes themselves, the roles and rules available to residents, and the way the elderly residents moved through them.

The five chapters in the second part, "What Actually Takes Place in Residential Settings?," examine the ways in which residents negotiated their statuses, the resources on which they drew, the shifting patterns of constraint, the support and power they encountered, and how their residential careers came to an end.

The final part, "Adaptations to a Changing Climate: Where We Are Now and What We Can Do," relates the two homes' adaptations to a changing political and demographic climate for long-term care and considers the three areas most deeply challenging to the preservation of self and most amenable to change: the management of incontinence, dementia, and staffing. The section closes with concrete steps physicians, nurses, social workers, and families can take while waiting for larger-system change. Despair is immobilizing; action is liberating.

Acknowledgments

Because all names have been changed to protect people's anonymity, I cannot thank as I would like to the wonderful residents and staff members who helped me write this book. I can only say that I owe a good deal to them and to Ludwig Geismar, my mentor, and Albert Schmidt, my husband.

I would also like to thank reviewers of the manuscript, especially Carolyn Wiener and Rosalie Kane, who contributed to my thinking and made this a better book, as did my editor, Gracia A. Alkema. I was never alone.

San Diego, California
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Mary Gwynne Schmidt

The Author

Mary Gwynne Schmidt is professor of social work at San Diego State University. She received her B.A. degree (1943) from the University of North Carolina, Chapel Hill, in American History; her M.A. degree (1958) from Teachers College, Columbia University, in the teaching of social studies in secondary school; and both her M.S.W. degree (1964) and her Ph.D. degree (1975) from Rutgers, the State University of New Jersey, in social work.

Schmidt's published papers have appeared in *Health & Social Work, Nursing and Health Care, The International Journal of Aging and Human Development,* the *Journal of Gerontological Social Work, Hospital & Community Psychiatry,* and *The Gerontologist,* and she serves on the latter publication's editorial board. She contributed a chapter in Irene Burnside's *Working with the Elderly: Group Process and Technique* (1984).

Schmidt previously taught at the Flinders University of South Australia. She presently serves on the faculties of the San Diego State University School of Social Work and the San Diego Geriatric Education Center, a partnership between the University of California San Diego School of Medicine and San Diego State University's Center on Aging. All of her consultation and most of her teaching have been in the field of aging, with special attention to long-term residential care.

Key Characters

Because this book deals with change over time, certain individuals appear more than once. To avoid having to reintroduce them and to aid the reader, some are listed below with a few words of introduction. These are not their real names, nor are Mountainside and Countryside the names of the two facilities.

Mountainside was a sectarian home in an urban setting. *Barbara Archer* was its administrator and *Beth McGann* its second director of nursing.

The *Santa Claus Society* helped educated persons maintain their lifestyle when their means were straitened because they had lived lives of service.

Characters

Evan Brewster fought an eight-year battle with cancer while living in the mansion he had admired as a boy. He was a table host, belonged to the Old Guard, and continued to drive his car.

Agnes Chase, a physical education teacher, entered Mountainside at seventy-five because she had only English cousins as her family. She brought much energy to her crusades for social justice.

Sarah Coleman, ninety-three, worried about rising costs and her fixed income. As she neared one hundred, she said, "I wish this wouldn't go on so long." She chose Mountainside in order to be close to her church and her friends.

Ramona Everly was a handsome, strong-minded woman, alert and mentally engaged, but she was very, very weary at the end. Like Sarah Penfield, she was an early peer leader.

Robert Farmer entered as a patient and later transferred to the boarding unit, where he became the unofficial organizer of games. His social resources included two physician sons.

Miss Godfrey, as a child, had romped with the children who lived at Mountainside when it was a family estate; in her nineties, she returned as a patient. A stockbroker's daughter, she retained her social connections.

Henry Hobart, legally blind, composed poetry on the typewriter to two loves. When the first died, he commented sadly, "Our children did not want us to marry."

John McGreevy, a Catholic, tweaked the blue noses in this nest of Protestants but basked in the affection of his family and his community and treasured his special telephone.

Dr. Ernest Magyar entered Mountainside at sixty-three with multiple sclerosis. When *Dr. Maria Magyar* came to visit her husband in the home, she deflected staff anger from him with her many demands.

Elka Miller was European in outlook and never quite at home at Mountainside, but she held on. Henry Hobart wrote poems to her.

John and Sarah Penfield had been active in Mountainside's founding and were respected peer leaders.

Elizabeth Reynolds had visited her church's home as a girl and knew "when the time had come." She carefully maintained her boarder status.

Margaret Wesley was pushed into the patient role when she entered the nursing unit as her husband's roommate. *John Wesley* had advanced Parkinson's disease but survived his wife.

Marcy Mae White was an English kindergarten teacher with a following of former pupils. She entered the nursing home rather than the boarding home because she was ninety-four.

Rachel Windsor, sixty-three, was Mountainside's youngest boarder.

Despite stroke-impaired speech and gait, she functioned well and had great symbolic importance for the group.

Countryside was a proprietary home in a rural setting. Most of its owners were physicians. At the study's start, *Ernest Miller* was its administrator and *Winnie Mason* its director of nursing.

Characters

The Commander was a feisty old explorer whose athleticism posed a problem. Colorful and a celebrity, he was "homesick" for flying.

Dorothy Dietrich, wealthy and unmarried, flourished with a private duty nurse while her ninety-year-old roommate, *Nellie Brown,* was often physically restrained and helpless.

Gretchen Elder alienated peers with her lamentations and staff with her rigidities. She spoke of her son's suicide with envy. She was a reliable informant.

Mrs. Flowers was unhappy in the home but fearful of leaving it because of her memories of lying helpless in her big house, waiting for her housekeeper to come. She had an attentive daughter.

Grace Gladwin, once head of a nursing agency, was a colorful, flamboyant figure whose descent into confusion troubled those who had known her.

Greta Hansen was taken from her husband's funeral straight to Countryside. She was cheerful and friendly but confused.

John McDevitt never ceased to complain about the "conspiracy" between physician and family that brought him to Countryside, where he was a peer leader in the boarding unit.

William McGillacudhy, a city politician, came to Countryside to be close to his daughter. A stroke sent him on a downward course. He and John McDevitt were Countryside's two Irishmen, but they were not friends.

Mamie Slocum tyrannized her fellow boarders. Among her prey was the sad widow she labeled "the Creep." Like Napoleon at Elba, she was angry at the cancer that cut short her late-life career and divorced her from her troops.

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