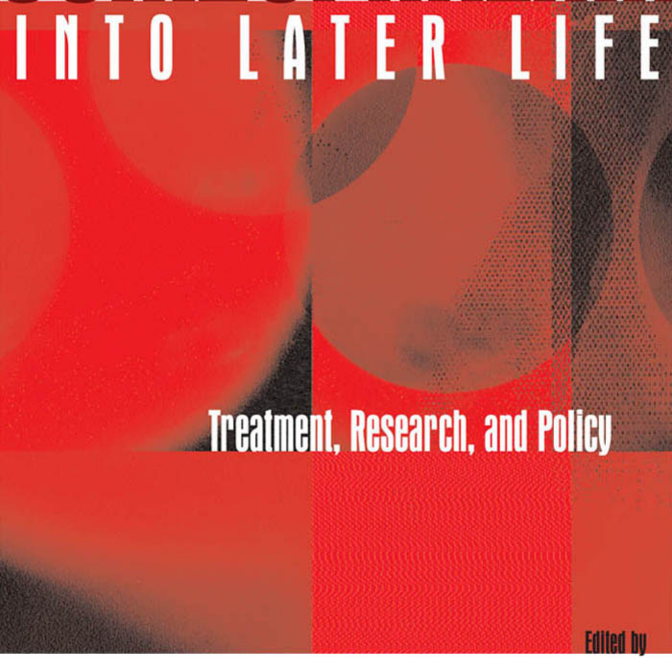
SCHIZOPHRENIA INTO LATER LIFE



Treatment, Research, and Policy

Edited by

Carl I. Cohen, M.D.

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Introduction

Carl I. Cohen, M.D.

A crisis has emerged in mental health care. It involves older persons with serious and persistent mental illness—those individuals 55 years and older with long-standing illnesses such as schizophrenia, bipolar disorder, or chronic depression—who have been largely invisible to mental health researchers, providers, and policy makers. Approximately 2% of the population older than 54 years—about 1 million persons—has a chronic mental illness other than dementia. Over the next 30 years, this number will double as postwar baby boomers reach old age. Importantly, this generation of persons with chronic mental illness will have spent considerably less time in mental institutions than earlier generations and consequently will need to negotiate health and social service systems that may be ill prepared to deal with them.

Because older persons with schizophrenia compose the majority of those with serious and persistent mental illness—and perhaps are most at risk with respect to clinical, social, and service needs—it is critical to focus initially on this population. Furthermore, an examination of schizophrenia in later life, when it has attained its most complex and developed forms, may provide many of the keys to the disorder itself. Remarkably little research is available on older persons with schizophrenia. For example, a search of PsycINFO and MEDLINE indicated that only 1% of the literature on schizophrenia has addressed issues of aging. No books devoted solely to the topic have been published in the United States since 1987, when Miller and Cohen's *Schizophrenia and Aging* was released. Moreover, few age-appropriate clinical, rehabilitative, or residential programs are available for older chronic mental patients. There is evidence that these deficiencies are even more pronounced in regard to minority populations, despite the fact that minorities are the fastest-growing segment of the aging population.

The aim of this book is to provide an overview of the current state of knowledge about schizophrenia in later life and to examine the implications for service, research, and policy. In recent years, late-onset schizophrenia (i.e., onset after age 44 years), which may be neurobiologically distinct from the early-onset disorder, has received disproportionately more attention than the latter in psychogeriatric journals and textbooks. However, persons who develop schizophrenia before age 45 years represent about 85% of all persons with schizophrenia. Therefore, we believe that it is important to redress this imbalance; the focus of this book will be primarily on the early-onset group.

A particular strength of this volume is its integration of a variety of perspectives about aging and schizophrenia. Many of the contributing authors have backgrounds in aging as well as other disciplines (e.g., biological psychiatry, social psychiatry, sociology, anthropology, social work, psychology, neuropsychology). Researchers, service providers, and policymakers are the principal target audience for this book, which will provide information on demographic and clinical characteristics of and treatment approaches to older persons with schizophrenia, as well as research strategies and economic and health policy issues. The book should also be of value to patients and their families.

A synopsis of the chapters illustrates the breadth of the content of this volume and provides a brief tour of the many elements that influence our understanding of schizophrenia into later life. The book is divided into five parts. Part I covers topics related to epidemiology, historical background and illness phenomenology, and diagnostic issues. In the first chapter, *Patterns of Care for Persons 65 Years and Older With Schizophrenia*, McAlpine provides a comprehensive review of existing research and analyses of national data sets that contains seminal data on the prevalence of schizophrenia in old age, the residential locations of aging persons with schizophrenia, and their patterns of mental health service use. Because of limitations in existing national surveys, her estimates of the size and characteristics of the older population treated in various settings and the costs of services must be viewed as provisional. Nonetheless, the data provide some benchmarks, help identify gaps in services, and point to potential future health system needs. In Chapter 2, *Changes in Schizophrenia Across Time: Paradoxes, Patterns, and Predictors,* Harding provides an in-depth review of the 10 long-term studies conducted around the world with a focus on the effects of aging on schizophrenia. The chapter uses these studies to explore issues related to diagnosis, symptomatology, social functioning, gender differences, work functioning, long-term use of psychopharmacology and other treatments, patterns of long-term course, and predictors of long-term outcome. In the third chapter in this part, *A Comparison of Early- and Late-Onset Schizophrenia*, Palmer, Nayak, and Jeste address the following questions: What is "late-onset schizophrenia"? In what ways, if any, does it differ from "regular" (earlier-onset) schizophrenia? Is the distinction between late- and earlier-onset schizophrenia purely a historical artifact, or does it have a neurobiological basis and/or heuristic utility in terms of the treatment and clinical management of affected individuals? In addressing these issues, the authors conclude that the evidence is sufficient to view late-onset schizophrenia as "true" schizophrenia, but the differences (which are usually matters of degree rather than of kind) suggest that there may be heuristic value in noting some distinctions. Thus, as was done in DSM-III-R (American Psychiatric Association 1987), but not in DSM-IV (American Psychiatric Association 1994), Palmer and colleagues advocate considering late-onset schizophrenia to be a subtype of schizophrenia. Finally, in the last chapter of Part I, *Differential Diagnosis of Psychotic Disorders in the Elderly*, Desai and Grossberg note that psychotic disorders are not uncommon in old age—the prevalence of psychotic disorders in the elderly ranges from 0.20%–4.75% in community-based samples to 10% in a nursing home population—and often have more toxic, metabolic, and structural associations that may cause greater difficulty in their treatment. The authors examine how various psychotic disorders occurring in older persons resemble and differ from each other with respect to onset, symptomatology, course, and management. Accurate differentiation of one psychotic disorder from another is the key to successful treatment.

Part II of the book deals with biological, neuropsychological, and medical issues in aging and schizophrenia. In Chapter 5, *Biological Changes in Older Adults With Schizophrenia*, Schultz notes how age-related biological changes will become increasingly important as the medical community adapts to the graying of our population. Within the mental health discipline, the effects of these biological changes superimposed on chronic schizophrenia will present even greater treatment challenges. In providing an overview of these challenges, Schultz addresses a number of key questions: 1) How do the brain differences observed in young adults with schizophrenia manifest in later life when additional structural and functional brain changes occur? 2) What is the evidence from postmortem studies of neurodegenerative processes in schizophrenia? 3) Do the probable neurodevelopmental abnormalities in schizophrenia predispose to a latent degenerative vulnerability? and 4) How do the effects of chronic medication exposure influence the biological features of schizophrenia in late life? In the next chapter, *Cognitive Functioning in Late-Life Schizophrenia: Course* *and Correlates*, Harvey and Friedman discuss cognitive functioning in older patients with schizophrenia. In so doing, they examine the characteristics of cognitive impairment in older patients with schizophrenia. They also compare recent findings from studies of older patients with the more thoroughly researched characteristics of younger patients. Moreover, the authors examine the association of cognition and functional impairment in older patients, evaluating whether the consistent relationships reported in younger patients still hold in older patients, particularly those with a chronic course of lifetime illness. Finally, they address the highly controversial issue of whether some older patients with schizophrenia have cognitive declines that are substantially greater than would be expected with normal aging. Although strong empirical findings are sparse at this point, Harvey and Friedman speculate about the biological factors that underlie both baseline cognitive deficits and cognitive decline. In the last chapter of Part II, *Medical Comorbidity in Older Persons With Schizophrenia*, Schoos and I review medical comorbidity in older schizophrenia patients, elaborating on several critical elements: 1) whether an increased or decreased susceptibility to certain medical problems is present in this population and, if so, what the most common problems are; 2) whether the services available to this population are comparable to those available to non–mentally ill elderly persons in the community, and whether any serious impediments to medical treatment exist; and 3) the extent to which existing services are used, as well as the level of consumer satisfaction with health care treatment received. Finally, the authors suggest theoretical pathways for future research concerning medical comorbidity in older persons with schizophrenia.

Part III transitions from the biomedical aspects of aging and schizophrenia into more social and cultural realms. In Chapter 8, *Gender Differences in Schizophrenia Across the Life Span*, which touches on the interface between biology and culture, Seeman discusses gender differences in the expression of schizophrenia across the life span and their implications for assessment and treatment. As an example, she points out that the strength of the connection between fetal insults and later schizophrenia is sex dependent. So it is between obstetric complications and schizophrenia, but in the opposite direction. Thus, the former more often affects females, whereas the latter more commonly affects males. These observations, when better understood, may lead to a clearer grasp of the pathophysiology involved and to more effective treatment. Moreover, in schizophrenia, premorbid functioning and quality of life during the first decade of illness are relatively superior in women, but the opposite is true in subsequent decades. Thus, compared with men, aging women with schizophrenia are more disadvantaged. In the next chapter, *Social Vicissitudes of Schizophrenia in Later Life*, I address the following questions: How do various social dimensions—e.g., social networks, coping strategies, functional adaptation, life satisfaction, and quality of life—differ between 1) older persons with schizophrenia and their same-age peers in the general population, and 2) older and younger schizophrenia patients? How does the aging process affect the various social dimensions? What are the best strategies for developing a conceptual model for studying the social world of older adults with schizophrenia?

Part IV of the book addresses issues related to services and treatment; the latter covers both formal interventions such as pharmacological and psychosocial treatment as well as informal care provided by kin. In Chapter 10, *What Are the Service Needs of Aging People With Schizophrenia?*, Meeks and Depp assert that until recently, much of what we knew about schizophrenia in late life came from studies of inpatient populations. Inpatients are to some extent homogeneous in their service needs: they are all experiencing severe enough symptoms to disrupt their community functioning and usually are in need of medication and support sufficient to restore a base level of functioning so that they can be discharged. These authors explore several broad areas that seem most pertinent to ascertaining the service needs of this population: What symptoms continue to be problematic after discharge? To where, to whom, and to what kind of ongoing treatment are persons discharged? What are the factors that maintain them in their community residences? What factors contribute to the most positive quality of life? In addressing these questions, Meeks and Depp examine what is known about the characteristics of older people with schizophrenia, the needs implied by these characteristics, the current data about service utilization, and potential models for service structure and delivery. In the second chapter in this part, *Use of Novel Antipsychotics in Older Patients With Schizophrenia*, Kasckow, Mohamed, Zisook, and Jeste note that treating older patients with schizophrenia involves numerous challenges. For example, because chronic medical illnesses increase with age, the use of multiple medications becomes more common with the elderly. Moreover, changes in drug metabolism and receptor sensitivity occur with aging. As a result, the appropriate choice of psychopharmacological agents becomes an important decision in treating these patients. The authors discuss the use of atypical antipsychotics in the older patient with schizophrenia within the context of the problems associated with aging.

In the third chapter of Part IV, *Community-Based Treatment of Schizophrenia and Other Severe Mental Illnesses*, Mohamed, Kasckow, Granholm, and Jeste observe that research on the effects of community-based treatments for schizophrenia has expanded rapidly in the past two decades. An emerging body of evidence now demonstrates that community interventions can indeed improve the long-term outcome of schizophrenia in younger patients. However, research in this area in older patients has been scarce and needs to be augmented. The authors' review provides an update on research on community-based treatment for schizophrenia and other severe psychiatric disorders, including assertive community treatment, case management, vocational rehabilitation, supported housing, day treatment, and patient clubhouses. Because only a few studies of these community-based treatments have focused specifically on older persons with schizophrenia, the authors have used age ranges, means, and standard deviations from extant studies of schizophrenia patients in general as well as extrapolating from studies of similar programs for older community residents without schizophrenia to speculate whether such programs might be effective with older populations with schizophrenia. In the fourth chapter in this part, *Biobehavioral Treatment and Rehabilitation for Older Adults With Schizophrenia*, Liberman observes that psychosocial interventions for elderly persons with schizophrenia and related disorders have only recently become evidence based and empirically validated. However, these interventions are evolving into well-specified mental health techniques, whether delivered individually or in groups within the context of residential, day treatment, or ambulatory programs, as well as through consultation and liaison to allied social and medical agencies and personnel. In this chapter, Liberman describes such interventions (e.g., cognitive behavioral therapy, social learning skills, and disease management and adaptation skills) and their impact on older persons with schizophrenia.

In the fifth chapter in Part IV, *Changing Caregiving Needs as Persons With Schizophrenia Grow Older*, Lefley writes that with progressive deinstitutionalization, many families have assumed the supportive functions of the old state hospitals for persons unable to survive on their own. Research both in the United States and throughout the world indicates that families are now the major caregivers and lifetime support systems of persons with schizophrenia. Even when patients reside in assisted-living facilities or residential housing affiliated with community mental health centers, families continue to be a significant source of financial, emotional, and social support. Thus, in this chapter, Lefley attempts to answer a number of questions with respect to caregiving and aging: What will happen when family caregivers grow older and are no longer able to fulfill their supportive roles? Are there cultural differences in caregiving patterns, in perception of family burden, and in the availability of substitute caregivers? Do experiences and expectations vary among ethnic groups in the United States and in other countries of the world? How is caregiving experienced during different stages of the life cycle? Does family burden increase with the age of the patients and the caregiver? What are the resources available to caregivers under these conditions? Finally, what are the issues facing aging caregivers, how do they perceive them, and to what extent are they able to plan for the future of their loved ones after they are gone? In the last chapter in Part IV, *Mental Health Policy and Financing of Services for Older Adults With Severe Mental Illness*, Bartels and Dums provide an overview of mental health policy and financing of services for older persons with severe mental illness (SMI). First, the authors discuss the need for services for older persons with SMI in the context of the shift from institution-based care to the community. Second, they discuss current fee-for-service mental health services and describe the role of Medicaid and Medicare financing. Third, they examine managed Medicaid and Medicare and consider whether mental health services should be "carved in" or "carved out." Fourth, they describe innovative models of organizing and financing long-term care and their implications for older persons with SMI. Finally, the authors identify priorities that mental health policy must address to meet the future needs of the growing population of older adults with SMI.

Part V contains the book's concluding chapter, *Toward the Development of Theory and Research in Aging and Schizophrenia;* here, I provide an overview of some of the critical issues that must be considered in the development of research on schizophrenia into later life: 1) the current state of theoretical models and the benefits and feasibility of developing a comprehensive model that incorporates biological, psychological, and social dimensions; 2) the various methodological problems inherent in conducting research, including the relative merit of qualitative versus quantitative methods, the dangers of prematurely circumscribing variables or using instruments that are inadequate for the object under study, the sociohistorical and value assumptions of research, the potential utility of nonlinear methods, the critical need to carefully consider the implications of so-called significant findings, and the value of establishing partnerships between researchers and participants; and 3) the practicality of adapting extant gerontological models for research with older populations with schizophrenia.

In addition to the contributors who made this volume possible, I wish to thank Barbara Singh, for her administrative and secretarial assistance, as well as the extraordinary editorial staff at APPI, including Jennifer Wood, Rebecca Richters, Pam Harley, Abdul Kargbo, and Judy Castagna. I also want to thank my three departmental chairs during this endeavor, Drs. Eugene Feigelson, Martin Kesselman, and Peter Weiden, who allowed me sufficient time to engage in scholarly activities. My work on this volume was supported in part by funding from the National Institute of Mental Health (RO1 MH53453) and the National Institute of General Medical Sciences (NIGMS; SO6 GM54650). The final acknowledgments must go to my wife, Kate, and my children, Sara and Zack, for their emotional support and to my parents and patients, who continue to teach me about aging

and life in general. I have created a web site (http://hometown.aol.com/cohenhenry/schizophreniaintolaterlife.html) for this volume in which authors have provided additional references and will periodically update their chapters.

In 1987, Nancy Miller and Gene Cohen concluded their introduction to the last volume published in this country on schizophrenia and aging by expressing the modest hope that the chapters in their book "might bring us one small step closer to understanding and curing this mysterious and devastating disorder" (p. xxix). Indeed, their work did bring us several steps forward. I hope that this volume can do the same.

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PART I

Epidemiology, Historical Background, Illness Phenomenology, and Diagnostic Issues

CHAPTER 1

Patterns of Care for Persons 65 Years and Older With Schizophrenia

Donna D. McAlpine, Ph.D.

Schizophrenia in Later Life: Patterns of Health Services Use and Need

Very little is known about health services utilization and needs among older persons with schizophrenia. The weight of research attention has focused either on the general population of persons with severe mental disorders or on the health services needs of young persons with schizophrenia. As a result, even basic data describing the types of services used by older persons with schizophrenia, sources of care, and potential costs are lacking.

In recent years, there has been increased recognition of the need to address the mental health needs of older persons, including those with schizo-

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phrenia (Cohen 2000; Palmer et al. 1999; U.S. Department of Health and Human Services 1999). In part, this increased attention has been driven by concern that as the population ages there will be an increased burden on the health care system to address the mental health needs of older persons. Schizophrenia accounts for about 25% of all mental health care costs and about 2.5% of total health care costs (Crown et al. 2001). Moreover, some research suggests that the treatment costs for older cohorts of persons with schizophrenia approach the high costs associated with treatment for young adults (Cuffel et al. 1996). Although the focus of researchers, policy makers, and providers has expanded to include older persons, we know little about the patterns of services utilization among this population.

This chapter seeks to begin to address this research gap. Through a review of existing research and analyses of national data sets, patterns of mental health service use among older persons with schizophrenia are outlined. The data presented are descriptive and are not meant to explain differences in patterns of care. Moreover, the estimates of the size and characteristics of the older population treated in various settings and the costs of services are tentative because of limitations in existing national surveys. Nonetheless, the descriptive data presented provide some benchmarks, help identify gaps in services, and point to potential future health system needs.

Trends in the Prevalence of Schizophrenia Among Older Persons

The best evidence from the United States about the prevalence of schizophrenia among persons 65 years and older comes from the Epidemiologic Catchment Area (ECA) study. The ECA was conducted in five sites in the early 1980s and focused on providing national estimates of the prevalence of specific mental illnesses. As shown in Table 1–1, the ECA studies estimated the prevalence of schizophrenia among persons 65 years and older at 0.3%; the comparable estimate for the total population was 1.5% (Keith et al. 1991). As also indicated in Table 1–1, the ECA found no significant gender, racial, or ethnic differences in the estimated prevalence of schizophrenia among older persons.

Although the ECA data provide the best national estimates of the prevalence of mental disorders, these estimates are limited by small sample sizes of persons with schizophrenia, especially older persons. Moreover, some have argued that the ECA study underestimated the prevalence of schizophrenia in later life, because the diagnostic criteria did not include schizophrenia with onset after age 45 years and the ECA study did not sample

TABLE 1–1. Lifetime prevalence of schizophrenia among persons 65 years and older: Epidemiological Catchment Area study

	Percentage (95% CI)[a]	**Estimated population (2000), *N* (95% CI)[b]**
Total ≥ 65 years	0.3 (0.10–0.50)	104,975 (36,391–173,559)
Male	0.2 (0.00–0.40)	28,819 (576–57,062)
Female	0.3 (0.10–0.50)	61,746 (21,405–102,087)
Hispanic	0.4 (–0.4–1.18)	6,934 (0–20,525)
African American	0.6 (0.21–0.99)	16,724 (5,797–27,651)
White	0.3 (0.10–0.50)	87,735 (30,415–145,055)

Note. CI=confidence interval.
[a] Based on estimates provided from the Epidemiologic Catchment Area study (Keith et al. 1991).
[b] Based on census 2000 estimates (U.S. Census Bureau 2001).

sufficiently in areas where elderly persons with schizophrenia were likely to be living (Palmer et al. 1999). Others have suggested that the actual prevalence of schizophrenia in later life is probably about 1% (Cohen 2000).

Assuming that the 1% estimate is close to the true prevalence, in 2000 there were appropriately 350,000 persons in the United States 65 years and older living with schizophrenia. As the population of older Americans grows, so will the numbers of older persons with schizophrenia. As shown in Figure 1–1, by 2020 the size of the population of persons 65 years and older with schizophrenia will have increased by more than 50%. By 2050 there will be more than 800,000 persons 65 years and older with schizophrenia—and by 2070 the estimate exceeds 1 million.

As the population ages, older persons with schizophrenia will constitute a larger proportion of all persons with schizophrenia. The National Comorbidity Study estimated the prevalence of nonaffective psychosis (schizophrenia and schizophreniform disorders) among persons ages 15 through 54 years to be 1.3% (Kendler et al. 1996). Assuming that this estimate reflects the true prevalence for persons under the age of 65, in 2000 adults 65 years and older composed approximately 13.6% of the total population of persons with schizophrenia. By 2020 this percentage will increase to 17.6%, and by 2035 to 21.5%—with older persons continually making up a larger proportion of the population with schizophrenia over the coming decades.

The increase in numbers of persons with schizophrenia in later life will challenge the existing system of care. Examination of current patterns of services utilization foreshadows the types of challenges that will be faced over the next few decades. In this chapter I review services in three areas:

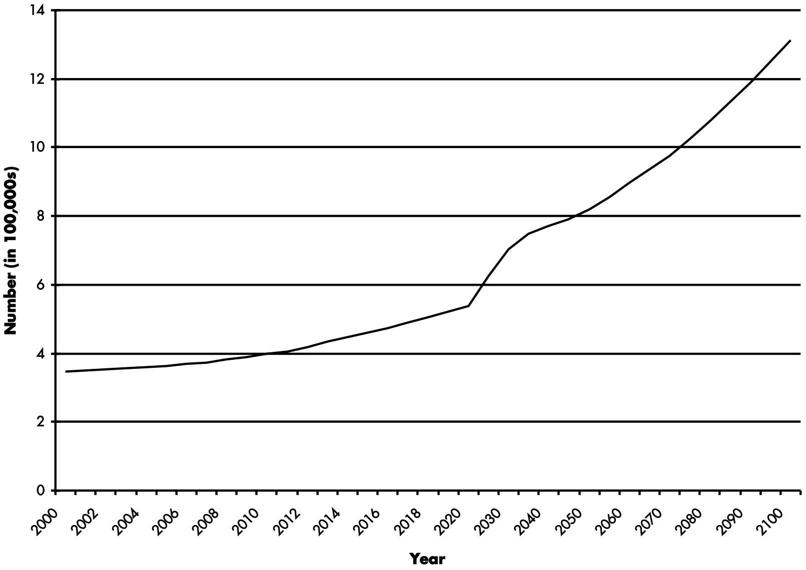

FIGURE 1–1. Estimated number of persons 65 years and older with schizophrenia.

inpatient care, nursing home care, and outpatient care. The financing of mental health care for elderly persons with schizophrenia is also discussed.

The Inpatient Sector: Psychiatric and General Hospitals

In the past half-century the population of persons in psychiatric hospitals has dramatically decreased, from more than 550,000 residents in mental hospitals at the end of 1955 (Mechanic 1999) to 78,433 residents at the end of 1998 (Manderscheid et al. 2001). Deinstitutionalization, the process of reducing the patient population cared for in psychiatric hospitals, had a particularly strong effect on patterns of mental health care for older persons. Frank (2000), for example, noted that as the number of residents in state psychiatric hospitals substantially declined from 1962 to 1972, the number of mentally ill elderly persons living in nursing homes increased, suggesting that nursing homes were replacing psychiatric hospitals as the most common sites of institutional care.

Psychiatric hospitals have a smaller role in the provision of mental health services than they once did; however, they remain an important sector of care, especially for persons with severe mental illnesses. Although detailed information is not available on the characteristics of older persons with schizophrenia currently residing in psychiatric hospitals, published data provide estimates of the size of this population.

The most recent detailed information about the diagnostic and age composition of persons in public psychiatric hospitals comes from the Center for Mental Health Services' 1994 enumeration of residents and annual additions to public hospitals. At the end of 1994, state and county mental hospitals housed approximately 3,770 patients 65 years and older with schizophrenia and related disorders. This group comprised about 40% of all patients in such hospitals who were 65 years and older. During the same year, there were 2,252 additions of older persons to public mental hospitals, making up about 24% of all admissions for persons in this age group (Atay et al. 1995). The number of admissions relative to the size of the resident population is a measure of the turnover in hospitals. In 1994, the number of admissions per 100 resident population was 59.7 for persons 65 years and older with schizophrenia, compared with 202.7 for persons ages 18–64 years. Older patients, therefore, have much longer lengths of stay in public mental hospitals than do younger patients.

These estimates, however, are based on data from the early 1990s, and it is unclear how well they apply in the current climate of continued deinstitutionalization, increased privatization, and expanded managed behavioral health care. More recent data from a sample of persons receiving care in specialty mental health organizations indicate that in 1997 the daily population of persons 65 years and older with schizophrenia in state and county mental hospitals was 6,529, compared with 9,376 in 1994 (Milazzo-Sayre et al. 2001). If we assume that the proportion of patients with a diagnosis of schizophrenia remained constant over those 3 years (40%), in 1997 the daily population of persons 65 years and older with schizophrenia in public psychiatric hospitals was about 3,917.

In 1997, private psychiatric hospitals cared for approximately 19% (*N*=1,508) of all patients 65 years and older in mental hospitals (Milazzo-Sayre et al. 2001). Private hospitals are less likely than public hospitals to include persons with schizophrenia; in 1997, approximately 18.8% of the resident population of private hospitals were patients with schizophrenia. If we assume that the percentage of patients with schizophrenia is similar across age groups, it is clear that private psychiatric hospitals are not a major source of care for elderly persons with schizophrenia. The approximate daily census at the end of 1997 was only 240 persons 65 years and older with schizophrenia.

As beds in psychiatric hospitals have declined, general hospitals have increasingly become the common site of care for persons with mental disorders (Mechanic et al. 1998). For instance, Ettner and Hermann (1998) estimated that of all inpatient stays for the diagnosis of schizophrenia among elderly Medicare recipients in 1990, one-third were in psychiatric hospitals and the remaining two-thirds were in general hospitals. Care in general hospitals includes beds in psychiatric units as well as scatter beds in general medical wards. Ettner and Hermann (1998) estimated that 19% of inpatient stays were in nonpsychiatric units. Even in hospitals that have separate psychiatric units, many patients with mental illnesses are treated in general medical wards. Ettner (2001) estimated that among Medicare beneficiaries admitted to hospitals with a psychiatric unit, approximately 37% are treated in general medical wards.

Recent data on the size and characteristics of the older population with schizophrenia receiving care in general hospitals are available from the National Hospital Discharge Survey (NHDS; U.S. Department of Health and Human Services 2001a). The NHDS is an annual probability survey of discharges from nonfederal, general hospitals with average lengths of stay of 30 days or less across the United States. Hospitals are sampled in the first stage of the survey, and discharges from selected hospitals are sampled in the second stage. The data presented come from the survey conducted in 1999 of 458 general hospitals and 300,460 discharges. The information collected from hospital records included demographic characteristics of the patients, admission and discharge dates, diagnoses and procedures, source of payment, and the like. As many as seven diagnoses could be coded, with the first-listed being the primary diagnosis. Analyses are computed separately for those with a first-listed diagnosis of schizophrenia and those with any listed diagnosis of schizophrenia (code 295 in the *International Statistical Classification of Diseases, 9th Revision, Clinical Modification* [ICD-9-CM; World Health Organization 1978]). These groups are also compared with the total population of discharges for persons 65 years and older.

Estimates are weighted to be representative of the nation. The National Center for Health Statistics does not release survey design information necessary to adjust standard errors for the complex sampling design. Thus, only approximate standard errors are calculated, consistent with the recommendations of the National Center for Health Statistics (U.S. Department of Health and Human Services 2001a). Nonoverlapping confidence intervals indicate significant difference between estimates.

As shown in Table 1–2, in 1999 there were approximately 24,000 discharges from general hospitals of persons 65 years and older with a primary diagnosis of schizophrenia. More than three times this many discharges occurred among this age group for persons with any listed diagnosis of schizophrenia, indicating that many older persons with schizophrenia receive treatment for other medical problems in general hospitals.

TABLE 1–2. Characteristics of discharges from general hospitals of persons 65 years and older with a diagnosis of schizophrenia

	Primary diagnosis of schizophrenia	**Any-listed diagnosis of schizophrenia**	**Total discharges for persons ≥ 65 years**
Female, %	71.6 (61.1–82.1)	61.5 (55.1–67.8)	58.7 (58.1–59.2)
Age ≥ 80 years, %	11.3 (4.0–18.7)	19.8 (14.5–24.8)	39.8 (39.3–40.3)
White, %	85.8 (77.3–94.3)	83.4 (78.1–88.7)	86.8 (86.4–87.0)
From public hospitals, %	11.5 (4.0–18.9)	11.1 (7.0–15.2)	9.9 (9.6–10.2)
Mean length of stay, days	15.5 (10.7–20.3)	9.6 (7.6–11.6)	6.09 (5.3–6.9)
Total	24,019 (18,010–30,027)	78,603 (66,246–90,960)	12,682,559 (11,536,164–13,808,954)

Note. 95% confidence intervals are presented in parentheses.

Discharged patients with a primary diagnosis of schizophrenia were significantly more likely to be women (71.6%) compared with the general population of older persons treated in general hospitals (58.7%). Moreover, approximately four times as many discharges for the total population were of patients 80 years and older compared with discharges for persons with a first-listed diagnosis of schizophrenia. Finally, the average length of stay was longest for persons with a first-listed diagnosis of schizophrenia, about 6 days longer than that for persons with any listed schizophrenia diagnosis, and more than twice as long as that for the total population of discharges of persons 65 years and older from general hospitals.

In sum, although patients 65 years and older with a first-listed diagnosis of schizophrenia make up only a small fraction (about one-tenth of 1%) of annual discharges from general hospitals, they consume significantly more days of care than the total population of older patients. Discharged persons with schizophrenia are also more likely to be female and younger in comparison with the total population of discharged patients 65 years and older.

Nursing Homes

Increasing numbers of persons with severe mental illness were housed in nursing homes as the availability of beds in psychiatric hospitals declined (Kruzich 1986; Schmidt et al. 1977). In response to this trend, the Omnibus Budget Reconciliation Act of 1987 (OBRA-87) was passed, which was intended to improve care for persons with mental illness in nursing homes and to prevent inappropriate admissions. OBRA-87 mandated preadmission screening (to ensure that only persons in need of nursing care were admitted) and annual reviews of residents to screen for mental health problems and service needs. Data suggest that since the passage of OBRA-87, the numbers of persons with mental illness inappropriately housed in nursing homes has been dramatically reduced, although the reductions have been greatest for younger people (Mechanic and McAlpine 2000).

The most recent data describing the characteristics of nursing home residents come from the National Nursing Home Survey (NNHS) conducted in 1999 by the National Center for Health Statistics (U.S. Department of Health and Human Services 2001b). The NNHS is a multistage stratified probability sample of nursing home facilities, current residents, and discharges. In the first stage, facilities were sampled; in the second stage, up to six current residents and discharged residents from each facility were sampled. A staff member who could refer to the medical record was interviewed about the resident's demographic characteristics, diagnoses, use of medical services, limitations in activities of daily living, and the like. Up to six current diagnoses could be listed. The data presented here focus on current residents with any diagnosis of schizophrenia (ICD-9-CM code 295). This group was compared with the total population of nursing home residents 65 years and older. Differences in demographics, including age, gender, and race, were examined. In addition, differences in degree of disability were assessed by comparing the proportion of residents with problems in activities of daily living (walking, dressing, eating, toileting, bathing) and instrumental activities of daily living (managing money, keeping possessions secure, using the telephone, caring for personal possessions). Characteristics of the stay include time since admission and whether the resident has received any mental health services during the last month of stay. The data are weighted to be nationally representative. Approximate standard errors are calculated consistent with National Center for Health Statistics guidelines (U.S. Department of Health and Human Services 2001b).

As shown in Table 1–3, nursing home residents 65 years and older with a diagnosis of schizophrenia are significantly younger than the total population of nursing home residents. Although about 38% of the residents with a diagnosis of schizophrenia are 80 years or older, more than 70% of the total nursing home population are in this older age group. Residents with a diagnosis of schizophrenia are also significantly less likely to be white (79.3%) compared with the total resident population (87.2%). The unweighted sample sizes are too small to permit reliable estimates of other racial/ethnic groups. However, preliminary estimates suggest that persons with schizophrenia are more likely to be African American (18.9%) relative to the total nursing home population of persons 65 years and older (9.7%).

Results from the NNHS also indicate that persons with schizophrenia in nursing homes are less disabled than the total population, as measured by problems in activities of daily living. A smaller proportion of the population with schizophrenia compared with the total nursing home population had three or more problems with activities of daily living. The opposite pattern held for problems in instrumental activities of daily living. Older persons with a schizophrenia diagnosis experienced a greater number of such problems than did other nursing home residents, although the difference was not statistically significant.

Nursing home residents with a schizophrenia diagnosis also had much longer lengths of stay in comparison with the general nursing home population. The average length of stay for older residents with schizophrenia was 4.41 years, compared with 2.37 years for the total resident population 65 years and older. Moreover, as is shown in Table 1–3, approximately twice as many of those with a schizophrenia diagnosis had lived in the

TABLE 1–3. Characteristics of persons 65 years and older with schizophrenia in nursing homes, 1999

	Schizophrenia diagnosis	**Total population**
Female, %	69.6 (63.3–72.9)	74.3 (73.3–75.3)
Age ≥ 80, %	37.6 (31.0–44.3)	72.1 (71.0–73.1)
White, %	79.3 (73.7–84.8)	87.2 (86.4–88.0)
Received mental health services, %	54.9 (48.1–61.7)	21.6 (20.5–22.4)
3+ ADLs, %	70.6 (64.4–76.9)	80.8 (79.9–81.7)
3+ IADLs, %	74.8 (68.9–80.8)	69.1 (68.0–70.2)
Length of stay, years		
<1	25.1 (19.2–31.0)	42.6 (41.4–43.8)
1–5	46.2 (40.1–53.7)	43.8 (42.6–45.0)
>5	27.8 (21.7–34.0)	13.6 (12.8–14.4)
Total	42,746 (35,368–50,122)	1,469,525 (1,311,679–1,627,371)

Note. 95% confidence intervals are presented in parentheses. ADLs=activities of daily living; IADLs=instrumental activities of daily living.

facility for 5 years or more, compared with the total population of nursing home residents 65 years and older.

In sum, nursing home residents 65 years and older with schizophrenia are more likely to be younger and nonwhite than are others housed in nursing homes. In addition, they have resided in nursing homes for longer periods, although they report significantly lower levels of disability, as measured by problems in activities of daily living. Finally, almost half of older nursing home residents with schizophrenia had received no mental health services in the past month.

Outpatient Care

Most care for older persons with schizophrenia is delivered in noninstitutional settings. Although the role of general hospitals in providing such care has been reviewed, most services are provided in the outpatient sector. Medicare is the primary payer source of outpatient services for persons 65 years and older; thus, analyses of data based on Medicare claims provide some evidence of patterns of outpatient service use for this population.

Dixon et al. (2001) examined the use and costs of ambulatory services in a national sample of more than 12,000 Medicare enrollees with a schizophrenia-associated service claim in 1991. They reported that Medicare enrollees 65 years and older with a diagnosis of schizophrenia who used mental health ambulatory services had approximately 4.8 visits in the past year, including individual therapy, group therapy, family therapy, and psychiatric somatotherapy. Extrapolating to the total Medicare population in 2000, this equates to about 1.1 million annual mental health visits for persons 65 years and older with schizophrenia.

However, this research also indicated that even among the Medicare population, all of whom are insured, many persons with schizophrenia did not receive services. Approximately 35% of the group 65 years and older with schizophrenia had no claims for ambulatory mental health services in the past year. Although the data do not include claims paid by other sources (i.e., Medicaid), the large percentage of people who do not have a Medicare claim for ambulatory services suggests that many older persons with schizophrenia do not receive adequate treatment.

Financing

Medicare is the primary insurer for the population 65 years and older, covering about 97% of the population (Health Care Financing Administration 2000). In 2000, Medicare was responsible for financing the care of about 13% of the total number of persons with schizophrenia, but as the population ages this percentage will substantially increase. For example, by 2025 approximately 20% of persons with schizophrenia will be 65 and over. The costs associated with treating persons with schizophrenia, therefore, will increasingly be the responsibility of the Medicare program.

Inpatient care continues to be the costliest service sector for persons with mental illness. Cano et al. (1997) estimated that in 1995 the costs of inpatient care (including care in general hospitals, psychiatric hospitals, and skilled nursing facilities) for Medicare beneficiaries with schizophrenia and related disorders were about 27% of the total inpatient costs for beneficiaries with a primary mental disorder. Such costs continue to rise. Between 1993 and 2000, the costs of care in psychiatric hospitals increased by about 9%. Over the same period, costs of care for Medicare patients in general hospitals increased by 11.8% (Bureau of Labor Statistics 2001).

Although less costly per episode of care, ambulatory services are more commonly used than inpatient care. Dixon et al. (2001) examined the costs of mental health ambulatory services among Medicare enrollees 65 years or older who used mental health services in 1991. They estimated that the cost per person was about $321 annually. Costs for persons with schizophrenia, however, include not only those associated with mental health care but also the substantial costs associated with general medical care. Husaini et al. (2000), for example, examined these costs in a sample of elderly Medicare beneficiaries in Tennessee. They reported that mental health costs composed only about 6% of total medical care costs for persons with schizophrenia.

Many Medicare beneficiaries also receive Medicaid, making this public insurer another important funding source for persons with mental illness. In the NNHS (National Center for Health Statistics 2001b), Medicaid was the primary payer for 81% of claims submitted by nursing home residents with schizophrenia in the past month, compared with about 6% of past-month claims for Medicare. Moreover, the average cost of a day of treatment for these residents was $108. Costs of care in skilled nursing facilities have also substantially increased in recent years. Between 1993 and 2000, the cost of care for public payers increased by more than one-third (Bureau of Labor Statistics 2001).

Conclusions

The data used are limited both by the types of information collected and by the small sample sizes that preclude extensive subgroup analyses. In particular, the sample sizes of race and ethnic subgroups with schizophrenia are too small to permit meaningful analyses. The results presented here, although tentative, suggest that elderly African Americans with schizophrenia are more likely to be housed in nursing homes than are white Americans. This finding is consistent with other research suggesting that, among Medicare beneficiaries, African Americans with mental health problems are more likely to receive care in institutional settings than are white Americans (Cano et al. 1997).

Substantial numbers of persons 65 years and older with schizophrenia receive care in other settings not covered in this review. Such settings include residential care, Department of Veterans Affairs hospitals, jails and prisons, and adult day care centers. Unfortunately, we lack the national data to sufficiently explore personal characteristics and types of services received for the elderly population treated in these settings.

The data presented are also limited because the public data files used do not include the information necessary to calculate exact standard errors. Thus, the statistics presented and the corresponding confidence intervals are only rough estimates. Despite these limitations, existing data do offer insight into existing patterns of care.

The results highlight the fact that older persons with schizophrenia are not treated in institutional settings—approximately 12% are residents of nursing homes, and only about 3% are in psychiatric hospitals each year.

However, elderly persons with schizophrenia are more likely to be admitted to institutional care at younger ages and, once admitted, have much longer lengths of stay than the general population 65 years and older.

These results also point to high levels of unmet need in services for the older population with schizophrenia. This finding is consistent with other research indicating that almost three-fifths of adults with severe psychiatric disorders do not receive specialty mental health services in a year (McAlpine and Mechanic 2000). It is somewhat surprising, however, to find among an insured population that many persons with schizophrenia still do not receive services. This applies to the nursing home population, in which almost 50% of persons with schizophrenia did not receive mental health services in a 1-month period. It also applies to the outpatient population, in which 35% of the population had no claims for mental health services in 1991 (Dixon et al. 2001).

As the size of the population 65 years and older increases in the coming decades, it is likely that meeting the needs of persons with schizophrenia will be even more difficult. Medicare, the primary payer of health care for the elderly population, currently does not pay for psychiatric services to the same extent that it pays for general medical services. For example, Medicare places a limit of 190 lifetime days in psychiatric hospitals, which creates an incentive for elderly persons with schizophrenia to seek and receive care in other settings after that limit is reached. The Mental Health Parity Act of 1996 did not include Medicare benefits. Legislation mandating parity between general medical and psychiatric care within Medicare has been proposed. Such parity may help address the large unmet need for care in the population of older persons with schizophrenia.

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CHAPTER 2

Changes in Schizophrenia Across Time

Paradoxes, Patterns, and Predictors

Courtenay M. Harding, Ph.D.

There exist two polar, yet accurate, views about the outcome of schizophrenia. Huber et al. (1979), after studying the outcome of schizophrenia in 502 patients for more than two decades, wrote: "Schizophrenia does not seem to be a disease of slow progressive deterioration. Even in the second and third decades of illness, there is still a potential for full or partial recovery" (p. 595). Nine other such studies agree. Yet today, we have dayrooms, shelters, and public mental health caseloads consistently overcrowded with persons chronically languishing with the diagnosis of schizophrenia. Furthermore, DSM-IV (American Psychiatric Association 1994) indicates that complete remission is likely uncommon, and they go on to describe a variable course of exacerbations and remissions for some patients and a chronic one for most persons. Although this is an improvement from earlier, more

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dire, predictions of a deteriorating course for all patients (e.g., American Psychiatric Association 1980, 1987; Kraepelin 1902), a significant discrepancy remains between the prognostic expectations of official psychiatry and the findings of 10 long-term studies completed during the last three decades of the twentieth century. Arguments against this paradox have often centered around the use of other diagnostic systems in these studies, although most are similar to the DSM-IV. This chapter shows that regardless how wide or narrow such systems are, patients still persist in improving across time and thus have much to teach us.

Some of the 10 catamnestic (or longitudinal follow-up) studies of schizophrenia analyzed particular areas of functioning, whereas others did not. Some of these reports were published in the authors' native languages and were only translated roughly by the author and colleagues. The end of the chapter will target a few implications for treatment and research. Other key factors that shape the long-term course of schizophrenia (but are not yet mentioned in DSM-IV) are discussed in more detail by other chapter authors. Other key factors that also shape the long-term course of schizophrenia (and that are not yet mentioned in the official diagnostic manual) are discussed in more detail by other chapter authors. These modifiers include 1) the neural plasticity and recalibration of the aging brain, 2) gender differences and the effects of hormones, 3) cognitive decline in the face of a nonstimulating environments, 4) medical comorbidities, and 5) misdiagnosis and other iatrogenic effects of treatment. Such crucial ingredients, which help or hinder forward progress in persons with schizophrenia, contribute further pieces of the puzzle inherent in the paradox.

Brief Overview of 10 Contemporary Follow-Up Studies of Two to Three Decades in Length

The common practice in psychiatric research is to follow samples of convenience for only those subjects who remain in treatment. However, the following longitudinal studies investigating schizophrenia and other serious mental illnesses followed intact cohorts across a period of two to three decades, regardless of whether the subjects were still in treatment. By not following samples of convenience and by maintaining follow-up for such a long time, these studies provide a new view of schizophrenia. They also give evidence that challenges our preconceptions about chronicity and allows us to rethink models and treatment. Each of these projects was reported within the past 30 years or so, during an era of keen interest and funding of such studies. Each provides significant evidence confirming the wide heterogeneity of outcome, and each finds that approximately one-half to two-thirds of people with schizophrenia can achieve a state of significant improvement or even recovery (M. Bleuler 1972/1978; Ciompi and Müller 1976; DeSisto et al. 1995a, 1995b; Harding et al. 1987b, 1987c; Hinterhuber 1973; Huber et al. 1979; Kreditor 1977; Marinow 1974; Ogawa et al. 1987; Tsuang et al. 1979). Table 2–1 summarizes data from these studies.

As can be seen in the table, the studies were conducted in seven countries. Studies outside the United States consisted of primarily urban samples, whereas the American studies examined rural samples. Altogether, a total of 2,429 patients (sample range 115–502) were followed for an average of approximately 28 years (range 20–37 years). The percentage of patients showing significant clinical improvement ranged from 46% to 84% (median value 53%), and the percentage of patients who were considered socially recovered ranged from 21% to 77% (median value 49%). Thus, a wider range among studies was found for social response than for clinical response. Together, these studies help to rebalance the picture of schizophrenia.

Switzerland #1—The Burghölzli Hospital Studies

The first of these studies was conducted in Zurich, Switzerland. Manfred Bleuler (1972/1978) began following a sample of patients admitted to the Burghölzli Hospital between April 1942 and December 1943 and maintained follow-up over the next two decades, regardless of whether the patients remained in treatment—something his father did not do. His sample consisted of 100 males and 108 females with diagnoses of schizophrenic psychoses. The diagnostic criteria used were a combination of those from his father, Eugen Bleuler, and Emil Kraepelin and were considered to be narrower than those of the American DSM-II (American Psychiatric Association 1968) and wider than the DSM-III (American Psychiatric Association 1980). M. Bleuler excluded patients with brain disease, endocrine disorders, poisoning, latent schizophrenia, neurosis, mixed psychosis (schizoaffective), or a previous course. This strategy had been unavailable to Kraepelin. Sixty-eight of the 208 (33%) probands studied were considered first admissions. Their ages ranged from 16.0 to 67.5 years, with an average age of 40 years. After considerable research, M. Bleuler (1972/1978) concluded that these subjects came from "the same sectors of the population as do all schizophrenics hospitalized in the Canton of Zürich during the period in question" (p. 12). None of the probands in this study died of brain disease during the follow-up period.

The Burghölzli Hospital Study was conducted in a systematic and comprehensive manner using structured instruments as well as clinical in-

TABLE 2–1. Long-term studies of schizophrenia

Study	**Sample size, *n***	**Average length, years**	**Percentage of subjects recovered and/or significantly improved***	**Percentage of subjects socially recovered**
M. Bleuler 1972/1978, Switzerland	208	23	53–68	46–59[a]
Hinterhuber 1973, Austria	157	30 (approx.)	75	77
Huber et al. 1975, Germany	502	22	57	56
Ciompi and Müller 1976, Switzerland	289	37	53	57
Kreditor 1977, Lithuania	115	20+	84	NI
Tsuang et al. 1979, United States	200	35	46	21[b]
Marinow 1986, Bulgaria	280	20	75	NI
Harding et al. 1987b, 1987c, United States	269	32	62–68	68[c]
Ogawa et al. 1987, Japan	140	22.5	56[d]	47
DeSisto et al. 1995a, 1995b, United States	269	35	49	[e]

Note. *Recovered = no further symptoms, no use of psychotropic drugs, living independently in the community, working, and relating well to others, with no behaviors that are considered to be odd or unusual; significantly improved = all of the above, but one domain of functioning. NI= not enough information to rate.

[a] Multiple admissions vs. first admissions.

[b] Marital status only recorded.

[c] Live interviewed DSM-III schizophrenia group—the hardest data.

[d] Derived by adding 33% recovered with a conservative 23% as improved (from 43% listed).

[e] When variables not chosen for matching criteria were covaried out of the Maine–Vermont comparison, differences in social functioning lost statistical significance.

Source. Adapted from Harding and Keller 1998.

terviews. M. Bleuler (1972/1978) found that 68% of the first-admission patients and 53% of the multiple-admission patients significantly improved or recovered. Among the many findings reported were that 1) life histories revealed that most patients had experienced "disturbances in their home life," but no one particular type stood out and no direct causal linkages could be established; 2) genetics appeared to play a role, but only a partial one (citing discordant monozygotic twins and other family data); 3) therapy may or may not have played a key role in the recovery process; 4) E. Bleuler's (1911/1950) "group of schizophrenias," which implied different etiologies, was still elusive; and 5) gender differences played a role. Bleuler focused on getting to know these patients and their relatives personally, and further social functioning was determined from criteria of work, independence from care, and living in a nonsheltered environment. No social impairment was observed for 46% of the overall cohort and for 59% of members of the first-admission subsample. With regard to sex differences, Bleuler found a 6:1 female-to-male ratio of improvement, and females showed a slight edge over the males in the recovered and mild impairment categories. He said, "I have found the prognosis of schizophrenia to be more hopeful than it has long been considered to be" (M. Bleuler 1984).

Austria—Hinterhuber's Study

Between 1930 and 1940, 157 people with schizophrenia were first admitted to the Innsbruck Psychiatric Clinic in Austria (Hinterhuber 1973). At follow-up, 99 (63%) of these patients had died or were presumed dead, and 58 (37%) were still alive. Data were extracted from several sources, including structured questionnaires, interviews with relatives, and biographies. Hinterhuber (1973) used diagnostic criteria from Bleuler, Kraepelin, and Schneider to study the sample, which was composed of 87 women and 70 men considered to have "obvious schizophrenia." Using data from all sources, the results, which were published primarily in German, revealed that 50% of these patients were "released from treatment," but 33% remained enrolled in continued full-time care. In measures of psychopathology, 29.2% of the sample were reportedly "cured" of their schizophrenia, with another 45.6% improved and 30.5% still ill. Work functioning had remarkably resumed, with 77% working full-time, 20% working part-time, and the remaining 8% in family care. Subjects who had incurred injuries prior to illness (34.6%) remained mostly in the "severe final stages" of illness, with only 21% falling into the "cured" category. Course modifiers leading to poorer outcomes included psychological trauma, genetic loadings, and interestingly, later onset (after age 40 years).

Switzerland #2—The Lausanne Investigations

The "Lausanne Investigations" were conducted by Ciompi and Müller (1976), who undertook the longest follow-up study reported in the world literature. They conducted assessments of 92 men and 197 women across a median length of 36.9 years (SD = 13.3 years), with a range of up to 64 years after first admission to the University Psychiatric Clinic. Of the sample, 20% had catamnestic histories of more than 50 years' duration. Thus, Ciompi and Müller's findings might be considered closer to E. Bleuler's concept of *Reichtung Prognose* ("final prognosis"). The average age of males at follow-up was 75.2 years; females averaged 75.8 years. This sample was considered to be representative of the 1,642 patients admitted to the clinic who were 64 years of age or younger at their first admission and who were 65 years of age or older at the beginning of the study in 1963 (Ciompi and Müller 1976). The initial large group (*N* = 1,642) was targeted to study mortality and causes of death.

These investigators used a combination of Kraepelinian and Bleulerian criteria. Inclusion symptoms for schizophrenia included "disturbance of psychotic proportions…marked by manifold and alternating combinations of the so-called primary disorders of thought and emotion, autism, ambivalence, loss of contact, and experience of depersonalization or derealization" (Ciompi 1980, p. 607). Patients with questionable diagnoses of schizophrenia were excluded. The research team conducted 2-hour semi-structured interviews in the probands' homes, and more data were collected through records, correspondence, and interviews of family, friends, and others in care systems (agencies and clinicians). Because of the complexities of human beings and schizophrenia, outcome domains were measured separately before being combined into a "recovered," "improved," or "deteriorated" status.

Results were quite varied. Highlights revealed that the average mortality rate for those in the sample was 173%, versus 100% for the Swiss population (Ciompi 1980), with women suffering the most, at 185% (vs. males at 161%). Twenty percent of subjects had been hospitalized for more than 20 years. Ciompi pointed out that hospitalization rates were also influenced by many social and economic factors (e.g., system, family, social structures).

Symptoms among the patients changed considerably over time. For example, 62% of all individual symptom profiles had "'vanished' in old age,…and [an] additional 11% were clearly improved, with just 20% who remained unchanged in old age or had intensified" (Ciompi 1980, p. 611). However, only about a third of these patients were doing exceptionally well in social relationships. Classical predictors, including "good premorbid social, familial, and professional adaptation, few premorbid personality disorders; a marriage, completion of vocational training, and a higher premorbid occupational level," held into old age. Furthermore, it was found that "the disease tends to run a more favorable course, the more acute, the more lively, and the more mobile the onset of the illness." Finally, Ciompi (1980) noted that "treatment factors were much less important for the long-term course than the above-described personality and disease factors" (p. 615).

Sex similarities were found, with 66.3% of the women in the "recovered" or "mild" categories compared with 61% of the men; whereas 7.1% of the men became worse, only 3.3% of the women did so (Ciompi 1980). Five patients demonstrated very late improvement. Using composite ratings, the team found "59% recovered or mild end states" (p. 616). Ciompi (1980) later concluded that "the long-term evolution of schizophrenia is much better than hitherto admitted," which was in keeping with the conclusions of "Bleuler and Huber, [who] both concluded that schizophrenia is in no way 'basically' or even 'predominately' [an] unfavorable 'disease process' running an inexorably deteriorating course" (Ciompi 1980, p. 616).

United States #1—The Iowa 500 Study

In the first American study, the Iowa 500 Study assessed 100 patients with mania, 225 patients with depression, and 200 patients with schizophrenia who had been part of the annual admissions to Iowa State Psychopathic Hospital during the 1930s and 1940s. An additional group of 160 nonpsychiatric surgical patients (appendectomy or herniorrhaphy) was selected for a control group (Tsuang et al. 1979). These investigators applied the narrow Feighner criteria and clinical judgment to the comprehensive records available of that era (Feighner et al. 1972). The study concluded that these diagnosis were validated by follow-up information (à la Kraepelin) as well as family studies. Of 3,800 admissions, 874 charts were initially reviewed, with 20%–63% of records rejected depending on the chart diagnosis for schizophrenia (i.e., 63% of those diagnosed with schizophrenia were rejected) (Winokur and Tsuang 1996).

In the schizophrenia sample, 48.5% were females; 20% were married; 50% had poor premorbid psychosocial adjustment; 28% were high school graduates; median age at onset was 25 years; age at admission was 27 years; and only 26% had been discharged to the community (this was an era of custodial care with essentially no treatment [Winokur and Tsuang 1996]). Follow-up data were extracted from letters sent by social workers to the families for several of the early years. No information was available on 4%, only 17% of patients were interviewed, and 25% had information supplied by family or friends, with 53% supplied by physicians or other hospital admissions (Winokur and Tsuang 1996). The fieldwork of the very-long-term follow-up period (average=37 years) consisted of interviewing those patients still living who could be found (*n*=86 of 200, or 43%) and first-degree relatives and evaluating all available records. The Iowa Structured Psychiatric Interview (ISPI; Tsuang et al. 1980) was administered by non-medical interviewers. Current diagnosis was based on data from the ISPI and on medical records through a consensus of three clinicians. Patients or first-degree relatives who had died or who refused to participate were given an "approximate" diagnosis based on medical records. Twenty screening questions were used for both reliability and validity of all diagnoses with little data reported.

Only four major outcome domains were measured: marital, residential, and occupational status and psychiatric symptoms. The criteria for good outcome were married or widowed, living in one's own home or with a relative, employed, retired, homemaker or student, and no symptoms. A fair rating was defined as divorced or separated, living in a nursing or county home, incapacitated due to physical illness, and some symptoms. A poor rating was considered if the patient was single or never married, living in a mental hospital, not working due to mental illness, and experiencing incapacitating symptoms. At long-term follow-up 30–40 years after the index hospitalization, 39 of 186 (21%) had a good marital outcome and 22 of 186 (12%) were rated as fair. For occupational status, 65 of 186 (35%) had good outcome, with an additional 14 of 186 (8%) with fair levels. For residential status, outcomes for 64 of 186 (34%) were good and another 89 (48%) were fair. For psychiatric status, 38 of 186 (20%) were rated as good, with 48 of 186 (26%) at fair levels. Winokur and Tsuang (1996) noted that disorientation and memory deficit at admission seemed to predict poorer outcome. Sex differences (men=102; women=98) were not reported in the overall outcome variables. Although these investigators focused on the 54% of patients who were rated as doing poorly, they neglected to point out that 46% of the cohort were actually doing much better. Nonetheless, the findings showed that outcomes for schizophrenia were at the end of a sequence ranging from affective disorders having the best outcome to schizoaffective disorders to paranoid-type schizophrenia to disorganized type having the worst outcome.

Lithuania—"Late Catamnesis of Recurrent Schizophrenia With Prolonged Remissions"

In an observational study, Kreditor (1977) studied patients with episodic schizophrenia (*N*=115) over a period of 20 years in five regions of Riga at the National Dispensary. The sample consisted of 38 men and 77 women with an age range of 35–82 years. Approximately 54% were 50 years or older. Diagnostic criteria for schizophrenia were fairly broad. Ninety-seven (84%) of these patients had long-term remissions that extended 8–40 years. Kreditor identified two types of episodic courses, one with occasional episodes and the other with multiple episodes. Ninety-seven subjects had prolonged remissions (including 39% with 20–40 years remitted), and only 18 became worse. Predictors of long-term remission were "harmony of premorbid personality," lack of or low occurrence of character pathology, late onset (ages 30–40 years), and affective stability. The two course-type groups differed in premorbid personality, age at onset, and illness course. "The data give ground to eliminate the prognostic criteria of the probability of long-term remissions" (Kreditor 1977, pp. 110–113).

Germany—The Bonn Investigations

Huber et al. (1979) followed 502 of 758 admissions to the University Psychiatric Clinic of Bonn, Germany, between 1945 and 1959. Of these patients, 142 died before follow-up (including 7 [4.9%] who were suicides). Of those probands still living, 209 males and 293 females were assessed for 22.4 catamnestic years with personal interviews by the clinical team between 1967 and 1973. This part of the sample was believed to be representative of the usual admission profile for the clinic. Relatives reported on the status of an additional 26 probands (4%); 34 (7%) more were lost to follow-up, and 6 (1%) had brain diseases. Forty-eight (10%) refused interviews; however, the investigators found that this group consisted mainly of persons with good prognostic factors such as above-average intelligence and upper-class status. The investigators used the combination criteria of Schneider (based primarily on Kraepelin) and Eugen Bleuler, which had also been used by Manfred Bleuler (1972/1978). Like Bleuler, Ciompi, Harding, and others, they did not use outcome to define the diagnosis. Furthermore, "no symptoms or syndromes at the time of onset could be used to predict with any certainty whatever, the differentiation between malignant or benign, process or nonprocess,...schizophrenic...psychoses" (Huber et al. 1980, p. 593). Sixty-seven percent became cohort members at first admission.

The authors reported that 57% of their subjects were improved and/or recovered. Other instruments found that 22.1% had achieved complete remission, with an additional 40.2% demonstrating "noncharacteristic residual syndromes." Thirty-five percent were considered to have "characteristic residual syndromes." Fifty-six percent of the cohort were judged to be socially recovered (meaning that they had returned to their premorbid fully employed status)—"all the more remarkable when only 13% had participated in any outpatient rehabilitation program" (p. 595). Social functioning was highly correlated with outcome of psychopathology (Huber et al. 1980). Sex differences were found in better outcome for females in general and specifically in social outcome. Schizophrenia in first-degree relatives tended to differentiate men with poorer outcomes. Females were more likely to have better outcomes if they had multiple episodes with clear-cut precipitating factors. Females also tended to have more florid symptoms but a later illness onset. Complete remission, more favorable outcomes, and social recovery tended to occur in females. Cerebral atrophies occurred more often in males, who also had more psycho-organic disorders of the elderly. Course was described as "phasic" in 22%, "surges" in 48%, and "sluggish" in 21%. The authors identified 76 course types, which they reduced to 12 categories. They also noted that outcome shifted among some cohort members no matter how long a certain status was in effect. However, they found that "no reasonably reliable prognosis for the individual patient is possible" (p. 604).

Bulgaria—Marinow's Long-Term Follow-Up Study

A two-decade study (mean=20.2 years) conducted in Bulgaria by Marinow (1986) followed 280 male schizophrenia patients who had been discharged from hospitalization between 1946 and 1950. The cross-sectional outcomes for members of this cohort were measured every 5 years. Subjects were assessed on variables such as psychopathology and social and work functioning. Each factor was then combined into a summed total outcome or "prognostic" score. Findings revealed that at least 50% of subjects had a "favorable" outcome, with approximately 25% improved and another 25% with a poor outcome. Marinow found the course picture to be one of mixed signals with conflicting indicators of long-term outcome and concluded that it was impossible to predict future status for individuals. In a later study of persons with schizophrenia (*N*=634) whose illness duration ranged from 2 to 20 years, Marinow (1988) found that long-term outcome had greater correlation with the patient's marital status, ability to work, and with neuroleptic treatment than with illness history, number of readmissions, and length of hospitalizations, but he was unable to "predict prognosis." The diagnostic criteria used in this study appear to have been wider than those used in American, Swiss, and German studies.

United States #2—The Vermont Longitudinal Research Study

A second American long-term catamnestic study was conducted in Vermont for which base reports were published in the 1980s (Harding et al. 1987b, 1987c). This study is the longest study of deinstitutionalized patients to be conducted in the United States (ranging up to 62 years after first admission) and one of the longest studies of schizophrenia. The sample of 269 patients (144 females and 125 males) with severe and persistent mental illness was selected from the back wards of Vermont State Hospital in the mid-1950s.

Probands were provided with a "rehabilitation unit" after 2 years of only modest responses to long trials of clinically therapeutic dosages of phenothiazine. The patients and their multidisciplinary clinicians jointly created a federally funded, comprehensive model demonstration, biopsychosocial rehabilitation program that targeted self-sufficiency and community integration (Chittick et al. 1961). Their combined effort in the hospital provided training in activities of daily living and social skills; continued medication; vocational assessment, training, placement, and continued supports; patient government; peer support groups; case management; and careful deinstitutionalization.

A substudy of the parametric characteristics of the entire hospital census (*N*=1,300) revealed that the back-ward patients in the cohort had the most chronic course and were the most severely ill and disabled (especially the males) patients compared with the hospital population at large (Harding et al. 1987b). The study cohort had an average of 16 years of illness and 10 years of total disability. Furthermore, these patients were shown to be among 19% who remained in the hospital during the previous 5 years or longer while other patients were admitted and discharged (G.W. Brooks, unpublished study ["Retained Patients With Schizophrenia From 1920s to 1970s"], October 1975). This group is considered to be the most chronic cohort ever studied in the world literature and therefore should have had the worst long-term outcome.

Members of the cohort were carefully deinstitutionalized in the late 1950s into a pioneering community mental health system and were provided rehabilitation for 10 years, until 1965, by the same team from the hospital (Chittick et al. 1961). In the community, all aspects of community care were established, including a range of residential and occupational placements and supports, outpatient clinics, inclusion in natural community organizations, and continuity of care long before community mental health centers were established (Chittick et al. 1961). They were followed for an average of 32 catamnestic years, with a range of 22–62 years after first admission. A major follow-up study funded by the National Institute of Mental Health was initiated in the early 1980s, at which time 97% of the Vermont cohort was located (262 of 269). The average age of the surviving interviewed cohort at follow-up was 61 years. A comprehensive and structured instrument battery was implemented, with all the interrater and interitem concordance testing reported (Harding et al. 1987b, 1987c). The field interviewers were blinded to the patients' records, and the record abstractors were blinded to outcome. Both cross-sectional and longitudinal measures were assessed. Prospectively gathered records and retrospective data were used to fill in the longitudinal picture, along with vocational rehabilitation records and structured interviews of family, friends, and clinicians. Recalibration of the index-admission diagnosis from the 1950s to the then-new DSM-III (American Psychiatric Association 1980) was performed with interrater trials that achieved a kappa level of .78 ($P<.0007$) (Harding et al. 1987c).

The original cohort was recorded to have 213 of 269 (79%) members with schizophrenia. The rediagnostic effort, done without the previous diagnosis assigned and according to DSM-III criteria, reduced that number to 118 (55%). Although the investigators followed 97% of the total sample of 269 subjects, only the hardest data were reported for outcome of schizophrenia, unlike in other studies. Those probands who were rediagnosed, primarily with schizoaffective disorders, psychosis not otherwise specified, and atypical psychosis, were excluded from the analysis of schizophrenia and outcome, as were those who were deceased.

In a review of North American follow-up studies, McGlashan (1988) mistakenly reported that these patients had very late average onsets, in their 30s. He later corrected that report to a mean onset of 24.2 years for males and of 27.1 years for females (Childers and Harding 1990; McGlashan 1991). McGlashan also originally thought that these patients were the workers of the hospital and were retained by the staff until the rehabilitation study, another misconception that he subsequently corrected (McGlashan 1991).

With 24% of the cohort deceased, an important methodological balance was introduced. Instead of simply comparing the demographic and illness variables with the surviving cohort, a special protocol was introduced that systematically interviewed the family, friends, and clinicians connected to these patients in one room in order to piece together the life lived by the patients until their deaths. This strategy revealed that instead of the most seriously ill cohort members dying first, leaving the less ill members reporting better outcomes, the subjects mirrored the same proportions of recovered, improved, or unimproved persons found in the live cohort (Harding et al. 1987b). Other long-term studies have combined information for the living and deceased subjects.

The interview instrument battery used in the follow-up study consisted of 15 standard scales and schedules (Harding et al. 1987a, 1987b). Much to their surprise, the Vermont investigators found that nearly two-thirds of the subjects from this chronic, severely ill cohort met stringent objective criteria for recovery and/or significant improvement. Of the whole, 62%–68% achieved significant improvement or recovery across multiple domains of function, increased work (40%), reestablished social relationships (68%), and self-care (81%) (Harding et al. 1987c). Sixty-eight percent showed no further signs or symptoms of schizophrenia, with 45% of that group having no symptoms at all. All of these areas were predicted in the DSM-III to deteriorate or remain at marginal levels (American Psychiatric Association 1980). Instead, the domains not only reconstituted and improved but also developed further in two-thirds of the cohort.

Recovery criteria included no psychiatric medications, no symptoms, no behaviors that could be construed as those of a "mental patient," being employed, relating well with others, and living outside the hospital. Significant improvement meant that the person had achieved recovery in all but one of these domains. Social functioning was measured by several widely used and standard structured assessments and was another area that showed reconstitution and further development in 62%–68% of subjects (Harding et al. 1987c). Sex differences were also examined in the surviving DSM-III schizophrenia sample, which had 41 men and 41 women. Females, who had had the better premorbid functioning scores (Childers and Harding 1990), were shown to have lost their competitive advantage and ended up at only a trend level better than their male counterparts, who had consistently performed more poorly on all subscales and overall score of the Premorbid Adjustment Scale (PAS). Harding and Hall (1997) suggested that the explanation for the performance decrement seen in women might be the loss of estrogen protection at midlife (see also Seeman 1995). Furthermore, the men appeared to have slowly gained in strength across time (Harding 1994; Harding and Hall 1997; Harding et al. 1987c). Nevertheless, women's scores on the Community Adjustment Scale (Consalvo et al. 1984, cited in Harding 1994) remained slightly higher than those of men, despite the fact that they had longer lengths of stay in the hospital. Women also demonstrated more productivity, had less evidence of psychotic symptomatology, and evidenced higher levels of functioning in social relationships (Harding and Hall 1997).

During the initial data analyses, Strauss and Harding wrote, "we have gathered some evidence that the course of schizophrenia is a more complex, dynamic, and heterogeneous process than has been heretofore appreciated or predicted by diagnostic specificity" (Strauss and Harding 1984, p. 349).

Japan—Gumma University Hospital Study

Ogawa et al. (1987) conducted a 21- to 27-year follow-up of 140 consecutive patients (67 males and 73 females) discharged from the Department of Neuropsychiatry at the Gumma University Hospital in Japan between

1958 and 1962. At entry to the cohort, 81% of these patients were younger than 30 years; 79% were first admissions and resided primarily in the provincial town of Maebashi, northwest of Tokyo. These patients were provided with a program of "neuroleptic drugs, the open-door system, and intensive aftercare" (Ogawa et al. 1987, p. 758). The hospital's rehabilitation model was called *Seikatasu-rinsko* and was described as "clinical work in a patient's everyday life" (p. 750), which was reported as a combination of case management and individual counseling techniques.

At follow-up, 93% of the 140 members of this cohort were assessed, with 105 still living an average of 23.6 years after index hospitalization (range=21–27 years). One hundred subjects were alive and interviewed. In addition to the *International Statistical Classification of Diseases, 9th Revision, Clinical Modification* (ICD-9-CM; World Health Organization 1978) rediagnosis, subjects were also evaluated on social functioning indices with Eguma's Social Adjustment Scale (ESAS; Eguma 1962; Ogawa et al. 1987). Information was acquired from multiple data sources. The data were not analyzed with regard to sex differences.

The results revealed that 57% of the subjects were considered to be "fully self-supportive" (i.e., fully productive, living in own home and often also married, psychologically recovered, with a return to premorbid levels of functioning and independent social life without clinical interventions as well as maintenance of a normal family life). "Semi-self-supportive" ratings were given to another 19%, and 34% were considered to be "hospitalized and maladjusted cases." The Japanese team concluded that social recovery was greater than improvement in psychiatric status. They conducted monthly assessments of social adjustment and reported patterns of adjustment across time. These patterns showed multiple fluctuations early in the illness course, with later differentiation between the self-supporting and chronically institutionalized groups (Ogawa et al. 1987).

United States #3—The Maine–Vermont Longitudinal Comparison Study

The most recent American study was conducted in Maine (DeSisto et al. 1995a, 1995b) and, to my knowledge, is the only matched comparison study of very long outcome ever reported in the world literature. In this study, patients from the Vermont Longitudinal Research Study (*N*=269) were matched by age, sex, diagnosis, and length of hospitalization with patients in Augusta State Hospital who were treated during the same era and in similar catchment areas as defined by health and census data. The Maine study employed the same research protocols as the earlier Vermont study and incorporated the careful rediagnostic workups that the Vermont Longitudinal Project had used (DeSisto et al. 1995a, 1995b). The study also used the same treatment era and intraproject reliability testing. Of the Vermont patients, 97% were tracked for an average of 32 years after first admission; 94% of Maine patients were tracked across an average of 36 years. The major difference between the two study cohorts was that whereas subjects in the Vermont cohort had been part of a comprehensive model rehabilitation demonstration program, the Maine patients had experienced primarily traditional custodial care.

The Maine–Vermont study had an average of 36 catamnestic (time since first admission) years. Following the rediagnostic work, the sample comprised 102 subjects with DSM-III schizophrenia (57 males and 45 females). Comparisons of the two matched cohorts revealed significant differences. After covarying out several variables that could not be matched (e.g., urban vs. rural residence, level of education), three very strong findings held: Vermont patients 1) had much stronger community functioning ($P<.001$), 2) much stronger work functioning ($P<.009$), and 3) substantially reduced symptoms ($P<.002$). Overall, global functioning results found Vermont patients at 68% and Maine patients at 49% ($P<.0001$). Sex differences were found in the Maine cohort, with women rated better in premorbid social functioning.

What Have We Learned From These Studies?

In the following sections I assess the combined findings described above to determine what we might learn about the domains of diagnosis and time, symptom course, social functioning, ability to work again, psychopharmacology and side effects, predictors of long-term outcome, and reconstitution of lives.

Diagnosis and Time: Not as Strong a Predictor as Once Thought

In the field of psychiatry, diagnosis has long been reified and conceived of as a "lifetime" label (American Psychiatric Association 1980, 1994). In the United States, psychiatry tended to be ethnocentric, especially after an analysis showed that American clinicians overdiagnosed schizophrenia based on DSM-II criteria (American Psychiatric Association 1968) in comparison with clinicians in the United Kingdom (Cooper et al. 1972). Thus, although the Swiss and German studies used criteria narrower than those of Eugen Bleuler but wider than the Kraepelinian-based DSM-III (American Psychiatric Association 1980), American investigators discounted the European findings and proceeded to make criteria narrower and narrower.

However, the narrowness of the criteria used does not predict uniformly poor outcome, as was once thought (Harding et al. 1979, 1987c). The narrow Feighner criteria employed by the Iowa 500 study identified such a poor-outcome group with more efficiency (Tsuang et al. 1979, 1981). This approach was a trade-off, because it made the cohort findings less generalizable to the entire population with schizophrenia. However, much to everyone's surprise, even the sample identified in this manner has found heterogeneity in outcome. With one exception, these long-term studies revealed that diagnoses could be reconceived as "cross-sectional working hypotheses" (Harding 1998, p. 321) that need to be reviewed and revised over time and in many cases eventually discarded. There is evidence that patients with schizophrenia have more difficulty in achieving good long-term outcome than do many patients coping with affective and schizoaffective disorders, as found by the Iowa 500 group and others. However, the Vermont sample and others have demonstrated that even this effect is reduced to a trend level across decades. In an opposite approach, Vaillant (1975) also found heterogeneity when he attempted to follow up the other end of the continuum, the so-called good-prognosis patients. Discovering heterogeneity after 10 years, he concluded that "prognosis and diagnosis are two different dimensions of psychosis," in direct contradiction to Kraepelin (1902).

Symptom Course—Ever-Widening Heterogeneity With Early Fluctuations and Later Decrease of Virulence

Eugen Bleuler (1911/1950) called the disorder "a group of schizophrenias," and follow-up investigators are aware of the wide variation of individual histories, which supports Kendler's complex model of gene–person–environment interaction (Kendler and Eaves 1986). Huber et al. (1975) suggested 76 course types, indicating the wide heterogeneity found, but eventually reduced these to 12. Ciompi (1980) also published a diagram of 8 course types. His chart, with accompanying percentages, has been perceived as *the* standard by which course and outcome regularly proceed. However, Childers and Harding (1990) found evidence in the Burghölzli Hospital reports and the Vermont findings that these percentages are not written in stone but rather depend on the composition of the cohort. This observation means that predicting a probable long-term course for individuals is difficult if not impossible.

Predictors of Long-Term Outcome Weaken Over Time

Although some studies, such as the Lausanne Investigations, found that the classical predictors held across time, an unpublished manuscript by Harding and colleagues showed that the classical predictors of outcome in schizophrenia research can also fade in power to trend levels across decades. Such predictors include gender, type of onset, early versus late onset, symptom profile, and age at onset. The predictive power of sex, which has classically shown strong evidence in favor of females, weakens across time, perhaps as the protective effects of estrogen wear off with menopause (see Seeman [Chapter 8] in this volume). Menopausal women in the Vermont cohort lost their edge to the trend level, whereas the men grew increasingly stronger (improved in functioning and had fewer symptoms) across time. The only predictors that showed resistance to weakening over time were certain types of negative symptoms.

Restoration of Social Functioning

Harding et al. (1987a) and Harding and Keller (1998) analyzed the literature on social functioning and schizophrenia, which describes poor premorbid adjustment, deterioration during illness, feelings of isolation and estrangement, disordered emotional responsivity, bizarre behavior and speech that can drive friends and family away, and the symptom of blunted affect, which increases social isolation. The long-term studies revealed that social functioning most often is restored and even undergoes further development after a schizophrenic psychosis. Many of the studies found that this effect happened with greater frequency or was highly correlated with improvement in psychological functioning.

Regaining the Ability to Work Again

The assumption that once-psychotic persons are unable to work has been challenged repeatedly by a number of investigators (e.g., Anthony et al. 1984; Drake et al. 1999). Strauss and Carpenter (1974) showed that the best predictor of working is past work experience. Furthermore, diagnosis and symptoms did not predict work or social functioning or outcome across 5 years of follow-up. Previous social functioning did cross over to help predict work functioning. In the Maine–Vermont comparison, the subjects were matched and also happened to have had similar work histories prior to being hospitalized. The Vermont patients, who had participated in an intensive vocational rehabilitation program, continued working throughout the follow-up period at a rate of 30%–40%, with an additional 20% engaging in volunteer work within their communities. The Maine patients who did not receive vocational rehabilitation struggled to regain their employment status. The Vermont model focused on rehabilitation, self-sufficiency, and community integration; by contrast, the Maine model emphasized stabilization, maintenance, and entitlements (DeSisto et al. 1995a; 1995b).

Psychopharmacology and the Assumption of Lifetime Use Not Supported

There is an assumption—albeit one not supported in the literature—that most persons with schizophrenia need to remain on antipsychotic medication all of their lives. However, the Vermont study revealed that 20% were no longer receiving prescriptions for medication; 30% had drawers full of medications never taken; 25% had invented targeted strategies before Herz et al. (1991) and Carpenter et al. (1988); and the remaining 25% were taking their medications religiously, having been so threatened with recurring psychosis by past clinicians that their current clinicians were unable to taper their dosage. Harding (1998) concluded that perhaps only a small group of patients really needed continuing medications across a lifetime and recommended that the findings be investigated further. The idea of lifetime use of antipsychotics has been assumed because of the myth "once a schizophrenic, always a schizophrenic" or nowadays reframed as "once a broken brain, always a broken brain."

Many Pathways to Improvement and Recovery

M. Bleuler (1972/1978) observed that "the long-term experience gleaned from my probands revealed one fact most impressively, namely that successful results can be achieved through totally different methods" (p. 441). Furthermore, in the Vermont–Maine comparison, the investigators were startled to find that although significant outcome differences were found between the samples (which may have been attributable to the rehabilitation program in Vermont versus the custodial care in Maine), 49% of Maine patients continued forward toward improvement. At first, DeSisto et al. (1991) thought that the greater forward progress of the Vermont patients was due to decisions made at the top of the system—that is, Vermont appeared clear and consistent in its mission and comprehensive in its programs whereas Maine did not. Although some of this environmental impact may have been operative, Maine patients continued to improve despite the vagaries of their system of care.

After looking at all of the long-term studies across many treatment eras and finding that patients persisted toward recovery and/or improvement, new thoughts began to emerge about the power of human relationships, no matter what services are being delivered. The Vermont patients reported that they received the greatest benefit when they were told that someone believed in them: "Someone believed in me, someone told me I had a chance to get better." To Harding, this illustrated the importance of hope and showed that hope was connected to the natural self-healing capacities of people. She began to write about neural plasticity (e.g., Harding 1998). Andreasen (2001, p. 31) stated recently, "brain plasticity…stresses that our brains are in constant dynamic change, which occurs as a consequence of the impact of experience on our mental functions and states." Strauss and Harding (1990) suggested that treatment providers and research investigations need to target developmental issues and course of disorder as "two interacting systems," especially in this era of biological psychiatry. They described both positive (amplifying) and negative (limiting) feedback loops within this interaction. Given the arguments of schools fighting for certain models of treatment as more effective than other models, one wonders whether clinicians may need to rethink this stance. An alternative plan calls for clinicians to collaborate with one another and with their patients by employing a range of treatment options—depending on the ever-changing needs of patients—with warmth, encouragement, optimism, and persistence.

Rebalancing the Picture for Schizophrenia

The long-term course of schizophrenia is vastly different than what has been extrapolated from short-term studies as well as from older cohorts of convenience formed by patients still in systems of care for a wide variety of reasons. Such reasons include lack of incentives to get better, self-fulfilling prophesies derived from pessimistic attitudes and continuing severity of symptoms, and the expectation of lifetime diagnostic specificity and need for psychopharmacology.

In regard to treatment, M. Bleuler (1972/1978) suggested that "The inner life of the schizophrenic is never 'burnt out.' It always continues on its way. When ceaseless attempts are made to establish contact with him as with a normal person, and he is not left to stand aside like an outsider, a communal relationship is established that means a great deal to both the patient and the doctor" (p. 442). In fact, Bleuler taught us to see "the person behind the disorder" with comments such as "seriously 'demented' schizophrenics have not lost touch with a healthy psychic life,…in their case, healthy perception, memory, recall, judgment, and feeling are merely concealed behind their pathological behavior" (M. Bleuler 1972/1978, p. 191).

Summary of Findings

For the past century, the course of schizophrenia has been thought to be a downward course for most if not all patients. In this chapter I presented evidence from the long-term literature that revealed a very different outcome. These studies found wide heterogeneity of course and social and work functioning, significant weakening of traditional predictors, and an interaction of adult development with symptom course. The discussion detailed the possibilities for a more positive outcome emerging from such studies. Explanatory models were proposed of neural plasticity, the change from extreme anxiety and fear arising from the experience of schizophrenia itself, to “active coping” through rehabilitation, hope and optimism, recalibration of neurobiological mechanisms during the aging process, and human endurance and resilience.

The most remarkable finding of these long-term studies is the confluence of results showing that at least 50%–60% of each intact cohort studied across two to three decades significantly reclaimed their lives, even in the face of persisting beliefs that this would be impossible. Reconstructed lives have begun to erode the old beliefs, and new strategies with a recovery vision are beginning to be employed.

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C•H•A•P•T•E•R 3

A Comparison of Early- and Late-Onset Schizophrenia

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Older patients with schizophrenia represent a rapidly growing population and include both those who developed schizophrenia earlier in life and have survived into older age and those whose symptoms first emerged in middle to late life. In this chapter we focus on the latter group—that is, those with late-onset schizophrenia.

What is "late-onset schizophrenia"? In what ways, if any, is it different from regular (earlier-onset) schizophrenia? Is the distinction between late- and earlier-onset schizophrenia purely a historical artifact, or does it have a neurobiological basis and/or heuristic utility in terms of the treatment and clinical management of affected individuals? These are the issues we address in this chapter.

Defining Late-Onset Schizophrenia

Late-onset schizophrenia has only rarely been a formal diagnostic term. The diagnostic criteria for schizophrenia in the fourth edition of the *Diag-*

nostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association 1994) and in its text revision (DSM-IV-TR; American Psychiatric Association 2000) make no restrictions or distinctions based on age at onset. That is, late-onset schizophrenia is included with "regular" schizophrenia with no specifier added to the label. The criteria in three of the preceding editions either contained no mention of late-onset schizophrenia or (in DSM-III; American Psychiatric Association 1980) prohibited diagnosis of schizophrenia in patients with onset after age 45. The only appearance of the term *late-onset schizophrenia* as a diagnostic entity was in DSM-III-R (American Psychiatric Association 1987), where the diagnostic criteria for schizophrenia included the instruction that one should "specify late onset if the disturbance (including the prodromal phase) develops after age 45" (p. 196).

Although not usually part of formal diagnostic criteria, the term *late-onset schizophrenia* has a long history. Manfred Bleuler is generally credited with coining the term in the early 1940s (cited in R. Howard et al. 2000). More recently, in a consensus statement by the International Late-Onset Schizophrenia Group, it was suggested that the term be applied to those cases wherein onset of prodromal symptoms occurs between the ages of 40 (rather than age 45) and 60 years (R. Howard et al. 2000). For rare instances wherein the onset of schizophrenia symptoms occurs after age 60, the consensus of the group was that such patients should be labeled with the less-definitive moniker *very-late-onset schizophrenia-like psychosis*. In short, the label *late-onset schizophrenia*, although not a formal diagnostic category separate from regular schizophrenia, is intended to refer to those patients who meet the diagnostic criteria for schizophrenia but whose clinical symptoms first emerged in middle age. As we discuss the similarities and differences between patients with late-onset versus regular schizophrenia, we shall refer to the latter as *earlier-onset schizophrenia* (i.e., prior to age 40). This term should not be confused with *early*-onset schizophrenia—a label that has historically been used to refer to patients who develop schizophrenia in childhood or early adolescence.

Lumping, Splitting, and Partial Splitting of Diagnostic Categories

Diagnostic categories can serve several purposes: to communicate the underlying cause of a syndrome, to guide effective treatment, to communicate the expected constellation of symptoms, or to communicate the expected course and prognosis of a disorder. To the extent that two syndromes are similar in any of these four respects, there is a heuristic value in applying a common label to both. To the extent that they differ on these dimensions, diagnostic distinctions may be valid and useful. Yet part of the difficulty in deciding whether to call late-onset schizophrenia "true" schizophrenia is that it is not yet fully clear what schizophrenia itself is.

The evidence has long been clear that schizophrenia is a disorder of the brain with genetic and neurodevelopmental components, yet the precise nature of the brain pathology and genetic vulnerability remain unknown. In addition, there is remarkable heterogeneity among schizophrenia patients in terms of symptom presentation, everyday functioning, treatment response, and course of illness. Indeed, in coining the modern term for this disorder, Eugen Bleuler (1911/1950) spoke not of "schizophrenia" but rather of "the group of schizophrenias." Such heterogeneity has led some to suggest that the term *schizophrenia* has itself outlived its usefulness (J. S. Howard 1996). A more common approach has been to divide schizophrenia into subtypes. Attempts to devise a meaningful subtyping scheme are as old as the concept of schizophrenia itself. Kraepelin initially divided the disorder into hebephrenic, catatonic, and paranoid forms, and later, in part inspired by E. Bleuler, he proposed an even more complex subtyping scheme (Kraepelin 1919/1971). E. Bleuler (1911/1950) proposed four major groupings based on symptoms (hebephrenia, catatonia, paranoid, and schizophrenia simplex) but also suggested the possibility of groupings based on periodicity, etiology, severity of symptoms, and—perhaps most important for our present purposes—age at onset.

Many of the divisions in schizophrenia made by Kraepelin and E. Bleuler approximately a century ago are still reflected in the contemporary diagnostic systems. Specifically, DSM-IV and DSM-IV-TR include paranoid, disorganized, catatonic, and undifferentiated as well as residual subtypes of schizophrenia. Similarly, the 10th revision of the *International Statistical Classification of Diseases and Related Health Problems* (ICD-10; World Health Organization 1992) includes paranoid, hebephrenic, catatonic, and undifferentiated subtypes of schizophrenia. Other common subtyping schemes proposed have been based on the prevalence of positive versus negative symptoms, the presence of gross neuroanatomic abnormalities, the level or pattern of cognitive deficits, and the long-term course (e.g., Andreasen and Olsen 1982; Carpenter et al. 1988; Seaton et al. 2001). However, no fully satisfactory subtyping scheme has yet emerged, in that there is still remarkable heterogeneity within subtypes that often obscures any differences between subtypes that may be present.

The criteria for determining the appropriate line between a "subtype" and a "separate but related disorder" are also less than fully clear, but we have argued that late-onset schizophrenia should be considered "real" schizophrenia, or at least a subtype of it, if examination of the similarities and differences between patients with late-onset schizophrenia and those with earlier-onset schizophrenia suggest no greater differences than those that are present among earlier-onset patients themselves (Jeste et al. 1997). Thus, consideration of the similarities and differences observed among late-onset versus earlier-onset patients may help in deciding whether the late-onset form should be considered regular schizophrenia (as in DSM-IV and DSM-IV-TR), a subtype (as implied in DSM-III-R), or a distinct disorder (as implied in DSM-III).

Comparisons of Characteristics of Patients With Late-Onset Versus Earlier-Onset Schizophrenia

What characteristics of patients with late-onset schizophrenia overlap with those of patients with earlier-onset schizophrenia, and what characteristics distinguish these groups? This question was the focus of much of the research conducted over the past decade at our research center on late-life psychoses at the University of California, San Diego (UCSD). The details of the methods used, as well as the results of these studies, have been presented extensively elsewhere (e.g., Jeste et al. 1997, 1998; Palmer et al. 2001); we shall provide only a summary of the main findings here.

Familial Risk

As noted by Kraepelin (1919/1971), "of the causal conditions of dementia praecox accessible to our investigation at present, hereditary predisposition must be named" (p. 232). E. Bleuler (1911/1950) also suspected that schizophrenia had a genetic influence, stating that "The heredity predisposition certainly plays an important role among the causes of schizophrenia. However, we do not know in what this predisposition consists and how it manifests itself in other ways. It appears to be specific for schizophrenia" (p. 340). E. Bleuler also acknowledged that there were probably some forms of schizophrenia that did not involve hereditary predisposition. In 1916, Rudin and colleagues were among the first to statistically prove that the incidence of schizophrenia is elevated among relatives of schizophrenia patients (cited in M. Bleuler 1972/1978).

Although the specific genes responsible are not yet known, the evidence of a genetic link to schizophrenia remains clear (Tsuang et al. 1999). Thus, if late-onset schizophrenia is not etiologically "true schizophrenia," then one might expect to find a lower prevalence of schizophrenia among family members of patients with late-onset schizophrenia than among family members of patients with earlier-onset schizophrenia. Yet, in comparisons from our center of earlier- versus late-onset schizophrenia patients, we found that the (self-reported) rates of individuals with family members who also have schizophrenia were very similar in both groups (approximately 10%–15%) (Jeste et al. 1997). This finding cannot by itself prove that the genetic factors for late- and earlier-onset schizophrenia are identical, but it is consistent with the conclusions of an earlier review by Kendler et al. (1987) that showed no consistent relationship between age at onset and genetic risk of schizophrenia.

Is Late-Onset Schizophrenia a Neurodevelopmental Condition?

A primary objection that is often raised to the concept of late-onset schizophrenia is that whereas "real" schizophrenia is generally thought to be a neurodevelopmental condition (Green 1998), people with late-onset schizophrenia have apparently been functioning "schizophrenia free" for the first half of their adult lives (Andreasen 1999; Taylor 2001). One of many pieces of evidence for this neurodevelopmental hypothesis has been the elevated rate among schizophrenia patients of minor physical anomalies (MPAs), which are believed to reflect aberrations in development occurring during gestation (reviewed in Green 1998). However, in a small study from our center, Lohr et al. (1997) found that patients with late-onset schizophrenia had elevated rates of MPAs relative to psychiatrically healthy comparison subjects, as did earlier-onset schizophrenia patients. Such elevations in MPAs may not be unique to schizophrenia, given that patients with major depression in the Lohr et al. study also had elevated rates of MPAs, but a lack of MPAs in patients with Alzheimer's disease was also consistent with the view that late-onset schizophrenia has a neurodevelopmental rather than a neurodegenerative origin.

Other evidence consistent with a neurodevelopmental origin for late-onset schizophrenia includes the presence of early/premorbid functional abnormalities. In that vein, results from our center have also suggested that levels of childhood maladjustment, as measured retrospectively with the Gittelman-Klein scale (Gittelman-Klein and Klein 1969), are similar among late-onset and similarly aged earlier-onset schizophrenia patients (Jeste et al. 1997). More specifically, the late-onset and earlier-onset schizophrenia patients both had elevated Gittelman-Klein scores on the childhood maladjustment subscale relative to psychiatrically healthy comparison subjects (Jeste et al. 1997). These results suggest that some early, premorbid abnormalities, albeit subtle or subclinical ones, are present in late-onset schizophrenia patients. By contrast, this pattern was not seen on the adolescent maladjustment subscale, where the late-onset schizophrenia patients' scores were intermediate between those of earlier-onset schizophrenia patients and those of the psychiatrically healthy comparison group (Jeste et al. 1997). Further studies are needed to assess whether late-onset schizophrenia patients show other evidence commonly cited in support of the neurodevelopmental hypothesis of schizophrenia, such as early motor abnormalities, aberrations in early neuronal migration, and increased prevalence of perinatal injury and/or maternal illness during gestation (reviewed in Green 1998).

Do Late-Onset Schizophrenia Patients Show Evidence of Recent/Acquired Neuropathological Changes?

An implicit hypothesis of those who assert that late-onset schizophrenia cannot be "true schizophrenia" because it is presumed to lack neurodevelopmental origins is the notion that late-onset schizophrenia reflects more recently acquired or emergent neuropathology. Certainly behavioral changes ultimately reflect parallel changes in the brain, so on some level the onset of psychosis in any schizophrenia patient must be associated with some parallel changes in brain activity. However, there is no consistent evidence for recently emergent neuropathology in late-onset schizophrenia patients. For example, in a study from our center employing structural brain magnetic resonance imaging (MRI), it was found that most late-onset patients had clinically normal structural MRI results, and comparison with earlier-onset patients revealed no increased prevalence of volume loss, strokes, tumors, or white matter hyperintensities (reviewed by Jeste et al. 1997). Similar negative results were recently reported by Rivkin et al. (2000), although it must be noted that conflicting findings have also been described (Sachdev and Brodaty 1999).

On the other hand, there may be differences in neuroanatomy or brain function (e.g., neurocognition) between late- and earlier-onset schizophrenia patients that influence the age at which clinical symptoms emerge. In one study from our center involving a small subsample of late-onset schizophrenia patients, Corey-Bloom et al. (1995) found that patients with late-onset schizophrenia had larger ventricular and thalamic volumes compared with earlier-onset patients. In addition, when we examined age at onset as a continuous variable, we found that thalamic and caudate volumes, as well as performance on neuropsychological measures of flexibility/abstraction ability, were significant predictors of age at onset (Jeste et al. 1998).

Other evidence relevant to neurodegenerative hypotheses of late-onset schizophrenia comes from studies of cognitive functioning. For example, in a recent study we administered an annually scheduled comprehensive neuropsychological evaluation to patients followed for several years. We found no evidence of cognitive decline in any subgroup of our schizophrenia patients, including those with late-onset schizophrenia (Heaton et al. 2001). On the other hand, late-onset schizophrenia patients do tend to show less impairment than earlier-onset schizophrenia patients in the specific cognitive areas of learning and abstraction/flexibility (Jeste et al. 1997). Together, the neuroimaging and neuropsychological results seem inconsistent with the notion that late-onset schizophrenia usually reflects late-acquired lesions or a neurodegenerative process, although there may some differences in brain structure or function that influence age at onset (Heaton et al. 2001; Jeste et al. 1997). Although the possibility of more recently emergent neuropathology cannot be completely ruled out, it seems incumbent on the proponents of the view that late-onset schizophrenia is not "true" schizophrenia to demonstrate the existence and nature of that pathology.

Sensory Deficits

Some evidence exists of an association between sensory deficits and psychotic symptoms (R. Howard et al. 1994). Thus, some have suggested that late-onset schizophrenia might reflect the impact of sensory deprivation due to uncorrected visual and hearing deficits associated with aging. In that vein, Prager and Jeste (1993) found that whereas patients with late-onset schizophrenia did indeed have worse corrected vision and hearing relative to psychiatrically healthy comparison subjects, similar elevations were seen in the comparably aged patients with earlier-onset schizophrenia. The authors concluded that older patients with schizophrenia (whether late- or earlier-onset) may receive suboptimal correction of their sensory deficits. In other words, the apparent link between sensory deficits and psychosis may in part reflect disparities in general health care experienced by schizophrenia patients relative to the general population, rather than a specific etiological link between sensory deficits and late-onset schizophrenia.

Do the Symptoms and Treatment Response of Late-Onset Schizophrenia Patients Resemble Those of Earlier-Onset Schizophrenia Patients?

As noted earlier, even if the etiology of a disorder or syndrome remains unknown or obscure, there may be utility in making diagnostic distinctions when the constellation of symptoms or response to treatment differs—that is, if late- and earlier-onset schizophrenia patients differ markedly in their symptom presentation or treatment response, then diagnostic distinctions could be heuristically valuable. Research from our center does in fact suggest a lower prevalence of the disorganized subtype and a higher prevalence of the paranoid subtype among late-onset schizophrenia patients. Approximately three-fourths of the late-onset patients in our sample had the paranoid subtype, compared with about half of similarly aged earlier-onset patients (Jeste et al. 1997). Similar observations were made 90 years ago by E. Bleuler (1911/1950), who noted that

> those [who succumb to schizophrenia] in the fourth decade, and even a little before this time, seem to show a preference for the paranoid form of the disease. This latter type continues to increase for some years after the fourth decade, so that Kraepelin was able to define a form of "delusion of being wronged and injured" as being "presenile" although we include it in schizophrenia. (p. 241)

But the increased prevalence of paranoid subtype with later age of onset does not mean that late-onset schizophrenia is different from "real" schizophrenia, at least no more than the paranoid subtype in general should be considered a disorder separate from the other forms of schizophrenia.

In regard to severity and type of symptoms, our research suggests no differences between earlier- and late-onset schizophrenia patients in severity of positive symptoms, although the latter do tend to have less-severe negative symptoms (Jeste et al. 1997). It should be noted, however, that whereas late-onset schizophrenia patients have less-severe negative symptoms than do earlier-onset patients as a group, the late-onset patients still have significantly worse negative symptoms in comparison with the general population (Palmer et al. 2001). In terms of the response of these symptoms to treatment, we have found that the symptoms of late-onset patients, like those of earlier-onset patients, are generally responsive to antipsychotic medications, although the earlier-onset patients tend to be on higher dosages of these medications (Jeste et al. 1997).

Gender Differences

One of the most firmly established findings in comparisons of late- versus earlier-onset schizophrenia patients is that the proportion of women tends to be higher among those with late-onset schizophrenia, whereas there is a higher prevalence of men among those with earlier-onset schizophrenia. For example, reviewing data from Wolfson, E. Bleuler (1911/1950) noted that "the [age at onset] curve of the male patients drops in fairly regular fashion from a maximum in the fifth quinquennium, while that of female patients show a small elevation between the ages of 40 and 45 years; this elevation becomes even more striking in the two following pentads, in which we find more female cases than male" (pp. 341–342). We and others still find this pattern in contemporary samples (Hafner et al. 1998; Jeste et al. 1997).

The reason there is a tendency for women with schizophrenia to have had later onset remains unknown, but several teams of investigators have suggested that changing estrogen levels may play a key role—for example, animal models indicate that estrogen may modulate the dopamine system in a manner similar to antipsychotics (Seeman 1996). In short, premenopausally, estrogen may be serving as an endogenous antipsychotic. The decreasing estrogen levels associated with menopause might then unmask a predisposition to psychotic symptoms in some postmenopausal women. On the basis of such "estrogen hypotheses," several investigators have begun to examine the potential use of estrogen replacement therapy as an adjunct to antipsychotic medication in postmenopausal women (Kulkarni et al. 1996; Lindamer et al. 2001; Seeman 1996). On the other hand, although late-onset schizophrenia is more common among women than among men, most women with schizophrenia develop the disorder before age 40, which is presumably prior to menopause or even perimenopause. Thus, the role of estrogen in schizophrenia is likely a complex one.

Summary and Conclusions

Although the concept of late-onset schizophrenia has been the source of considerable debate and diagnostic confusion over the past century, studies comparing late- and earlier-onset schizophrenia patients suggest more similarities than differences. Similarities include family risk of schizophrenia, elevated prevalence of MPAs, a generally minimal level of clinically relevant brain lesions, stability of cognitive deficits, and general response to antipsychotic medications. Thus, we contend that late-onset schizophrenia (or at least midlife-onset schizophrenia) should be considered "real" schizophrenia. On the other hand, there are some differences, such as the higher prevalence of the paranoid subtype among late-onset patients and the tendency for late-onset patients to have less severe negative symptoms, to evidence less impairment in certain aspects of cognitive functioning, and to require lower doses of antipsychotic medication, as well as the overrepresentation of women among those with late-onset schizophrenia (vs. the overrepresentation of men among those with earlier-onset schizophrenia). These general differences are mostly ones of degree rather than of kind, but they suggest to us that a distinction in terms of age at onset may be warranted at some level. For example, the tendency for late-onset patients to be on lower dosages of antipsychotic medication may constitute a clinical reason to draw some distinctions.

There is also an enormous potential advantage to keeping late-onset schizophrenia under the schizophrenia umbrella. This advantage is illustrated in the recent studies of estrogen replacement therapy as an adjunct antipsychotic treatment. These efforts evolved from the estrogen hypothesis, which in turn was developed to explain the tendency for women to have later onset than men. Regardless of whether estrogen replacement therapy turns out to be an effective adjunct treatment, it serves to illustrate how examining heterogeneity within schizophrenia may lead to novel treatment approaches. If we can understand the forces responsible for delayed onset of psychosis, we may be able to apply that knowledge to the treatment of both late- and earlier-onset schizophrenia.

In short, we believe that the weight of the evidence suggests that late-onset schizophrenia (or at least midlife-onset schizophrenia) is indeed "true" schizophrenia, as there seem to be more similarities than differences between the two disorders, and certainly no more differences than are present among earlier-onset schizophrenia patients as a group. However, for the reasons discussed earlier, there also appears to be heuristic value in drawing a distinction between earlier- and late-onset schizophrenia. Indeed, this distinction may be more valuable than many of the traditional symptom-based subtype distinctions that still appear in DSM-IV/DSM-IV-TR and ICD-10. Thus, as was done in DSM-III-R but not in DSM-IV/DSM-IV-TR, the diagnostic categories should include a late-onset subtype or specifier.

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CHAPTER 4

Differential Diagnosis of Psychotic Disorders in the Elderly

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Psychosis is a serious psychiatric disorder that can present in different forms in the elderly. Delusions and hallucinations are the hallmarks of psychotic disorders. In comparison with early-onset psychosis, late-onset psychosis is characterized by differences in both risk factors and typical signs and symptoms (Lake et al. 1997). Psychotic disorders in old age have more associations with toxic–metabolic–structural problems and with dementia, which may cause greater difficulty in their treatment. The prevalence of psychotic disorders in the elderly ranges from 0.20%–4.75% in community-based samples to 10% in a nursing home population (Zayas and Grossberg 1998). The prevalence of psychotic symptoms in individuals older than age 85 without dementia is also very high (Ostling and Skoog 2002). In this chapter we compare the various psychotic disorders of older persons with respect to onset, symptomatology, course, and management. Accurate differentiation of one psychotic disorder from another is the key to successful treatment.

Classification of Psychotic Disorders in the Elderly

It is important to approach the differential diagnosis of psychosis in the elderly in a structured manner (Table 4–1). Psychotic disorders can be classified as follows:

1. Primary psychotic disorders include schizophrenia and related disorders, bipolar disorder, unipolar psychotic depression, and delusional disorder.
2. Secondary psychotic disorders include delirium associated with psychotic symptoms, psychosis associated with dementia, and psychotic symptoms secondary to an identifiable medical condition or chemical agent (e.g., prescription medications, street drugs, alcohol).

TABLE 4–1. Psychotic disorders in the elderly

Primary psychotic disorders

- Schizophrenia and related disorders
  - Schizophrenia
  - Schizoaffective disorder
  - Schizophreniform disorder
  - Delusional disorder
  - Brief psychotic disorder
- Affective psychosis
  - Bipolar disorder with psychotic features
  - Unipolar depression with psychotic features

Secondary psychotic disorders

- Psychotic symptoms associated with dementia
  - Alzheimer's disease with psychosis
  - Vascular dementia with psychosis
  - Lewy body disease with psychosis
  - Other dementias with psychosis
- Psychotic symptoms during delirium
  - Psychotic symptoms associated with medications and substance abuse
  - Psychotic symptoms due to medical and surgical disorders

Differentiating these two types is important because of their different prognoses and treatment approaches. Because delirium often results from an underlying medical condition, prognoses of patients with psychotic symptoms associated with delirium depend largely on how quickly that condition is identified and appropriately treated. Patients with cognitive impairment are at greater risk for antipsychotic-induced tardive dyskinesia. High-potency antipsychotics such as haloperidol are contraindicated in patients with Lewy body disease (LBD), in contrast to the usefulness of haloperidol for severe agitation associated with delirium. Therapeutic dosages of atypical antipsychotics (which are preferred over conventional antipsychotics in the elderly) are much lower in elderly patients with psychosis associated with dementia. Treatment goals and duration also depend on the diagnosis. The goals in psychosis associated with dementia should be modest (reduction of emotional distress and behavioral disturbances caused by psychotic symptoms may be sufficient), in contrast to the more aggressive goal of remission in affective psychosis. A dosage decrease or discontinuation is recommended periodically for all patients with psychosis associated with dementia who receive antipsychotic medications. Although withdrawal of antipsychotics should be considered in elderly patients with schizophrenia, discontinuation of antipsychotic medication is associated with a high incidence of psychotic relapse. Many chronically mentally ill elderly persons develop secondary psychotic disorders (e.g., psychotic symptoms in the wake of a delirium during the course of hospitalization for an acute medical problem, psychotic symptoms due to alcohol abuse). Early recognition of comorbid medical and psychiatric disorders will minimize serious complications requiring hospitalization.

Risk Factors Associated With Psychosis in the Elderly

A number of potential risk factors may predispose elderly persons to developing psychotic symptoms (Grossberg and Manepalli 1995). These include comorbid psychiatric illnesses (especially dementia and delirium), social isolation, sensory deficits (visual and hearing impairment), cognitive changes, polypharmacy, abnormal personality (cold and querulous), and substance abuse. The association of psychosis with sensory deficits may be due, at least in part, to a suboptimal correction of sensory deficits in older psychiatric patients. Social isolation could also reflect premorbid traits or an adaptive response to having psychotic symptoms. Addressing risk factors (e.g., correction of visual deficits or hearing impairment) in management will improve treatment outcomes.

Treatment Approach to Elderly Patients With Psychotic Symptoms

In determining the etiology of psychotic symptoms in late life, a thorough history is critical (Figure 4–1). History is obtained from the

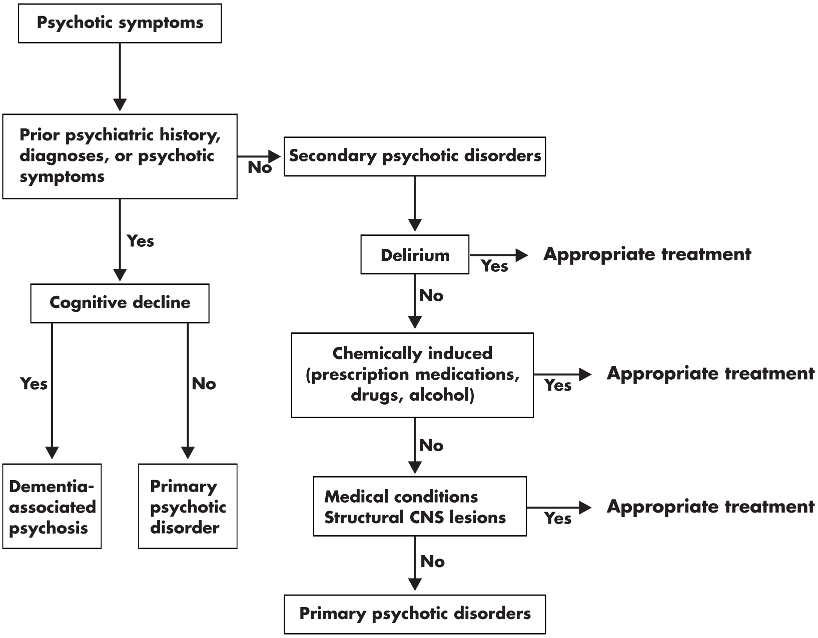

FIGURE 4–1. Decision tree for determining etiology of psychotic symptoms in elderly patients.
CNS=central nervous system.

patient and at least one significant other who is most familiar with the patient. For patients who are socially isolated, information from neighbors, home health workers, or staff from state agencies that assist the patient should be sought. The physician should also ask about a family history of psychiatric illness (mood disorder, suicide, schizophrenia, dementia). Initially, the purpose of the assessment is to delineate the nature of the psychotic symptoms, their onset and relationship to stressors, and the degree of disability they are causing. The clinician also inquires about a history of psychosis, mood disorder, and cognitive impairment.

In older adults presenting with psychotic symptoms, toxic–metabolic–structural etiologies need to be ruled out. First and foremost is drug toxicity (Wood et al. 1988). A thorough review of prescription and over-the-counter medications is recommended. Evidence of alcohol and illicit drug use should be sought. Once drug toxicity and substance use disorders have been ruled out, the possibility of either a structural brain lesion (e.g., tumor or stroke) or a subtle seizure disorder (e.g., temporal lobe dysfunction) should be considered.

After secondary causes have been excluded, psychotic symptoms related to prior psychotic diagnoses need to be considered. For example, are the symptoms manifestations of existing schizophrenia or bipolar disorder? Is the patient psychotically depressed? Is the psychosis part of a progressive dementia such as Alzheimer's disease or of an acute impairment such as delirium? In the patient without a history of psychiatric illness, diagnoses of late-life delusional disorder, late-onset schizophrenia, or late-onset depression with psychotic features need to be considered. The latter diagnosis is particularly critical to investigate, given the high risk of suicide in this age group. "First rank" symptoms of schizophrenia can occur in psychosis accompanying diagnosable brain disease (Feinstein and Ron 1990). Visual hallucinations without other psychopathology, usually in the presence of ocular disease with visual loss, are also common, especially in the elderly. Olfactory (smell), gustatory (taste), or kinesthetic (body movements) hallucinations are relatively rare and are most commonly experienced by patients with partial complex seizures, although they may be seen in patients with primary psychotic disorders. Careful delineation of onset (acute or chronic), nature of psychotic symptoms (simple or complex delusions, type of hallucinations), nature of associated psychiatric symptoms (cognitive and affective), presence of associated physical signs and symptoms (visual deficit, focal neurological deficits), and course (episodic or gradual decline) during history and physical examination—as well as pertinent bedside and laboratory tests (brain imaging when clinically indicated)—will usually lead to correct diagnosis.

Onset of Psychotic Symptoms

It is important to determine when the psychotic symptoms first began. Onset early in life (youth or adulthood) and episodic or chronic course suggest a primary psychotic disorder. In one study (Webster and Grossberg 1998), nearly 10% of more than 1,700 consecutive geriatric patients admitted to an acute inpatient psychogeriatric unit had late-life-onset psychotic symptoms. About three-fourths of these were women, usually in their 70s. Dementia of the Alzheimer's type was the most common cause of psychosis. First onset of psychotic symptoms in late life is commonly associated with identifiable structural brain abnormalities and reflects underlying brain pathology.

Primary Psychotic Disorders

Primary psychotic disorders constitute the bulk of chronic mental illness in the elderly. A thorough past history is crucial to early accurate diagnosis.

Cognitive symptoms, if present, are usually mild, and the course is variable rather than the relentless decline over years seen in patients with dementia.

Schizophrenia

Schizophrenia is one of the most important psychotic disorders in the elderly population and should be considered in the differential diagnosis of all elderly persons with chronic (more than 6 months' duration) psychotic symptoms. Delusions and hallucinations are the hallmarks of this disorder. Mood symptoms are present in many patients but are mild compared with psychotic symptoms. Most elderly persons with schizophrenia have a long history of psychiatric symptoms. Approximately 15% have late-onset schizophrenia (onset of symptoms after age 44 years). Late-onset schizophrenia is more common in women than in men, is more typically of the paranoid type, and is characterized by better premorbid adjustment and a requirement for lower dosages of antipsychotic medications in comparison with early-onset schizophrenia. Late-onset schizophrenia is associated with lower prevalence of negative symptoms and formal thought disorder. As patients with early-onset schizophrenia reach middle and old age, their positive symptoms tend to become less severe and negative symptoms tend to increase. Aging is associated with complete remission in social deficits in more than 25% of schizophrenia patients, whereas another 40% show a marked improvement in symptoms, especially positive symptoms (DeSisto et al. 1995). Although cognitive impairment is the hallmark of dementias, mild cognitive impairment is also seen in elderly patients with schizophrenia. Cognitive impairment, social isolation, and poor self-care may make differentiation from dementia difficult in some cases. Past history of psychotic symptoms and lack of significant short-term memory deficits will help differentiate schizophrenia from psychosis associated with degenerative dementias such as Alzheimer's disease (Table 4–2). Elderly patients with schizophrenia are more likely to be single and socially isolated.

Details about delusions and hallucinations may help in the differential diagnosis. No one type of delusion or hallucination is pathognomonic of schizophrenia. Delusions in schizophrenia are complex and well systematized in comparison with simple delusions in dementia patients. Persecutory delusions are the most common; the person believes he or she is being tormented, followed, tricked, spied on, or ridiculed. Referential delusions are also common; in these, the person believes that certain gestures, comments, or other environmental cues are specifically directed at him or her. Evidence of bizarre delusions (e.g., a stranger has removed the person's organs and replaced them with someone else's organs) or delusions of control

TABLE 4–2. Differentiating chronic schizophrenia from Alzheimer's disease with psychotic symptoms

Symptoms	**Alzheimer's disease**	**Schizophrenia**
Delusions		
Someone stealing	+++	++
Thought control	+/–	++/+++
Hallucinations		
Auditory	+/++	++/+++
Visual	++/+++	+
Cognitive impairment		
Short-term memory loss	+++	+
Word-finding difficulties	++/+++	–/+
Disorientation	++	–/+
MMSE	Gradual decline	More or less constant
Family history	Alzheimer's disease	Major mental disorder
Course	Progressive decline	Variable
Typical social situation	Married, widowed, divorced, not socially isolated	Single, socially isolated

Note. +/–=may or may not be present; +=may be present; ++=often present; +++=present in most; MMSE=Mini-Mental State Examination.

and passivity should be sought. There may be a higher prevalence of partition delusions—the sense that walls, floors, ceilings, or doors are permeable—in those with late-onset schizophrenia. Hallucinations are usually auditory, and certain types of auditory hallucinations (e.g., two or more voices conversing with one another; voices maintaining a running commentary on the person's thoughts or behavior) in the absence of mood symptoms strongly suggest schizophrenia. Visual hallucinations have correctly been taken as suggestive of toxic–metabolic–structural states, especially if auditory hallucinations are absent, but it must be recalled that visual hallucinations may be present in idiopathic schizophrenia. The schizophrenic patient may have a disturbance in language production but relative paucity of neologisms (compared with an aphasic patient); excellent comprehension, lack of significant cognitive loss, and lack of altered consciousness will usually readily differentiate patients with schizophrenia from those with aphasia, dementia, or delirium.

Affective Psychosis

Affective psychosis encompasses bipolar disorder with psychotic symptoms and major depressive disorder with psychotic features. Patients typically have psychotic symptoms along with significant mood symptoms. Psychotic symptoms do not occur in the absence of mood symptoms. Psychotic symptoms may be mood congruent or mood incongruent. Family history may be positive for mood disorder. A detailed past history from patient and family usually elicits at least one previous episode of affective disorder (which may or may not have been treated).

Psychosis Associated With Bipolar Disorder

Bipolar disorders may account for 5%–19% of elderly patients presenting for treatment of mood disorder. Although most patients with bipolar disorder have their first episode in their younger days, onset as late as the ninth and tenth decades has been reported (Umapathy et al. 2000). In comparison with early-onset bipolar disorder, late-onset bipolar disorder (onset after age 49 years) is more likely to have psychotic features; in addition, it is associated with lower rates of familial illness and with greater medical and neurological comorbidity. Some cases of mania may be etiologically related to medical diseases and drugs. Cerebrovascular disease, especially right-sided lesions, has been implicated in late-onset mania. Because manic states in the elderly probably represent various disorders with multiple biological determinants, no single characterization of "mania" can be considered to be prototypic. Older age appears to be associated with chronic mania. The mortality rate for elderly bipolar disorder patients seems to be greater than the community base rate for this age group and also appears to exceed that of geriatric depression patients. Psychotic symptoms can occur with depression, mania, or mixed episode. Nature of psychotic symptoms is less useful in differential diagnosis than are severity and duration of mood symptoms.

Psychotic Unipolar Depression

Patients with psychotic unipolar depression have symptoms of major depression and accompanying delusions and/or hallucinations. Unipolar depression in later life is often of a psychotic or delusional nature. Psychotic depression occurs in 20%–45% of hospitalized elderly depressed patients (Meyers 1992). Elderly depressed patients have a higher percentage of cognitive symptoms like disorientation, memory loss, and distractibility, making differentiation from dementia difficult at times. The Geriatric Depression Scale (Yesavage et al. 1983) may be a useful tool to aid in differential diagnosis. The usual delusional themes are guilt, hypochondriasis, nihilism, persecution, and sometimes jealousy. Depressive delusions can be distinguished from delusions of dementia patients in that the latter are less systematized and less congruent to the affective disturbance.

Schizoaffective Disorder

DSM-IV-TR (American Psychiatric Association 2000) mentions that young adults with schizoaffective disorder more likely have a bipolar type, whereas older adults more commonly have a depressive type. If a patient has significant mood and psychotic symptoms for 6 or more months and there is at least a 2-week period of psychotic symptoms in the absence of mood symptoms, this disorder should be considered. Very little research has been done regarding this disorder in the elderly.

Delusional Disorder

The essential feature of delusional disorder is the presence of one or more nonbizarre delusions that persist for at least 1 month. Auditory or visual hallucinations, if present, are not prominent. These patients are often single women who live alone and are socially isolated; not uncommonly, patients have auditory or visual deficits. Tactile or olfactory hallucinations may be present (and prominent) if they are related to the delusional theme (e.g., the sensation of being infested with insects associated with delusions of infestation, or the perception that one emits a foul odor from a body orifice associated with delusion of reference). Apart from the direct impact of the delusions, psychosocial functioning is not markedly impaired, and behavior is neither obviously odd nor bizarre. Mood symptoms, if present, occur briefly compared with the total duration of the delusional periods. DSM-IV-TR mentions that delusional disorder tends to have an onset in middle or late adult life. Typically, patients have been experiencing symptoms for months to years before they are identified and treated. Delusions of persecution, delusions of reference, and delusions of infidelity are typical, although somatic delusions and delusions of infestation (also called delusional parasitosis) are not uncommon.

Paraphrenia

Paraphrenia (also called late-life paraphrenia) is another diagnostic term commonly used in many research studies (especially in the United Kingdom) involving psychotic disorders in the elderly. It includes paranoid schizophrenia as well as delusional disorders. Women appear to run a greater risk of developing late paraphrenia, especially those who are socially isolated and who present with associated hearing impairment (Almeida et al. 1995).

Other Psychotic Disorders

Brief psychotic disorder (formerly known as reactive psychotic disorder) involves psychotic symptoms of less than 1 month in duration that usually appear after a severe stressor. Schizophreniform disorder is diagnosed when a patient's symptoms meet the criteria for schizophrenia but have a duration of less than 6 months but more than 1 month. Very little research has been conducted of these disorders in the elderly. The vivid symptoms of reliving past trauma manifested in posttraumatic stress disorder (PTSD) may closely mimic auditory and visual hallucinations; thus, PTSD should be considered in the differential diagnosis of psychosis in vulnerable patient groups (elderly veterans, elderly victims of domestic abuse).

Secondary Psychotic Disorders

Delusions, hallucinations, and other psychotic symptoms may accompany dementias and medical conditions (Harris 1997). Psychotic symptoms are also seen in patients with substance use disorder(s) and secondary to prescribed or over-the-counter medications.

Psychotic Symptoms Associated With Dementias

Late-life dementias are associated not only with deficits in cognition and self-care, but also with noncognitive psychiatric and behavioral symptoms, including delusions and hallucinations. Paranoia may be most prominent in the middle stages of the illness. The most common delusions associated with dementias involve people stealing, breaking in, or having intentions to persecute the patient or to poison his or her food. Often the delusional ideas in dementia have an ad hoc quality: a purse is misplaced, and the delusion arises that someone is stealing one's personal items. When delusions or hallucinations occur in a patient with dementia, the clinician must rule out a supervening toxic or metabolic encephalopathy. The Mini-Mental State Examination (MMSE; Folstein et al. 1975) may be a useful tool in the differential diagnosis. It may help in evaluating the presence and severity of cognitive deficits.

Psychosis in Patients With Alzheimer's Disease

Delusions are common in Alzheimer's disease (AD), affecting between 30% and 50% of patients. In a recent study, the cumulative incidence of hallucinations and delusions was 20.1% at 1 year, 36.15% at 2 years, 49.5% at 3 years, and 51.3% at 4 years (Paulsen et al. 2000). Parkinsonian gait, bradyphrenia, exaggerated general cognitive decline, and exaggerated semantic memory decline were significant predictors in that study. AD patients who had an AD sibling with psychosis were found to be more than twice as likely to also have psychotic symptoms (Sweet et al. 2002). The most common delusions involve false beliefs of theft, infidelity of one's spouse, abandonment, the house not being one's real home, and persecution. With increasing cognitive impairment, the complexity of delusions is reduced. Misidentification syndromes—including misidentification of the patient's own self (often manifesting as the patient's not recognizing his or her own mirror reflection), misidentification of other persons including family members, misidentification of events on television (the patient imagines that these events are occurring in real three-dimensional space)—may also be seen in patients with AD. Capgras syndrome (the delusion that familiar people have been replaced by identical impostors) is also seen in patients with dementia. Between 9% and 27% of patients with AD have hallucinatory behavior. Visual hallucinations are most common, followed by auditory hallucinations or combined auditory and visual hallucinating experiences. Typically, the content of visual hallucinations involves persons from the past (such as deceased parents), intruders, animals, complex scenes, or inanimate objects. Auditory hallucinations are often persecutory and usually accompany delusions. Visual hallucinations may be indicative of a co-occurring delirium. Delusions or hallucinations in AD may be a marker of a more severe or rapidly progressive disease process. Visual hallucinations in AD may be associated with neuropathology of the occipital lobe. Impaired visual acuity and severe cognitive impairment may be associated with visual hallucinations in patients with AD. Glasses and cataract surgery need evaluation as prophylactic or adjunctive treatment for visual hallucinations in patients with probable AD.

Psychosis in Patients With Vascular Dementia

Vascular dementia (VaD), formerly called multi-infarct dementia, may be associated with paranoid psychotic features. The prevalence of delusions in VaD ranges from 9% to 40%. Delusional content is similar to that in AD and may include persecutory beliefs, fears of infidelity, and the Capgras syndrome. Paranoia is common, and the quality of delusions varies from vague shifting references to elaborate, florid constructions; complex delusions are more characteristic of VaD than of AD. Hallucinations are commonly visual and many underlie delusions. Most patients have a history of significant cerebrovascular disease and multiple risk factors (e.g., diabetes, hypertension) accompanying cognitive impairment. Multiple small infarcts are associated with VaD. T2-weighted magnetic resonance imaging scans are superior to computed tomography in depicting such infarctions, which may be subtle.

Psychosis Associated With Lewy Body Disease

Dementia with Lewy bodies is probably the second most common form of degenerative dementia, accounting for up to 20% of cases in the elderly. It is characterized by fluctuating cognitive impairment, spontaneous parkinsonism, and recurrent visual hallucinations. Visual hallucinations early in the course of dementia should alert the clinician to the possibility of Lewy body disease. Parkinsonian manifestations are usually mild and do not respond well to dopamimetic agents. Fluctuating cognitive impairment is quite dramatic. Impairment in reaction time, attentional impairments, and fluctuation of attentional impairments are more marked in patients with LBD than in patients with AD and may help differentiate the two in early stages of dementia (Ballard et al. 2001). Patients with LBD are very sensitive to even microdoses of antipsychotics such as haloperidol and may become rigid and immobile even after one or two doses. Accurate diagnosis of LBD as a cause of psychotic symptoms is clinically important in view of the high incidence (60%) of adverse and life-threatening reactions to antipsychotics and the potential role of cholinergic therapy such as rivastigmine in improving psychotic symptoms.

Psychosis Associated With Frontotemporal Dementias

Frontotemporal dementias are a group of degenerative dementias that are less common than AD, VaD, or LBD and are frequently misdiagnosed. They may account for up to 25% of presenile dementias (dementia before the age of 65). Language impairment, personality changes (especially apathy), and behavioral disturbances dominate the clinical picture for several years before cognitive decline is recognized. Bizarre and grandiose delusions are seen, reflecting loss of frontal lobe monitoring of thought.

Psychotic Symptoms Accompanying Delirium

Delirium is an acute confusional state characterized by fluctuating levels of consciousness, sometimes accompanied by illusions, visual hallucinations, and delusions. It is particularly common among elderly medical and surgical patients. Drugs with anticholinergic properties (e.g., diphenhydramine—present in some over-the-counter medications) and benzodiazepines may precipitate acute agitation and delirium in the elderly. Patients with dementia or other brain damage (cerebrovascular disease) have a lower threshold for developing delirium and do so with greater frequency in comparison with patients with intact cognition. Nursing home residents are at particular risk for delirium when hospitalized because of their high rate of predisposing factors, such as advanced age, impaired cognition, decreased sensory input, polypharmacy, and poor functional status. “ICU psychosis” is a term used to describe delirium with psychotic symptoms that occurs in the intensive care unit setting. Postoperative delirium is also common in the elderly, particularly postcardiotomy delirium.

Hallucinations in delirium are typically visual and are accompanied by illusions—visual misinterpretation of things seen in the environment. Paranoid delusions may be present. The latter may be found in up to 40% of elderly patients with delirium (Grief and Eastwood 1993). Themes of “imminent misadventure to others” and “bizarre happenings in the immediate vicinity” differentiate the delusions in delirium from those in acute schizophrenic psychosis. Physicians should suspect delirium in any elderly patient with an acute change in mental status, personality, or behavior. The Confusion Assessment Method (CAM; Inouye et al. 1990) is a bedside rating scale developed to assist clinicians in the rapid and accurate diagnosis of delirium in both clinical and research settings.

Delirium characterized by delusions, disordered thinking, and agitation must be distinguished from schizophrenia, schizophreniform disorder, and mania. The symptoms of mania overlap with those of delirium and sometimes occur secondary to a general medical condition. In delirium, the symptoms tend to fluctuate over the course of the day, and delusions are fragmented and unsystematized, in contrast to symptoms in schizophrenia or mania. Impairment in orientation or memory is usually also present in delirium, in contrast to the other disorders. Electroencephalogram findings are also more likely to be abnormal in delirium than in the other disorders.

Psychosis Due to Medical Illness

DSM-IV-TR criteria for a psychotic disorder caused by a general medical condition require prominent hallucinations or delusions, with evidence from the history, physical examination, or laboratory findings that the disturbance is the direct physiological consequence of a general medical condition (Table 4–3). By definition, the disturbance is not better accounted for by another mental disorder and does not occur exclusively during the course of a delirium. Whether the predominant symptoms are delusions or hallucinations also is specified.

Elderly individuals are at increased risk for such syndromes because of their higher rates of physical illness and resultant polypharmacy as well as because of aging-related susceptibility to disruption of brain function (Marsh 1997). More than 70 medical causes have been implicated in producing delusions. Delusions in the geriatric population can be induced by metabolic disturbances, systemic lupus erythematosus, endocrinopathies,

TABLE 4–3. Medical and surgical causes of psychotic symptoms in the elderly

Neurological	Parkinson's disease, epilepsy, subdural hematoma, stroke Rarely: Huntington's disease, brain tumor
Infectious	Meningitis, encephalitis (e.g., herpes), syphilis, HIV/AIDS
Metabolic	Vitamin B_{12} or folate deficiency, electrolyte imbalance (e.g., hyponatremia, hypocalcemia)
Endocrine	Thyroid disease, adrenal disease, hypo- or hyperglycemia

nutritional deficiency states, and inflammatory disorders. Disorders affecting the temporolimbic regions (e.g., epilepsy, herpes encephalitis) and tumors and strokes involving the temporal lobe or subcortical regions all are implicated in the development of delusions. Usually, a routine history and physical examination will suffice, but some cases can be identified only by laboratory tests, because psychotic symptoms may be the sole overt manifestation. Psychotic states related to deep brain lesions (e.g., basal ganglion disease) resemble idiopathic schizophrenia more closely than those seen with cortical disease. Vivid, elaborate, and well-formed visual hallucinations (so-called peduncular hallucinosis) may occur with disease in the upper brain stem. Some of the abnormal experiences that are well known in temporal lobe epilepsy, including déjà vu, jamais vu, metamorphosia, and the like, may occur in affective disorders as well.

Psychosis is a rare but devastating sequela of traumatic brain injury (TBI). A recent study (Fujii and Ahmed 2001) evaluating risk factors in psychosis secondary to TBI (PSTBI) found that patients in the PSTBI group were more likely to have had a preexisting congenital neurological disorder. The PSTBI group also contained a higher proportion of males. It is believed that TBI contributes to the development of a psychosis by damaging frontal and temporal structures. Schizophrenia-like symptoms observed in patients after TBI were "indistinguishable" from symptoms of the "naturally occurring" disorder (Fujii and Ahmed 2001). The psychotic symptoms may persist despite improvement in the cognitive deficits caused by trauma. Physical illness has been reported to be very common at the onset of catatonic psychosis (Wilcox and Nasrallah 1986). The delusions may be related to specific neurological deficits such as anosognosia, denial of blindness (Anton's syndrome), or reduplicative paramnesia (in which a patient claims to be present simultaneously in two locations). Clinicians should have a high index of suspicion for these etiologies. Careful consideration of various etiological possibilities is critical to early and accurate diagnosis.

Psychosis Related to Parkinson's Disease

The incidence of psychotic symptoms in patients with Parkinson's disease ranges from 10% to 40% (Factor et al. 1995). Patients with psychosis associated with Parkinson's disease may present to the emergency department. Although these symptoms are frequently caused by the dopamimetic agents used to treat parkinsonian symptoms, withdrawal of those agents is seldom considered because of the predictable aggravation of parkinsonian symptoms. In many patients, psychotic symptoms can be more disabling than the motor features of Parkinson's disease, and thus may pose a serious threat to the patient's ability to maintain independence. Drug-induced psychoses consist of several distinct psychiatric syndromes, which can be divided broadly into those occurring against a background of a clear sensorium and those accompanied by confusion and clouding of consciousness. Benign organic hallucinosis is the most common of these syndromes (30%) (Factor et al. 1995). It usually occurs against a background of a clear sensorium and may not be a particularly troublesome problem if the patient is able to retain insight into the nature of the symptoms. More disabling syndromes include delusional thinking (which is frequently paranoid), confusion, and even frank delirium. Although all of these psychotic syndromes can occur in isolation, there is a tendency for mild symptoms to progress to more disabling ones if adequate and timely treatment is not instituted. Abnormal dreaming and sleep disruption often precede these difficulties by weeks to months and may provide an important early clue to their onset. If reducing the dosage of antiparkinsonian drugs is not feasible, low-dose antipsychotics with the least potential for drug-induced parkinsonism, such as clozapine and quetiapine, may be useful.

Psychosis Associated With Retinal Disease

Visual hallucinations among patients with retinal disease are common, underdiagnosed, and not associated with cognitive deficits, abnormal personality traits, or a family or personal history of psychiatric morbidity (Scott et al. 2001). Among patients with relatively good vision, hallucinations are associated with increased emotional distress and decreased quality of life. Clinicians should consider ocular pathology in the differential diagnosis of all elderly patients with visual hallucinations.

Psychosis Due to Prescription Drugs

When medication-induced psychosis occurs in the elderly, the most common offenders are antiparkinsonian drugs (e.g., levodopa, bromocriptine, amantadine); anticholinergic drugs (e.g., diphenhydramine); cimetidine, digoxin; antiarrhythmic drugs (e.g., lidocaine, quinidine, procainamide); and corticosteroids (Hubbard et al. 1991) (Table 4–4). The elderly are particularly susceptible to neuropsychiatric complications of medications, with susceptibility attributable both to exposure frequency and to sensitivity. Tactile hallucinations occur most commonly in toxic and metabolic disturbances or drug withdrawal states.

TABLE 4–4. Medication- and substance-induced psychotic symptoms in the elderly

Prescription medications

- Antiparkinsonian drugs
  - L-dopa or carbidopa
  - Amantadine
  - Bromocriptine
- Anticholinergic and antihistaminic agents
  - Diphenhydramine
  - Hydroxizine
- Tricyclic antidepressants
- Cimetidine
- Stimulants
  - Methylphenidate
  - Amphetamine
  - Thyroid
  - Ephedrine
- Analgesics and anti-inflammatory agents
  - Indomethacin
- Antineoplastic agents
- Oral or parenteral steroids
  - Prednisone
  - Dexamethasone
- Antiarrythmic and cardiac drugs
  - Digitalis
  - Quinidine
  - Procainamide
  - Propranolol
- Sedative-hypnotics
  - Benzodiazepines
  - Barbiturates
  - Chloral hydrate

Over-the-counter medications

- Antihistaminics
- Cold medications
- Cough suppressants
- Sleep aids
- Allergy medications

Substance abuse

- Alcohol
- Cocaine
- Opioids
- Benzodiazepines
- Cannabis

Psychosis Related to Substance Abuse

Substance abuse is considerably more common in older adults than most physicians appreciate, and it often remains undiagnosed and untreated. Alcohol and benzodiazepine abuse are by far the most common substances of abuse in this population. Psychotic symptoms typically occur during intoxication and withdrawal. In elderly persons with a history of substance abuse and in patients for whom there are clinical reasons to suspect street drug abuse, a thorough history relative to the use of substances such as cocaine, opioids, and cannabis is needed. Urine drug screening should be considered in all elderly persons with acute onset of psychotic symptoms.

Psychosis Related to Alcohol Abuse

Psychotic symptoms can occur during alcohol withdrawal, alcohol intoxication, and as a separate syndrome of alcohol-induced psychotic disorder with delusions (e.g., of infidelity) and/or hallucinations. In older persons, alcohol withdrawal disorders can be intensely symptomatic and difficult to treat. Alcoholic hallucinosis may resemble paranoid schizophrenia (Surawicz 1980). However, a history of heavy alcohol use, an absence of formal thought disorder, and a personal or family history negative for schizophrenia or mania helps differentiate the two. Maintenance of a high index of suspicion, use of screening instruments such as the Michigan Alcoholism Screening Test—Geriatric Version (MAST-G; Selzer 1971), and acquisition of information from additional sources (e.g., family member, home health worker, neighbor) will identify most cases. Many patients with alcohol use disorder also have another psychiatric disorder ("dual diagnoses"). In older alcoholic individuals, the coexisting problem is most commonly an affective or organic mental disorder, although anxiety disorders and schizophrenia also frequently coexist with alcoholism in older patients treated in general psychiatric clinic settings.

Psychosis Related to Benzodiazepine Abuse

Psychotic symptoms typically occur during severe withdrawal and usually take the form of visual hallucinations and illusions. A high degree of suspicion, a thorough medication history (often from family), and urine drug screening will identify most cases.

Rare Causes of Psychosis in the Elderly

Patients with malingering and factitious disorder may complain of psychosis-like symptoms, and these disorders should be considered if there is significant secondary gain (e.g., legal cases, inheritance issues, need to play a sick role) involved. In some cultures, visual or auditory hallucinations with a religious content may be a normal part of religious experience (e.g., seeing the Virgin Mary, hearing God's voice). Language barriers and cultural issues may present obstacles to accurate differential diagnosis of psychotic disorders in the elderly, especially with dementia. Use of interpreters and input from family to clarify cultural issues will help considerably. Patients with confabulation (amnestic disorder, dementia) and patients with incoherent speech (Wernicke's aphasia) may be mistaken for psychotic patients. Careful assessment of language and memory during the mental status examination will usually identify these patients.

Clinical Indications of Structural Brain Imaging in Elderly Persons With Psychotic Symptoms

The most important use of neuroimaging is in differential diagnosis (see Table 4–5). Common geriatric psychiatric disorders that can be evaluated by structural neuroimaging include AD, stroke and VaD, tumors (both benign and malignant), hydrocephalus (including normal-pressure hydrocephalus), brain trauma and hemorrhage, subdural hematoma, abscess, and encephalitis (including HIV-induced neuropathology). In approximately 50%–60% of psychosis cases, structural or metabolic brain disease will be a significant contributing factor (Miller and Lesser 1988). Structural imaging should also be considered in patients with primary psychotic disorder who show an atypical or resistant response to standard pharmacotherapy.

Conclusions

Psychotic disorders in the elderly present a diagnostic challenge. The main diagnostic categories of psychosis in the elderly include dementia with psychotic symptoms, psychotic symptoms in delirium, medical illness causing psychosis, drug- (prescription and street drugs) and alcohol-induced psychosis, affective disorders (depression especially, but also mania) with psychosis, schizophrenia (early-onset extending into late life; and late-onset), and delusional disorder. A thorough history, psychosocial evaluation, comprehensive mental status and physical examination, and appropriate diagnostic tests will reveal the correct diagnosis in most cases (Table 4–5). An organized, systematic approach to differential diagnosis of psychosis in the elderly is critical because of the high morbidity and mortality associated with incorrect diagnosis and treatment. The limited literature available in several areas points to the need for further studies of psychotic disorders in the geriatric population.

TABLE 4–5. Clinical tips in differential diagnosis of psychosis in the elderly

History	
Current illness	Onset—acute, chronic Accompanying mood symptoms Accompanying cognitive symptoms Visual vs. auditory hallucinations Presence of fluctuating consciousness—altered sensorium
Psychiatric history	Inpatient psychiatric treatment Diagnosed with major mental disorder History of taking psychotropic medications
Medical history	Thyroid disease Anticholinergic or antiparkinsonian medications, benzodiazepines
Habits	Alcohol, street drug use
Physical examination	
	Vital signs Stigma of substance abuse Abnormal physical examination results
Mental status examination	
	Inattention with fluctuating consciousness Short-term memory impairment Mood and affect Nature of delusions or hallucinations Dangerousness
Screening scales/questionnaires	
	Confusion Assessment Method (CAM) Geriatric Depression Scale (GDS) Michigan Alcohol Screening Test—Geriatric (MAST-G) Mini-Mental State Examination (MMSE)
Laboratory and imaging studies	
	Routine: complete blood count, electrolytes, liver and kidney function tests TSH test, urine drug screen In suspected cases: HIV test, VDRL/RPR, vitamin B_{12} and folate levels, computed tomography scan

Note. RPR = rapid plasma reagin; TSH = thyroid-stimulating hormone; VDRL = venereal disease research laboratory.

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P•A•R•T II

Biological and Medical Aspects

CHAPTER 5

Biological Changes in Older Adults With Schizophrenia

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Age-related biological changes will become increasingly important as the medical community adapts to the graying of our population. Within the mental health discipline, the additive effects of these biological changes superimposed on chronic schizophrenia will present even greater treatment challenges. In this chapter I present an overview of these challenges, addressing a number of key questions:

1. How do the brain differences observed in schizophrenia in young adults manifest in later life when additional structural and functional brain changes occur?
2. What is the evidence from postmortem work of neurodegenerative processes in schizophrenia?
3. Do the probable neurodevelopmental abnormalities in schizophrenia predispose to a latent degenerative vulnerability?
4. How do the effects of chronic medication exposure influence the biological features of schizophrenia in late life?

I will review some of the fundamental issues that underlie future investigations seeking to answer these questions.

Neuroimaging in Schizophrenia

Early Studies

Studies using computed tomography (CT) led the way in establishing schizophrenia as an illness associated with neurobiological abnormalities that are discernable early in its course. Initial brain imaging studies in schizophrenia demonstrated an increase in the ventricle-to-brain ratio (VBR), suggesting a deficit of cerebral tissue relative to cerebrospinal fluid (CSF) volume (Johnstone et al. 1976; Weinberger et al. 1979). Interestingly, this is precisely the same finding reported in early CT studies seeking to delineate the presence of Alzheimer's disease—that is, an increased VBR distinguishing patients from comparison subjects (De Leon et al. 1980). Clearly, the VBR is a nonspecific measure that may be influenced by any number of pathogenic processes that either increase the ventricular volume or reduce tissue volumes. However, the presence of brain abnormalities early in the course of schizophrenia does raise the possibility of a vulnerability to age-related deterioration.

In the case of schizophrenia, neuroimaging studies in young adults have discerned specific features that appear to be prognostically meaningful. For example, enlarged ventricles have been associated with negative symptoms as well as a greater likelihood of cognitive impairment and greater impairment in premorbid functioning (Putnam and Harvey 2000; Seno et al. 1997). As further studies explore morphometric measures in schizophrenia among older individuals, there appears to be a continued relationship between enlarged ventricles and a poor outcome, including a greater likelihood of progressive cognitive decline and more severe negative symptoms in late life (Rossi et al. 2000; Tandon et al. 2000).

Magnetic Resonance Imaging

Further innovations in imaging research have brought about magnetic resonance imaging (MRI), which allows for high levels of contrast between gray and white matter and CSF through superior resolution capabilities. For example, MRI studies in nonelderly adults with schizophrenia have previously demonstrated reduced tissue volumes in a variety of regions, including the frontal and temporal cortex, amygdala, thalamus, and hippocampus (Pearlson and Marsh 1999). In contrast, studies of schizophrenia withonset in later life have reported a greater variety of nonspecific structural changes, such as increased deep white matter hyperintensities (Keshavan et al. 1996). A more detailed discussion of the differences between late-and early-onset illness is presented by Palmer and colleagues in Chapter 3 of this volume.

For the most part, the imaging data suggest that the brain abnormalities characteristic of young-onset schizophrenia are present at the onset of illness if not earlier. Whether these brain differences invoke a more progressive course of age-related deterioration remains unresolved at this point. One study reported that enlarged ventricles are indeed detectable early in the illness and furthermore are accompanied by progressive cortical loss with age (Waddington et al. 1991). In summary, age-related structural findings to date have been mixed, and whereas no clear progressive deterioration is evident with morphometric imaging, a recurring theme suggests a possible vulnerability to atrophic change. This vulnerability may correlate with impairments in cognition and occur preferentially in a subgroup of patients with pronounced negative symptoms (Mathalon 2001). Given the subtleties of the morphological differences observed with MRI, functional imaging may be especially valuable in future studies attempting to identify specific substrates of age-related change in schizophrenia.

Functional Imaging

Functional imaging may provide answers to some of the more complex questions regarding changes in neural activity over the lifetime in schizophrenia. Functional neuroimaging allows exploration of relationships between cognitive tasks and regional brain activity. Earlier work used single photon emission computed tomography (SPECT), whereas more recent studies used positron emission tomography (PET). PET imaging affords the versatility of measuring either cerebral blood flow (CBF) through $[^{15}O]$ H_2O tracer during cognitive activation tasks or cerebral glucose metabolism through 2-deoxyfluoroglucose imaging. Another newer method, functional magnetic resonance imaging (fMRI), uses the paramagnetic effects of deoxyhemoglobin to measure regional blood flow and metabolic activity.

Functional neuroimaging studies have demonstrated both early-onset abnormalities and probable later-life vulnerabilities among patients with schizophrenia. For example, reduced frontal CBF and reduced frontal cerebral glucose metabolism have been demonstrated at illness onset in association with impaired performance on tasks of frontal lobe function (Buchsbaum and Hazlett 1997). In addition to these abnormalities early in the course of illness, aging appears to be associated with further attenuation in frontal blood flow. For example, Goldstein et al. (1990) reported a negative correlation between age and mean frontal CBF ($r=-.36$) on SPECT imaging among patients with schizophrenia in middle adulthood. It is of note, however, that a negative correlation with age was also observed in the nonschizophrenic comparison subjects in this study. Therefore, decreased frontal CBF appears to be a consequence of both aging and the presence of schizophrenia. However, it may be surmised that individuals with schizophrenia are vulnerable to greater age-related decrements. Along these lines, Dupont et al. (1994) reported decreased left posterior frontal and bilateral inferior temporal blood flow in older patients relative to age-matched control subjects. In contrast, one longitudinal study encompassing nearly 20 years of follow-up of patients with schizophrenia (mean age = 25–41 years) showed no significant change in CBF over time (Cantor-Graae et al. 1991).

These mixed findings imply that the issue of whether schizophrenia imparts a special vulnerability to neurodegeneration remains unresolved. Buchsbaum and Hazlett (1997) demonstrated evidence in support of unique differences in schizophrenia through a series of PET studies of cerebral metabolism showing decreased anterior cingulate activity with increased age. This association was present in both patients with schizophrenia and healthy comparison subjects (Buchsbaum and Hazlett 1997). With age, however, the patients with schizophrenia showed additional areas of reduced metabolism in the lateral and medial superior frontal cortex and the anterior temporal regions. Along the lines of the Buchsbaum and Hazlett study, Schultz et al. (2002) investigated whether similar age-related differences in schizophrenia could be identified with the use of [^{15}O] H_2O PET imaging, with particular attention to the frontal and temporal regions. This study examined patients ranging from young adulthood into midlife and noted regionally reduced blood flow with increased age in the anterior cingulate as well as bilateral frontal and parietal regions (Schultz et al. 2002) (Figure 5–1).

The age-related reduction in cerebral activity observed in some frontal regions may be meaningfully related to the probable neurodevelopmental abnormalities in schizophrenia. For example, one current influential model proposes that the dorsolateral prefrontal cortex is impaired in schizophrenia, as are the working-memory functions mediated by this brain region (Goldman-Rakic and Selemon 1997). Reductions in frontal activity may relate directly to the expression of negative symptoms such as avolition. This notion is consistent with clinical descriptions of schizophrenia in later life—that is, negative symptoms may persist or worsen with age, in contrast to psychotic symptoms, which may improve (Harvey et al. 1996). As mentioned previously and discussed in other chapters, negative symptoms have also been associated with both cognitive and adaptive impairment among patients with schizophrenia in late life (McGurk et al. 2000).

Therefore, it appears that patients with schizophrenia may experience unique impairments with aging that manifest in concert with changes in

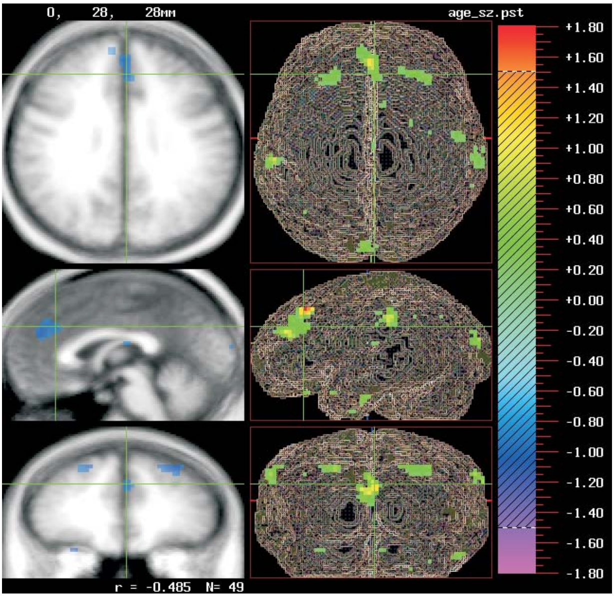

FIGURE 5–1. Positron emission tomography ($[^{15}O]H_2O$ PET) image demonstrating the relationship between age and regional cerebral blood flow (rCBF) in schizophrenia. Negative correlations are present in the anterior cingulate and the frontal and parietal cortex bilaterally.

Figure printed in color in original publication.

Source. Reprinted from Schultz SK, O'Leary DS, Boles Ponto LL, et al.: "Age and Regional Cerebral Blood Flow in Schizophrenia: Age Effects in Anterior Cingulate, Frontal, and Parietal Cortex." *The Journal of Neuropsychiatry and Clinical Neurosciences* 14:19–24, 2002. Copyright 2002, American Psychiatric Publishing, Inc. Used with permission.

symptom characteristics. This scenario sharply contrasts with the more global impairments associated with conditions such as Alzheimer's disease. The more circumscribed deficits with aging in schizophrenia are likely tied to greater negative symptom severity, such as increased avolition. In addition to these symptom changes, current research is also seeking to better characterize discrete cognitive deficits associated with aging in schizophrenia. For example, Harvey et al. (2000) recently demonstrated a relative preservation of reading skills in late life schizophrenia, even in the face of other, more marked cognitive impairments. Further elaboration regarding the literature on cognitive change over the life course of schizophrenia is contained within the "Cognitive Functioning" chapter in this text.

Given the functional imaging literature described above suggesting a host of illness-related abnormalities in regional brain activity, one would expect that age-related changes in at least some cognitive spheres would be vulnerable to more rapid deterioration in schizophrenia compared with normal aging. One study by Heckers et al. (1998), for example, demonstrated impaired activation of hippocampal regions during a verbal memory retrieval task in adults with schizophrenia. In view of the sensitivity of the hippocampus to degenerative change with aging, one might expect a more rapid than typical rate of change in memory function with age, although this study did not address that question directly. It is also important to note that neuroimaging may provide clues regarding abnormalities not only in specific regions of dysfunction but also in more diffuse distributed circuits that may have "downstream" effects on still more brain regions and/or cognitive processes. As we move into the era of even more sophisticated functional imaging, with a contemporaneous cohort of aging patients with lifelong schizophrenia, these issues can and will be further clarified.

Neuropathological Studies

In view of the previous discussion regarding neuroimaging, one would expect that persons with schizophrenia would similarly show marked differences from comparison subjects in histological findings on postmortem evaluation. This is indeed the case, and furthermore this literature is perhaps more mixed and complex than the imaging literature discussed above. Despite extensive antemortem assessments for diagnostic clarification and rigorous postmortem analyses, no clear neuropathological changes have been found in postmortem examinations of elderly patients with long-term schizophrenia. For example, Arnold et al. (1998) evaluated the temporal, frontal, and calcarine cortices of 23 patients with chronic schizophrenia after obtaining antemortem symptom ratings in an attempt to identify a "poor prognosis" group. Despite these efforts, evaluation of neurofibrillary tangles, amyloid plaques, Lewy bodies, and other cellular reactions revealed no significant histological differences between patients and a comparison group, nor were there any significant correlations between symptom or cognitive ratings and postmortem findings (Arnold et al. 1998). Similarly, other studies have been unable to demonstrate significant differences in patients with schizophrenia on postmortem evaluation, despite notable antemortem cognitive deficits (Arnold and Trojanowski 1996; Dwork et al. 1998). A recent study investigated whether chronic schizophrenia is associated with glial changes in the dorsolateral prefrontal cortex, superior temporal gyrus, and anterior cingulate gyrus (Radewicz et al. 2000). The researchers demonstrated a specific increase in the numerical density of microglia in the temporal and frontal cortex of patients with chronic schizophrenia, which was not related to aging. They interpreted this finding to reflect fundamental differences in cortical neuropil architecture in schizophrenia (Radewicz et al. 2000). This latter theme seems to be most compelling in postmortem studies—that is, the differences observed histologically reflect relatively static neurodevelopmental differences that do not necessarily undergo marked degenerative change, although they may impart a vulnerability to functional cognitive deficits with age.

Probable Neurodevelopmental Abnormalities and Aging

Along the neurodevelopmental theme, Zaidel et al. (1997) examined cytoarchitectural differences in the hippocampi of patients with schizophrenia and comparison subjects, assessing neuronal density in the left and right hippocampus. They observed that neuronal density was increased in right CA3 and CA1 in patients and that the intrahippocampal correlations of neuronal density between pairs of subfields were similar in both hippocampi of the schizophrenia patients, in contrast to the typical asymmetrical distribution in comparison subjects. These findings suggested a neurodevelopmental abnormality of hippocampal cytoarchitecture in schizophrenia that affects cerebral asymmetry (Zaidel et al. 1997). This again supports the premise that the neurocognitive features of schizophrenia reflect aberrant brain development and abnormal connectivity, including abnormalities in cytoarchitecture and abnormal signaling pathways. These developmental abnormalities may create a state of decreased cerebral resilience that results in a more ready expression of functional impairments in the face of age-related changes.

Progress in the area of molecular biology is continuing to provide innovative techniques that may help delineate the interplay between neurodevelopmental abnormalities and vulnerability to age-related cognitive changes. For example, one study examined neural cellular adhesion molecule (NCAM) polysialylation, which is postulated to undergo an age-related reduction that correlates with decrements in cognition, based on animal studies (Ni Dhuill et al. 1999). To examine whether this relationship exists in humans, the age-dependent expression of NCAM polysialylation in the hippocampal dentate gyrus was assessed in a postmortem study. Overall hippocampal cell numbers were observed to decline substantially between the second and third decades and to remain relatively constant thereafter. In contrast, the numerous polysialylated hilar neurons were noted to become evident at 2–3 years of age and to remain constant until the eighth decade of life. These findings suggest that NCAM polysialylation may play a crucial developmental role, conferring neuroplasticity throughout the human life span. Lack of NCAM polysialic acid (PSA)–mediated neuroplasticity may therefore accelerate hippocampal cell reduction between the second and third decade. This suggests that the developmental phase of NCAM PSA expression may play a significant role in the emergence of neurodevelopmental disorders that express in adolescence, such as schizophrenia (Ni Dhuill et al. 1999). Other recent work supporting the dysregulation of cell recognition molecules such as NCAM protein continues to advance the neurodevelopmental hypothesis of schizophrenia (van Kammen et al. 1998; Vawter 2000).

The possibility that these abnormalities predispose to a latent degenerative vulnerability is quite valid, although—much like the occurrence of dementia of the Alzheimer's type—these abnormalities may play just one role in a multitude of convergent processes culminating in each individual's total burden of dementia risk. In the case of schizophrenia, lifelong exposure to social adversities, institutionalization, and chronic treatment creates an enormous pool of additional contributing factors. In the following section we address one of these factors with discernable biological effects—that is, the role of chronic exposure to antipsychotic medication.

Long-Term Antipsychotic Treatment

The confounding influence of chronic medication adds yet another layer of complexity to an already complex situation. We are currently entering an important era in time, in which we may now evaluate persons entering late life who have had the benefit of effective antipsychotic medication throughout the course of their chronic illnesses. As will be discussed, long-term antipsychotic use has a number of advantages and disadvantages but certainly is preferable to exposure to insulin coma, social isolation and restraints, hydrotherapy, and leucotomy commonly used prior to the advent of conventional antipsychotics. Unfortunately, many older persons with schizophrenia were in fact exposed to many of these treatments as well as to long-term institutionalization, a fact that must be taken into account in assessing outcome measures over the life course of the illness.

The advent of conventional dopamine antagonist antipsychotic medication 50 years ago brought in an era of substantial symptom reduction as well as a host of baggage such as extrapyramidal side effects and tardive dyskinesia. When considering the addition of a chronic medication-induced dopamine blockade in the context of probable neurodevelopmental dopaminergic dysregulation (Wong et al. 1997), a number of possibilities may be surmised in terms of receptor changes over the life span. The typical model postulated to account for the occurrence of tardive dyskinesia has been the induction of dopamine hypersensitivity secondary to chronic blockade, although early on it was evident that dopamine hypersensitivity did not entirely account for the problem (Gerlach 1981). Furthermore, the advent of the novel antipsychotic medications over the past decade, some with relatively minimal dopamine blockade, creates a new set of possibilities for the future outcome with chronic treatment.

Among the newer possibilities permitted by the novel antipsychotics is the lesser likelihood of parkinsonian symptoms of cogwheel rigidity, bradykinesia, and tremor among older patients. These extrapyramidal side effects are a particular problem in late life, most likely due to subcortical degenerative changes as well as decreased physiological clearance of medication (Byne et al. 2000). Furthermore, with normal aging there is a reduction in dopaminergic tone in a number of brain regions that may underlie vulnerabilities to these adverse effects as well as the decline in cognitive performance associated with aging (Volkow et al. 2000).

On the more positive side, an age-related decrement in dopaminergic activity may account for the relative decrease in positive symptom severity that has been observed over the life span in studies of clinical outcome (Harding et al. 1987; McGlashan 1988). Clearly, the dopamine hypothesis has increasingly become only one small piece in the maelstrom of dysregulation identified in schizophrenia, as studies are increasingly implicating abnormalities in glutamatergic systems, γ-aminobutyric acid (GABA) activity, serotonin function, and nicotinic receptor activity (Benes 2000; Carlsson et al. 2001; Meador-Woodruff and Healy 2000). Hence, the challenge for future research largely lies in first delineating these many mechanisms, then proceeding to ascertain the added influence of aging. This will undoubtedly require a concerted effort in research, with contributions from animal researchers to clinicians. Perhaps the greatest challenge inherent in this charge is the symptomatic complexity of the illness itself. Hence, the clinician-researcher will be a critical team member in future studies of the biological life course of the illness.

As mentioned earlier, current treatments for schizophrenia continue to dispense with the earlier problems of extrapyramidal side effects and the development of abnormal movements. However, the problem of tardive dyskinesia continues to be of substantial importance, given the many years of previous exposure to conventional medications that may be present in the patient entering late life. In terms of medication-induced brain changes over the life span, observable changes—including both structural enlargement and increased functional activity (Gur et al. 1998; Miller et al.

1997)—have been documented in the basal ganglia regions secondary to antipsychotic medications. Intuitively, these changes most likely underlie the potential development of movement disorders. Other efforts to define relationships between medications exposure and neural changes through imaging and histological studies have largely been unsuccessful, although one group has suggested that haloperidol exposure may be associated with attenuated production of beta-amyloid, suggesting it may deter the development of Alzheimer's disease (Higaki et al. 1997).

Conclusions

The study of biological aging in the context of lifelong psychiatric disorders represents a special challenge for researchers. This challenge may particularly apply to disorders in which neurodevelopmental abnormalities influence the clinical appearance of neurodegenerative changes in late life. For example, if static cognitive impairments are present neurodevelopmentally in schizophrenia, then age-related changes resulting in a loss of cognitive function may represent a relatively smaller burden if the individual has adapted to make use of compensatory functions. This possibility of attenuated clinical deterioration, or the more likely case of enhanced vulnerability, awaits further clarification through research.

What we can conclude from current literature, reviewed above, is the presence of fundamental biological disturbances in a variety of brain regions in schizophrenia that are discernable at the onset of illness. Furthermore, evidence from both structural and functional imaging studies suggests that these disturbances may predispose individuals with schizophrenia to a greater degree of age-related deterioration in neural function and/or to greater impairment in task performance in the context of even typical age-related deterioration. Unfortunately, at this time, the data are sufficiently mixed to preclude a definitive conclusion from investigations exploring histopathological and neurodevelopmental sources of this increased vulnerability. This variability in findings is most likely a reflection of the extreme complexity in trying to understand the relative influences of neurodevelopmental abnormalities, medication effects, and the vicissitudes of aging with a chronic mental illness.

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Cognitive Functioning in Late-Life Schizophrenia

Course and Correlates

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In this chapter we review cognitive functioning in older patients with schizophrenia. In so doing, we examine the characteristics of cognitive impairment in older patients with schizophrenia. We compare the recent findings from studies of older patients to the more thoroughly researched characteristics of younger patients. Also, we examine the association of cognition and functional impairment in older patients, evaluating whether the consistent relationships reported in younger patients still hold in older patients, particularly those with a chronic course of lifetime illness. Finally, we examine the highly controversial issue of whether some older patients with schizophrenia have cognitive declines that are substantially greater than those that would be expected with normal aging. Biological factors that underlie both baseline cognitive deficits and cognitive decline are evaluated, although strong empirical findings in this area are relatively few at this point.

Cognitive impairment has been known to be a feature of schizophrenia since the illness was first described in a systematic manner. Beginning with the first clinical descriptions of the illness, impairments in cognitive functioning have been noted and described. Since that time, it has been discovered that patients with schizophrenia perform very poorly on many different tests of cognitive functioning, including both clinical neuropsychological tests and experimental measures of attention and information processing. This is not, however, a new finding. In 1944, Hunt and Cofer reviewed the first 50 years of research on cognitive impairment in schizophrenia, covering many of the same areas of deficit that receive research attention today. What have come to be appreciated more recently, however, are the functional implications of these impairments. As in other neuropsychiatric conditions, poorer cognitive performance is found in schizophrenia patients whose overall level of functional performance is lower (Green et al. 2000). Since the functional importance of the cognitive impairments of schizophrenia has become better understood, there has been a surge of interest in cognitive impairments, including the course and treatment of these impairments. In this chapter we review both functional and cognitive changes with aging, because it is not reasonable to examine one of these aspects without considering the other.

As noted repeatedly throughout this volume, aging in schizophrenia has been a neglected topic. The course of cognition and functional status in schizophrenia remains an area of significant controversy and an area marked by conflicting findings. One of the reasons for this controversy is that cognitive and functional changes occur with normal aging in the population as a whole. These changes raise a variety of questions about the status of later-life cognitive and functional performance in individuals with a lifelong history of cognitive compromise. Because patients with schizophrenia have cognitive and functional deficits early in life, what would be expected over the life span, and what would be the level of functioning seen in patients after a lifetime of illness? Does the early course of schizophrenia predict the later course? Is cognitive functioning truly static over the life span, as has been suggested on the basis of studies of young patients? A further question is that of the interaction between degenerative conditions that occur most frequently in late life and schizophrenia. It would be important not to mistake changes in cognitive or functional status caused by illnesses such as Alzheimer's disease for changes associated with the course of schizophrenia in late life.

There is evidence that variability in the cognitive and functional status of elderly patients with schizophrenia may, if anything, be greater than that in younger patients. Although some elderly individuals with a history of schizophrenia are apparently symptom-free and have little residual deficits in late life (see Harding [Chapter 2] in this volume), many patients with a lifelong history of chronic schizophrenia either experience lengthy stays in chronic hospitals (Harvey et al. 1998) or nursing home care (Bartels et al. 1997b; Harvey et al. 1998) or have extensive social and self-care deficits while living in the community after deinstitutionalization (Bartels et al. 1997a).

Cross-Sectional Data on Effects of Age on Cognitive and Functional Status

In beginning to address the question of whether changes in cognitive functioning occur among older patients with schizophrenia relative to younger patients, cross-sectional studies can provide some information. Specifically, if older patients are not relatively more impaired than younger patients in their performance on cognitive tests, then it is unlikely that cognitive change has occurred. As can be seen from the research presented in this section, this simple question has proven somewhat complicated to answer. Extensive studies of the cognitive and functional characteristics of ambulatory schizophrenia patients (i.e., those with a lifetime history of adequate functioning between psychotic episodes) conducted by the research group at the University of California at San Diego (UCSD) have suggested no evidence of increasing cognitive impairment with age. For instance, Heaton et al. (1994) reported that older patients with schizophrenia did not show greater cognitive impairment than younger patients on a comprehensive cognitive assessment battery indexed to age-specific normative standards. A similar finding was recently reported from a more abbreviated assessment. Eyler-Zorilla et al. (2000) found that 116 outpatients with schizophrenia had no more evidence of greater age-related changes than would be expected with normal aging, as indexed by the performance of nonpsychiatric comparison subjects, in their Dementia Rating Scale (DRS) scores with subjects ranging in age from 40 to 80 years. These patients had significant levels of impairment, with as many as 70% being found to meet clinical criteria for neuropsychological deficit. Furthermore, these patients demonstrated considerable functional deficits on performance measures of adaptive skills relative to normal standards (Klapow et al. 1997). Thus, in ambulatory patients, significant cognitive and functional deficits have been reported in late life, although no evidence of age-related differences in performance was found. These data argue against the notion that complete recovery of function is common in older patients with schizophrenia. Given that the patients studied by the UCSD group would generally be considered to be quite mildly ill over their lifetimes (i.e., many have never been treated as an inpatient for schizophrenia), it can be concluded that even good-outcome patients have persistent, but possibly not progressive, cognitive and functional deficits in later life.

There are, however, a substantial number of schizophrenia patients whose global functional status is greatly impaired over the course of their entire lifetime. In the past, these patients might have been institutionalized for life. At present, however, most large-scale psychiatric hospitals have downsized to the point where very few patients remain, regardless of age; there are other institutions where older poor-outcome schizophrenia patients receive their care. It is estimated that more than 200,000 patients with lifelong chronic schizophrenia have been transferred to nursing homes as a part of this deinstitutionalization movement. As a result, even though the overall number of patients who undergo extended psychiatric hospital stays throughout late life is reduced, many schizophrenia patients are receiving institutional care of some type into late life. It is believed that approximately 300,000 individuals with lifelong schizophrenia are currently residents of nursing homes, and most of the 10,000 current residents of chronic psychiatric care facilities in the United States are elderly. It is not well understood exactly how many formerly institutionalized patients are fully disabled despite living in the community, but this number may be substantial. As a result, as many as 15% of all schizophrenia patients over the age of 65 may be considered to be completely disabled.

Three cross-sectional studies have examined the effects of age on cognitive performance in schizophrenia patients with a history of persistent symptoms over the life span and chronic institutional care. Results differed according to the type of assessments performed. Putnam and Harvey (1999) found that younger and older poor-outcome patients performed about 2.7 and 2.3 standard deviations below normative expectations in secondary memory. In contrast to the lack of age-associated differences seen on clinical neuropsychological tests, performance on global measures of cognitive functioning such as the Mini-Mental State Examination (MMSE; Folstein et al. 1975) clearly shows more deterioration in older poor-outcome patients than in younger patients. As reported by Davidson et al. (1995), a 3-point-per-decade difference in MMSE scores was seen across the age range of 25–95 years. The average MMSE score of patients between the ages of 85 and 95 years was 9.6, which is extremely low, considering that patients whose scores were 0 on the instrument were excluded from the analysis. When healthy individuals of similar age and educational status were tested on the MMSE, the relative change over the life span from ages 25 to 95 years was about 10 points (Crum et al. 1993), whereas it was about 17 points for the schizophrenia patients in the Davidson et al. study. Thus, these results suggest that there may be age-associated worsening in performance, relative to the performance of healthy individuals, in older poor-outcome patients with schizophrenia.

One possible reason for the lack of increasing impairment, relative to the performance of healthy individuals, in these studies of neuropsychological test performance may be selection bias. To obtain valid data without floor effects, both of those studies excluded patients with low MMSE scores. Thus, the samples studied excluded all patients whose MMSE scores were less than 18, thus selecting the group with better cognitive performance. Given that the study of Davidson et al. (1995) found that low MMSE scores were more common in older than in younger patients, it is likely that more older patients were excluded for low MMSE scores, a circumstance that would tend to mask cognitive deterioration on the neuropsychological measures in older patients.

Comparisons of Good- and Poor-Outcome Patients

The disparity of the findings across these studies of patients with very different lifetime courses of illness preliminarily suggests that lifetime course of illness may serve as a risk factor for cognitive and functional decline in later life. Direct comparative studies of these two groups of patients are rare at this time; however, one comparative study of geriatric patients with schizophrenia who were either acutely admitted patients with a good lifetime functional performance or chronically institutionalized patients (Harvey et al. 1998) found substantial differences in cognitive and functional status. The acutely admitted patients, although not differing from the chronic patients in severity of psychosis, outperformed the institutionalized patients by 12 points on the MMSE and by more than 1 full standard deviation on a composite score from a neuropsychological battery. Adaptive deficits were also more severe in the poor-outcome patients, although the correlates of functional deficit were the same in good- and poor-outcome patients, in that cognitive performance deficit was the best predictor of adaptive functioning deficit.

When studies of poor-outcome (i.e., institutionalized) patients are compared across different research sites, considerable consistency is observed across studies. Arnold et al. (1995) found that their poor-outcome patients in suburban Philadelphia had MMSE scores that were essentially identical to those of poor-outcome patients in New York (Davidson et al. 1995). When institutionalized patients in the United States and the United Kingdom were compared (Harvey et al. 1997), the patients' performance across the two countries was found to be within 1 MMSE point. Finally, patients in New Hampshire nursing homes who were studied by Bartels et al. (1997b) were found to have MMSE scores in the severely demented range, consistent with the scores of nursing home patients described by

Harvey et al. (1998). These data suggest consistency in performance and indicate that variations across different systems of care are not strongly associated with cognitive functioning of geriatric patients with poor-outcome schizophrenia.

Similarity of Cognitive Deficits in Geriatric Schizophrenia and Degenerative Dementia

On the basis of the severe cognitive impairments seen in older patients with schizophrenia, several studies have been conducted to examine the profile and course of cognitive deficits in Alzheimer's disease and schizophrenia. In regard to the profile, Heaton et al. (1994) found that patients with schizophrenia performed less well than patients with Alzheimer's disease on most aspects of a comprehensive neuropsychological battery. Alzheimer's disease patients, in contrast, were more impaired on delayed recall. Similarly, Davidson et al. (1996) compared schizophrenia patients and Alzheimer's disease patients with a sample of psychiatrically healthy individuals of the same age. The Alzheimer's disease and schizophrenia patients were matched on global cognitive status (as indexed by MMSE total scores), age, and gender and were matched to healthy subjects on the basis of age, gender, and relative levels of education. The control subjects performed better than either of the patient groups on all measures. Among the patient groups, the patients with schizophrenia performed more poorly than the patients with Alzheimer's disease on naming and praxic skills, whereas the two groups performed equivalently on verbal learning. Similar to the findings of Heaton et al. (1994), performance of patients with Alzheimer's disease was poorer than that of patients with schizophrenia on delayed-recall memory.

Dementing conditions cause a certain profile of cognitive impairments, with subcortical dementias being associated with sparing of recognition memory and naming performance. Paulsen et al. (1995) examined the prevalence of various profiles of memory impairment in schizophrenia and compared them with these previously established profiles of cortical and subcortical dementia. They found that the most common profile in their sample of patients, all of whom had a relatively good lifetime functional status, was most similar to the profile of subcortical dementia (over 50%), followed by unimpaired profiles and then, least commonly, the profile of cortical dementia. In contrast, when Putnam and Harvey (1999) examined the profile of memory dysfunction in patients with lifetime poor functional status, they found that the modal profile was cortical in character. Specifically, they found that recognition memory was as or more impaired than delayed recall in both verbal and visuospatial stimulus modalities. As a result, these studies suggest, again, that poor outcome in schizophrenia may be associated with a different profile of impairment than that seen in patients with a lifetime of better functional status.

The Course of Cognitive and Functional Deficits in Late Life

Few studies have examined the longitudinal course of cognitive and functional deficits in schizophrenia in late life. In contrast to other areas of schizophrenia, the longitudinal course of cognitive impairment is understudied in general. In a review of the international literature, Rund (1998) concluded that the course of cognitive impairment was stable over time. However, the entire worldwide literature at that time consisted of 438 patients younger than 65 years and a single study (Harvey et al. 1995) that followed 225 patients older than 65 for 1 year. Consistent with the increased attention paid to cognition in general and to late-life schizophrenia in particular, this worldwide database has increased markedly in the past few years alone.

In two different studies of the same sample of patients, Harvey et al. (1995) found that, as a group, there was no decline in MMSE scores over a 1-year follow-up of 225 elderly patients with schizophrenia. In contrast, previous studies of patients with Alzheimer's disease have revealed statistically significant cognitive declines for follow-up periods of this duration. Similarly, studying a larger but generally younger sample of patients with a better lifetime functional status, Heaton et al. (2001) found no evidence of cognitive changes over longer (60 months) or shorter (30 months) follow-up periods. In summary, both good- and poor-outcome patients show little evidence of generalized changes in cognitive functioning over shorter or longer follow-up studies. However, these results from group mean change scores cannot directly address the question of whether individual patients with schizophrenia show evidence of decline over the same periods.

Evidence Regarding Progressive Decline in Individual Patients With Schizophrenia

Group differences in cognitive performance tell us little about the prevalence or rate of individual changes. It appears clear that year-to-year change is not detected for older schizophrenic patients as a group. However, there are several reasons that individual patients could be declining while the group as a whole does not. First, if a number of patients were manifesting trivial improvements (1–2 points) in their cognitive performance scores as a result of practice effects, this could mask larger drops in functioning experienced by a smaller number of declining patients. Second, patients with a declining course might be more likely than those without such a course to be discharged to a nursing home, which would mask group changes based on assessment of patients who remained behind. Finally, if the number of patients whose performance declined were small enough and the amount of that decline were limited enough, an increase in variance at the follow-up assessment might be the only measurable signal for the group as a whole.

To examine these issues, we performed three studies of the pattern of cognitive and functional change in poor-outcome patients with late-life schizophrenia. In the first of these, we examined the course of cognitive and functional impairment in chronically institutionalized schizophrenic inpatients over a 30-month period (Harvey et al. 1999). In this study we examined the longitudinal course of overall functional status for a sample of more than 300 patients (mean age=75 years) on whom we had previously reported at baseline (Davidson et al. 1995). The focus was on those patients who had evidence of generally mild cognitive and functional impairment at the onset of the study ($n=148$). These patients were selected for having global Clinical Dementia Rating (CDR) scores of 1.0 (mild impairment) or less at baseline. (CDR scores can range from 0 [no impairment] to 4 [profound impairment].) Scores of 0.5 reflect questionable impairment, which may suggest the development of dementia in an individual with a lifetime history of adequate functioning. Although a CDR score of 1.0 might be seen as a substantial level of cognitive impairment, it is in fact no greater than that expected in first-episode patients as a group.) We then identified newly incident cases of significant cognitive and functional impairment. Survival analysis was used to examine the risk for new-onset moderate to severe cognitive and functional impairment for the previously less impaired patients over the follow-up period.

At the first follow-up (12 months), the risk of cognitive and functional decline (defined as conversion of a CDR score of ≤1 [mild or less] to 2 [moderate or greater] was 12.6%. At the second follow-up (30 months), an additional 15% of the subjects in the study met criteria for similar worsening, for a total rate of cognitive and functional decline of 27.6% over a total follow-up period of 42 months. This decline was consistent with a drop in MMSE scores of 3.2 points, which, although substantial, is not consistent with catastrophic decline in functioning or changes in motivation.

Additional analyses of the baseline higher-functioning patients were performed to identify potential factors that increased patients' risk for cognitive and functional decline. Gender was not associated with risk for cognitive and functional decline, nor was antipsychotic treatment status, negative symptom severity at the baseline assessment, or age at first psychiatric admission. Baseline factors found to be associated with increases in risk for cognitive and functional decline over the total 42-month follow-up period included older age, lower levels of formal education, and more severe positive symptoms. Given that positive symptoms were not found to be associated with functional status at baseline, these data suggest a longitudinal relationship between more severe positive symptoms and subsequent risk for decline during a brief follow-up period. Because the CDR global score is an aggregate of cognitive and functional status, it is not possible to determine whether the risk factor of severe positive symptoms influences cognitive functioning, which then leads to functional decline, or whether positive symptoms influence these two factors simultaneously.

In another study (Friedman et al. 2001), 108 schizophrenia patients ranging in age from 20 to 80 years were followed over 6 years and assessed with the CDR and the MMSE. The schizophrenic subjects over age 50 were compared with a group of 126 healthy comparison subjects and 118 Alzheimer's disease patients from the Consortium to Establish a Registry for Alzheimer Disease (CERAD) study (Morris et al. 1989) who were selected for assessment over a similar time span. Each patient was required to have a CDR score of 1.0 or less at entry. When the risk for cognitive decline—defined similarly to prior studies as a worsening in CDR scores from 1.0 (mild) to 2.0 (moderate) or greater over the follow-up period—was compared across the groups, age-related risks were found to vary. More than 90% of the Alzheimer's disease patients, regardless of age, manifested a worsening in their cognitive status, in contrast to the healthy subjects, who did not worsen regardless of age. Schizophrenia patients younger than age 65 demonstrated no risk of worsening over the 6-year follow-up; however, those older than 65 years showed a consistent age-related increase in risk for decline over the follow-up period. These findings were replicated with MMSE scores, with Alzheimer's disease patients declining an average of 12 MMSE points over 6 years and the healthy sample showing a 1-point change in the oldest patients. Although no declines were noted in the schizophrenia group before age 65, patients older than 65 years demonstrated increased worsening, with a drop of 2 points in patients ages 65–69, 3 points for ages 70–74, and 5 points for ages 75–80. Thus, although younger schizophrenic patients do not decline in their cognitive functioning at a rate greater than that seen in healthy individuals, older schizophrenic patients experience functional declines greater than those seen in healthy individuals, albeit never as great as those seen in patients with Alzheimer's disease.

The question arises as to why older patients experience decline whereas younger ones do not. Several possible explanations exist, all of which are somewhat speculative because of the limited research in this population. First, normal changes in cognitive functioning accelerate after age 65, suggesting that the normal brain is likely to experience a decline in functioning with aging during this time period. Interestingly, this decline is most substantial in areas of secondary memory, executive functions, and attention, the domains most affected in schizophrenia from the time of the first episode. Second, the brain is more vulnerable to the influence of trauma and toxins (e.g., alcohol) with aging. Thus, if persistent psychotic symptoms exert a stressful or toxic effect on the brain, as discussed above, this effect would be expected to be more pronounced with aging. Finally, nonpsychotic individuals with a history of lower educational attainment show evidence of greater cognitive changes with aging and increased risk for the development of dementia in later life. Given that greater educational attainment appears to be a protective factor for decline in older patients with schizophrenia, it may also be that this same "cognitive reserve" factor has an exaggerated effect in older patients with schizophrenia. More research in this area will clearly be required to refine our understanding of the risk factors associated with aging that influence cognitive changes in patients with schizophrenia.

Methodological Points

There are, of course, many possible alternative reasons for findings of poor cognitive performance in chronically institutionalized patients. The superficial ease with which these findings can be dismissed as due to "institutionalization," to "demoralization," to "amotivation," or simply to basic cohort effects in the samples does not hold up to close scrutiny. For example, the suggestion that patients with schizophrenia do not exert adequate effort when tested on cognitive measures is not empirically supported. J.M. Gold et al. (1992) found a notable discrepancy between intelligence measured with a comprehensive testing procedure and memory estimates in patients with schizophrenia, with memory more impaired. It is logically difficult to explain discrepancies in performance across two different cognitive domains (i.e., one normal, one impaired) as being the result of a single global factor, such as "amotivation" or "demoralization," which should logically reduce performance across all of the domains examined. In a study that compared elderly schizophrenic patients with a large sample of psychiatrically healthy comparison subjects, Harvey et al. (2000) found that whereas the performance of schizophrenia patients was within one-half grade of their lifetime educational attainment on a reading test, it was 1 to 2 standard deviations below normal comparison subjects on tests of learning, memory, verbal, and spatial skills. Again, differential preservation of skills argues against a global deficit caused by symptomatic, personality, or emotional factors.

In regard to the issue of cohort effects, it is important to keep in mind that the average education level completed by both the population as a whole and by demographically similar patients with schizophrenia is greater in younger individuals than in older ones. As a result, cross-sectional comparisons almost always exaggerate the level of within-individual change over time. An excellent example of this effect is provided by the data from Davidson et al. (1995), wherein the youngest patients (ages 25–34 years) had completed 3 more years of education on average than had the oldest patients (ages 85–94 years). The difference in MMSE scores between these groups was quite large, with the youngest patients' scores 19 points higher. Thus, on the surface, it could appear that differences in education account for these differences in cognitive performance.

Two circumstances argue against this interpretation. The first is that psychiatrically healthy individuals older than 85 years with less than 4 years of formal education have been found to have much higher MMSE scores than schizophrenic patients, with average MMSE scores over 20 (Crum et al. 1993). The second argument is that the patients manifest a pattern of performance that is inconsistent with lifelong impairment of this magnitude. In a reanalysis of the Davidson et al. (1995) data, 8 of the 24 patients (33%) over age 65 who had completed more than 12 years of education had MMSE scores less than 10. Thus, patients who had attended college had MMSE scores in a range suggestive of profound dementia, arguing quite strongly that this could not be their lifelong level of functioning.

Heterogeneity of Course and Outcome in Schizophrenia

As seen in the reviews just described, controversy has plagued follow-up studies examining the stability of neuropsychological impairments of schizophrenia patients. These contradictions are likely to be related to differences in sample selection and length of follow-up, as well as to the often simplistic definition of outcome as recovered or not recovered. However, the contradictory nature of these findings is consistent with modern notions that recognize substantial heterogeneity in symptom manifestation and course in schizophrenia. The studies reviewed above suggest that cross-sectional cognitive impairments associated with aging are more common and severe in patients with lifelong poor functional outcomes and chronic institutional stays (Bartels et al. 1997a, 1997b; Davidson et al. 1995; Harvey et al. 1998). Moreover, significant decrements in the cognitive performance of chronically institutionalized schizophrenia patients has been observed longitudinally (Friedman et al. 2001). However, ambulatory schizophrenic patients demonstrate no such decline in cognitive performance over time (Heaton et al. 2001). There are important distinctions between these studies that may indicate that these apparently different outcomes are really not inconsistent at all. The subjects from the Heaton et al. study were better educated, had lower levels of positive and negative symptoms, and demonstrated much higher baseline levels of cognitive performance compared with the Friedman et al. sample. Indeed, these are the very factors that have been observed to produce an increased risk for cognitive decline in follow-up studies of poor-outcome schizophrenia patients (Harvey et al. 1999).

In addition to the outcome differences of the subjects assessed in the Heaton et al. (2001) and the Friedman et al. (2001) studies, differences in the sampling of geriatric schizophrenia patients and the interval of follow-up may have also contributed to the contradictory findings. The study by Friedman and colleagues included, in addition to 50 nongeriatric schizophrenia patients, a sample of 58 geriatric schizophrenia patients who were followed for an average of 6 years. Moreover, the results of that study demonstrated that the progressive cognitive decline experienced by poor-outcome schizophrenia patients is not a linear process across the life span; rather, the rate of cognitive change accelerates beyond age 65 years (Friedman et al. 2001). Research has consistently demonstrated that the cognitive functions of schizophrenia patients are fairly stable early in the course of illness (e.g., S. Gold et al. 1999), which has led to the conclusion—in our opinion, premature—that cognitive functioning remains stable over the entire life span. The longitudinal study of Heaton et al. (2001) included only 22 elderly (age 65 years or older at entry) schizophrenia patients, and older patients were more likely to drop out after baseline assessments. Although 67 of the 142 subjects with schizophrenia were followed for a period of 36 months or more, it is not clear how many of those subjects were older than age 65 years.

Risk Factors for Age-Related Changes in Schizophrenia

Although the pathophysiological mechanisms of the observed progression of cognitive impairments in poor-outcome schizophrenia patients have not yet been elucidated, risk factors for poor outcome have been identified. Lower levels of education and poorer premorbid adjustment are associated with a poorer outcome at follow-up. Educational status plays a role in outcome in late life as well. A prospective study of geriatric schizophrenia patients who developed moderate to severe cognitive impairment over a 30-month follow-up revealed that patients with lower levels of education were at significantly greater risk for this decline (Harvey et al. 1999). Albeit controversial, some data suggest that significant delays in initiating antipsychotic treatment early in the course of illness may be associated with poorer treatment response and more severe symptoms subsequently (Haas et al. 1998). Indeed, it has been demonstrated that early intervention with antipsychotic medication may reduce some of the long-term morbidity associated with schizophrenia (Wyatt and Henter 1998). Because the effects of severe positive symptoms on outcome are potentially present in both first-admission patients and chronic schizophrenia patients with multiple previous hospitalizations (Haas et al. 1998), it appears that the deleterious effects of severe positive symptoms continue to exert an effect on outcome later in the illness. The longitudinal data of Harvey et al. (1999) demonstrated that geriatric patients at greater risk for cognitive and functional decline during a 30-month follow-up period had more severe positive symptoms at baseline. The severity of positive symptoms was not found to be associated with cognitive and functional status at baseline, suggesting that severe positive symptoms may exert a long-term effect on cognitive and functional status.

Biological Correlates of Age-Related Changes in Schizophrenia

Absence of Classical Neuropathology of Neurodegeneration

Early theories about the progression of impairment in schizophrenia involved progressive neural degeneration; however, despite some early reports to the contrary (for a review, see Shapiro 1993), the brains of patients with schizophrenia do not exhibit high levels of the classical manifestations of neurodegenerative change (e.g., reactive gliosis, plaques, tangles, vascular changes, dystrophic neurites; for a typical example, see Powchik et al. 1998). Postmortem studies of schizophrenia patients with severe cognitive impairment have demonstrated that most cases of cognitive impairment in schizophrenia are not the result of Alzheimer's disease. Even among the most severe cases of cognitive impairment, plaque counts were less than half those seen in Alzheimer's disease patients of identical age. The prevalence of vascular dementia and other identifiable neuropathology in this sample was found to be less than 10%; thus, such etiologies cannot account for the high prevalence of profound impairment—as high as 66%—seen in this patient sample (Powchik et al. 1998).

The absence of classical histopathological evidence of degeneration, together with evidence of possible lifelong neurodevelopmental anomalies, has led many researchers to abandon the simple hypothesis of neural degeneration. Currently, a more complex picture is evolving. It is likely that an early neurodevelopmental abnormality sets the stage for subsequent neuronal changes. These changes may vary across patients and be expressed as cognitive and functional deterioration in some patients, particularly in those whose lifelong functioning is more impaired. Moreover, the fact that the progressive changes may be atrophic (i.e., involving neuronal shrinkage or retraction of processes and synapses; see Selemon and Goldman-Rakic [1998] for a description) rather than necrotic (i.e., involving the death of one or more neurons or the destruction of neuronal processes) may explain the absence of markers of degeneration.

Possible Neurochemical Correlates

Despite the lack of identifiable pathological lesions in patients with schizophrenia, it is still possible that patients with substantial cognitive impairments may suffer from more subtle neurochemical changes. In an ongoing, as-yet-unpublished study (Friedman and Haroutunian, May 2002) of neurochemical characteristics of postmortem brain tissue from schizophrenic subjects, samples from six cortical regions have been derived from 19 elderly subjects with chronic schizophrenia (12 of whom were cognitively impaired [i.e., CDR score ≥1]). All of the subjects in this study had antemortem evaluations of cognitive functioning within 1 year of death. The subjects with cognitive impairment (i.e., those with CDR scores ≥1) showed marked deficits in the cortical serotonergic markers 5-hydroxytryptamine (Brodmann area 32 and 22) and 5-hydroxyindoleacetic acid, compared with subjects whose CDR scores were 0 or 0.5. Because serotonergic deficits can be age related, it is important to note that age was not significantly different in the two groups.

Similar to the serotonin findings, norepinephrine was significantly reduced in the frontal cortex in 12 cognitively impaired (i.e., CDR score ≥1) schizophrenic subjects compared with 7 schizophrenic subjects with CDR scores of 0 or 0.5. Only trend-level reductions were seen in temporal cortical norepinephrine. Similar but less pronounced deficits of 3-methoxy-4-hydroxyphenylglycol (MHPG) were also found. The data for norepinephrine are consistent with the report of Bridge et al. (1985), which described norepinephrine deficits in the hippocampus and nucleus accumbens that correlated with the severity of cognitive impairment close to the time of death. Again, because noradrenergic deficits can be age related, it is important to note that age was not significantly different in the two groups.

Possible White Matter Correlates

Although schizophrenia has been described as a disease of brain connectivity, few studies have examined white matter changes in schizophrenia. Indeed, demyelinating diseases have a well-established association with behavioral disturbances. For example, metachromatic leukodystrophy has been reported to present in early adulthood as a schizophrenia-like psychosis in more than 50% of cases (Hyde et al. 1992). In addition, there are striking similarities between the profile of cognitive impairments seen in demyelinating diseases such as multiple sclerosis and the profile seen in schizophrenia. Observations by a number of groups support the notion of a possible myelin-related abnormality in schizophrenia. Postmortem studies have reported white matter abnormalities, such as a selective maldistribution of interstitial neurons in prefrontal white matter, in schizophrenia (Akbarian et al. 1996). In addition, DNA microarray analysis of postmortem tissue from the dorsolateral prefrontal cortex of 12 schizophrenic and 12 control subjects demonstrated that five genes, whose expression is enriched in myelin-forming oligodendrocytes, were downregulated in the schizophrenic subjects (Hakak et al. 2001). Furthermore, using only the myelin-related genes on the microarray to discriminate the control subjects from the schizophrenic patients resulted in a perfect separation of the groups. These five genes have been implicated in the formation and maintenance of myelin sheaths, which are critical for efficient axonal signal propagation and provide extrinsic trophic signals that affect the development and long-term survival of axons. In addition, linkages to these myelin genes have been established in genetic studies of schizophrenia.

Additional support for the involvement of white matter abnormalities in the presentation of schizophrenia symptoms comes from neuroimaging studies. Diffusion tensor imaging by MRI, which measures the coherence of white matter tracts in the brain, has demonstrated significant alterations in the directionality of white matter tracts in the frontal and temporal cortices of schizophrenia patients (e.g., Lim et al. 1999). The technique of magnetization transfer imaging (MTI) provides a new contrast mechanism that may be more specific for myelin destruction. In MTI, the exchange of magnetization between the bound protons and free water is represented by the magnetization transfer ratio (MTR), which is considered to be an index of myelin or axonal integrity. Diseases associated with demyelinating processes, such as multiple sclerosis and progressive multifocal leukoencephalopathy, cause dramatic reductions in magnetization transfer. To date, one MTI study in schizophrenia has shown significantly different MTR values between schizophrenic patients and control subjects (Foong et al. 2000). Although an approximate 2% reduction was found in the schizophrenic group compared with control subjects for right and left temporal regions, there were no significant differences in frontal or other regional MTR values between the two groups. This result suggests a decrease in myelin in the brains of schizophrenic patients that may be localized to the temporal regions. Foong and colleagues also noted that if MTR changes occur in other white matter regions, they are probably very subtle. It is therefore possible that subtle changes in axonal and myelin structure in other areas may exist in these schizophrenic patients, but the technique used was not sensitive enough to detect these subtle changes. Whether progressive loss of myelin structure may correlate with the progressive changes in cognitive and functional status observed in older schizophrenic patients is a question that should be addressed in future imaging studies.

Summary and Conclusions

Significant cognitive and functional deficits are commonly seen in elderly patients with schizophrenia, particularly those whose lifetime course of illness has been chronic. These deficits appear to be qualitatively similar to those seen in younger patients with schizophrenia, and the correlation between cognitive and functional deficits is similar. Although these symptoms appear superficially to resemble the deficits seen in cortical dementias such as Alzheimer's disease, direct comparative data regarding the course and profile of cognitive functioning do not support that impression. Patients with schizophrenia are more impaired in most domains of functioning and less impaired in memory than are patients with Alzheimer's disease. The course of cognitive deficit in poor-outcome patients suggests that cognitive decline is not uniform across patients, with some proportion of patients showing a cognitive and functional decline even in brief follow-up periods. Risk factors for decline include less education, advanced age, and more severe positive symptoms of schizophrenia at the time of assessment. Only patients older than 65 years show substantial evidence of cognitive decline when followed over periods long enough to reveal substantial declines in MMSE scores in patients with Alzheimer's disease.

These data indicate that poor outcome over the course of the entire life span may be a risk factor for further decline in late life. Although the specific mechanisms that predict lifetime poor outcome and the factors that lead to late-life deterioration are not completely understood at this time, the need to identify these processes is clear. Biological research has clearly indicated that classical neuropathological changes such as those seen in Alzheimer's disease are not the factor responsible for these changes. Candidate processes include changes in norepinephrine and serotonin, as well as the possibility of white matter pathology. The latter possibility appears to be one of the most promising areas, as convergent findings from postmortem neuropathology, neuroimaging, and genetics all point to white matter abnormalities. Future neurobiological research needs to identify any potential direct influences of psychotic symptoms on the process of decline to determine whether this relationship is direct or mediated by other factors.

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C•H•A•P•T•E•R 7

Medical Comorbidity in Older Persons With Schizophrenia

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In this chapter we examine aspects of medical comorbidity in older persons with schizophrenia. In our review, we elaborate on several critical elements. First, we consider whether this population has an increased susceptibility to certain medical problems, and if so, of what the most common problems consist. Second, we assess whether the services available to this population are comparable with those available to other elderly persons in the general population and whether any serious impediments to medical treatment exist. Third, we examine the extent to which existing services are utilized, as well as the level of patient satisfaction with health care treatment. Finally, we suggest theoretical pathways for future research on medical comorbidity in older persons with schizophrenia.

Background

It should be noted that medical comorbidity in schizophrenia has not been widely studied, with few papers specifically addressing issues of health among aging individuals with schizophrenia. Cohen et al. (2000) found that only 1% of the literature on schizophrenia has been devoted to issues of aging. Similarly, research on medical comorbidity among persons with schizophrenia has been limited by the fact that most studies cover a wide range of ages but predominantly focus on younger persons. Comparisons between studies are further hampered by differences in the sample populations. For example, studies have come from various regions in the United States and abroad, as well as from different clinical sites, including university programs, private hospitals, public and state hospitals, community mental health clinics, Department of Veterans Affairs (VA) facilities, and inpatient and outpatient sites. Moreover, because most studies focus on disease prevalence rather than incidence, it is unclear whether older persons with schizophrenia are more apt to develop various disorders or simply less apt to get better. Diagnostic inconsistencies constitute another potential confounder. Contemporary criteria differ from those used in the past, particularly before the publication of DSM-III (American Psychiatric Association 1980).

Despite these limitations, we tried wherever possible to compare older persons with schizophrenia with their same-age peers in the general population or with other psychiatric populations and to compare older and younger persons with schizophrenia. Methodologically, we first attempted to use studies that focused exclusively on older persons with schizophrenia or in which a schizophrenic sample was subdivided by age, thereby allowing examination of older and younger groups . If the sample was not divided by age, we looked for any statistical tests in which age was examined. Finally, in some instances we were compelled to use general schizophrenic samples, although wherever possible, we have noted the age range or estimated the range from the mean and standard deviation.

General Physical Health

Three issues need to be considered: 1) Are there new and/or separate medical risks associated with aging among persons with schizophrenia? 2) Does schizophrenia per se confer greater risk for physical disease? 3) Does aging confer more health risks for persons with schizophrenia relative to their same-age peers?

First, it is well established that medical conditions can cause or exacerbate psychiatric illness. The most common cause of psychiatric disturbance in the geriatric population is medical illness (Marsh 1997). As reported by Levenson and Hall (1981), mental symptoms develop in up to 30% of the geriatric population as a consequence of an unrecognized medical disease. Delirium is a more common herald of the onset of a general medical condition in the elderly than fever, pain, or tachycardia (Marsh 1997). Sensory impairments are very common in older persons, and more severe impairments have been linked to the development of hallucinations and delusions and have been associated with disorders such as late-onset schizophrenia, other paranoid psychoses, depression, and the Charles Bonnet syndrome (see Desai and Goldberg [Chapter 4] in this volume). Approximately 25% of individuals between the ages of 65 and 74 years and 50% of those older than 75 years have impaired hearing (Mhoon 1990), and 75% of persons over age 60 years have cataracts, with about 15% experiencing a significant visual loss. It is reasonable to assume that for older persons with schizophrenia, like older persons in general, health problems may precipitate or exacerbate psychiatric disturbances. Indeed, the Schizophrenia Patient Outcomes Research Team (PORT) survey (Dixon et al. 1999)—which included 719 outpatients with schizophrenia (mean age=43 years; approximately 17% older than 55 years)—and the San Diego Clinical Research Center group (Jeste et al. 1996; Jin et al. 2001) found that the number of medical conditions correlated significantly with psychotic symptoms and depression. Of course, a reciprocal interaction may be operative in which psychosis or depression enhances physical disease.

It is generally believed that persons with schizophrenia have worse health than their same-age peers in the general population and that, for various reasons to be described later in this chapter, their conditions often go undiagnosed and untreated. For example, increased rates of comorbid physical illness in schizophrenia patients have been reported to occur primarily in the categories of non-insulin-dependent diabetes mellitus (NIDDM), cardiovascular disease, infectious diseases, respiratory disease, some forms of cancer, and a variety of other illnesses (Dixon et al. 1999). It has also been suggested that persons with schizophrenia may have more severe forms of these disorders (Jeste et al. 1996).

Furthermore, the widespread use of medications in the elderly schizophrenic population, particularly of antipsychotic medications, can affect persons either directly through their effects on various body systems or indirectly through interactions that may increase the blood levels of other medications. Side effects that are of greater concern in older persons include anticholinergic effects (because they can affect bowel and bladder function, cognition, heart rate, and vision), central nervous system effects such as sedation, cardiovascular effects such as orthostatic hypotension and prolongation of the QTc interval, extrapyramidal symptoms and tardive dyskinesia, and metabolic changes such as weight gain and glucose intolerance (Jeste et al. 1996).

If studies of schizophrenia across all age ranges suggest that the disorder and its treatment confer greater risk for physical illness, it might be assumed that older persons with schizophrenia would have more medical illnesses relative to their same-age peers. Moreover, it is conceivable that age may interact with schizophrenia so that older persons with schizophrenia might be disproportionately more ill in comparison with their same-age peers than younger persons with schizophrenia. Nevertheless, in two separate studies, researchers in San Diego (Lacro and Jeste 1994; Jeste et al. 1996) found that middle-aged and older persons with schizophrenia had fewer medical illnesses (mean=1.0) than did persons with Alzheimer's disease (mean=1.4) and major depression (mean=2.4), although they endorsed an equivalent number of medical categories (mean=2.2) and had a comparable severity index on the Cumulative Illness Rating Scale for Geriatrics (CIRS-G; Miller et al. 1992) compared with an older, psychiatrically healthy control group (mean age=12 years older). The CIRS-G total scores correlated with positive symptoms, depression, and overall psychopathology but not with negative symptoms, cognitive impairment, duration of schizophrenia, and age. The difference in age between the schizophrenia group and the comparison group made definitive interpretation somewhat more difficult, especially because it could be argued that the schizophrenia group should have had fewer symptoms because of their younger age.

Data from a study in New York City of 117 persons with schizophrenia 55 years and older with a mean age of 63 years (C.I. Cohen, unpublished data) attending outpatient programs and/or living in supportive housing programs yielded findings that were similar to those of the San Diego group. To better assess health status, a subsample (*n*=86; mean age=64 years) consisting of African Americans and whites was compared with a community sample consisting of 522 white and U.S.-born African Americans 55 years and older (mean age=70 years). On a scale consisting of the summed total of physical disorders, 33% of the schizophrenia sample and 48% of the community sample reported 2 or more disorders; the mean numbers of disorders reported were 1.35 and 1.66 for the schizophrenia and community groups, respectively. For the schizophrenia sample, no significant correlations were observed between positive, negative, and depressive symptoms and the number of physical disorders; however, all three correlations were modestly positive (*r*=.12 to .15). Although the annual rate of hospitalization was comparable in the two groups (21% in community group, 22% in schizophrenia group), more than half of the hospitalizations in the schizophrenia group had been for psychiatric illness, whereas only about 1 in 20 hospitalizations in the community sample had been psychiatric in nature. This study also used a comparison group that was slightly older (by 6 years) than the schizophrenia group; however, in contrast to the San Diego study, in this case the somewhat younger schizophrenia group did have fewer disorders than the community group.

The studies in New York and San Diego did not suggest that older outpatients with schizophrenia have more physical disorders or greater severity of these disorders than do their same-age peers from comparable backgrounds, although results from the San Diego study were more equivocal. One possible explanation for these findings is that persons in the schizophrenia samples were all involved to some extent in clinical programs, most of which encouraged or provided physical examinations. Moreover, because psychopathology tends to diminish with age, older persons are more apt to attend to medical problems and to be better received by other health professionals. The San Diego researchers interpreted the significant correlation between positive symptoms and physical health as reflecting the fact that whereas physical symptoms may seem less important or may be overlooked in the presence of florid psychosis, such symptoms are more apt to be addressed when the patient is less symptomatic. A "survivor effect" may be another plausible explanation for the lack of differences between older persons with schizophrenia and community persons. That is, because mortality rates among persons with schizophrenia substantially exceed those in the general population throughout the life span (see "Mortality Rates" section later in chapter), those who are oldest are presumably the heartiest, both physically and emotionally.

Specific Medical Disorders

Diabetes

In 1899, Sir Henry Maudsley commented that diabetes and insanity run together in families far more commonly than can be accounted for by chance or mere coincidence (Mukherjee 1995). More recently, schizophrenia has been found to be associated with impaired glucose tolerance and insulin resistance (Dixon et al. 2000), and as many as one-third of young schizophrenia patients have been found to have a family history of type II diabetes, a rate far in excess of that in the general population (Mukherjee et al. 1989). Therefore, because diabetes increases with age and affects about 20% of the geriatric population (Marsh 1997), it might be assumed that the prevalence of diabetes among persons with schizophrenia would increase with age and would likely be higher in older persons with schizophrenia than in their same-age peers. Although the prevalence rates of diabetes among schizophrenic versus healthy persons seems to be consistently higher in younger and middle-aged groups, differences in the geriatric population are less apparent. Jeste et al. (1996) found no significant differences in the prevalence of diabetes mellitus when studying a group of middle-aged and elderly schizophrenia patients with other psychiatric disorders. Similar results were obtained in a study of older persons with schizophrenia (mean age=64) in New York City in which rates of self-reported diabetes in persons with schizophrenia (20%) were nearly identical to those in the comparison community group (19%) (C.I. Cohen, unpublished data). Two studies (Mukherjee 1995) of VA system inpatients and outpatients have also confirmed that the prevalence of diabetes among persons with schizophrenia increases with age, with rates of 0% and 1.6% for persons under 40 years growing to rates of 25% and 50% for those 70 years and above. In another study, conducted in Italy, Mukherjee et al. (1996) found an inverted U-shaped prevalence curve—that is, in a sample of 95 schizophrenia patients, the prevalence of diabetes increased from 0% in those younger than 50 years, to 12.9% in those age 50–59, and to 18.9% in those age 60–69, and then decreased to 16.7% in the 70- to 74-year age group. Thus, an age-dependent increase in the prevalence of diabetes was present up to age 70 years; thereafter, it declined. The authors speculated that this pattern occurred because individuals with type II diabetes have an increased risk of developing coronary heart disease, which is a principal cause of the excess mortality in schizophrenia.

In addition to potential genetic linkages between schizophrenia and type II diabetes, other risk factors for diabetes in schizophrenic individuals of all ages are similar to those in the general population. The PORT study found an increased risk for diabetes in individuals who were older, female, or of African American/“other” race (Dixon et al. 2000). Women were 2.1 times more likely to have diabetes than were men, and nonwhites were 2 times as likely as whites to have diabetes. The schizophrenia patients with diabetes were more likely to have hypertension, heart problems, seizures, and hearing/vision problems than were those without diabetes.

Although several studies have suggested a positive association between NIDDM and schizophrenia (Brambilla et al. 1976; McKee et al. 1986), these findings were confounded by the use of antipsychotic medication, which has the well-documented effect of inducing glucose intolerance (Mukherjee et al. 1989). Mukherjee et al.’s (1996) review of the literature found two studies in which the prevalence of diabetes was higher in patients who were not taking antipsychotics than in those who were. They noted, “More critically it bears emphasizing that high rates of insulin resistance and impaired glucose tolerance had been noted in schizophrenia patients before the introduction of neuroleptics” (Mukherjee et al. 1996, p. 71). Thus, it is uncertain whether the increased association between schizophrenia and type II diabetes is genetic or possibly a by-product of antipsychotic drug treatment (Jeste et al. 1996).

Mukherjee et al. (1996) cited five studies in which the presence of diabetes was associated with an increased risk of neurological complications such as tardive dyskinesia in patients treated with antipsychotic medication. This intriguing finding linking diabetes to higher rates of tardive dyskinesia is of special concern for older persons with schizophrenia, because they are already at greater risk for tardive dyskinesia because of their age.

In regard to treatment, the PORT study found that 86% of schizophrenia patients who reported having diabetes mellitus said that they were receiving treatment for it (Dixon et al. 1999). This is consistent with data from the study of older persons with schizophrenia in New York City that was cited earlier, in which 85% of persons with diabetes reported receiving treatment for it (C.I. Cohen, unpublished data). The PORT study also examined the cost of health care for schizophrenia patients. Total Medicare and Medicaid costs were found to be significantly higher in schizophrenia patients with diabetes. Because it may be difficult to implement the panoply of lifestyle changes and the health team approach necessary for the treatment of diabetes, Dixon et al. (1999) concluded that the cost of care for elderly schizophrenia patients with diabetes is likely to be greater than that for nonschizophrenic elderly patients with diabetes, which suggests that the implications of diabetes for costs and services are considerable.

Cardiovascular Disease

Cardiovascular diseases are among the most common disorders found among persons with schizophrenia. Cardiovascular disease is reported to occur more frequently and to be responsible for higher mortality rates in individuals with schizophrenia versus individuals in the general population (Dixon et al. 1999; Tsuang et al. 1983). A variety of investigators have reported an increased incidence of cardiovascular and pulmonary disease in study samples of schizophrenia patients (Baldwin 1980; Lovett Doust 1980; Harris 1988; Tsuang et al. 1983). However, the prevalence of hypertension, coronary artery disease, and congestive heart failure is significantly lower in schizophrenia patients compared with all other psychiatric patients (Jeste et al. 1996). The Oxford Record Linkage Study (ORLS) found that a sample of 2,314 persons with schizophrenia (one-third were ages 55 years or older) showed a significant increase in relative risk for arteriosclerotic heart disease but not in risk for other forms of cardiac, hypertensive, or circulatory diseases (Baldwin 1979).

As is the case with other health topics, it is difficult to find information on cardiovascular disease that is specific to the elderly population with schizophrenia; in addition, the limited data on older groups have tended in some instances to contradict the findings for schizophrenia in general. In

Sajatovic et al.'s (1996) study of 23 bipolar and 49 schizophrenia patients (mean age=72, 96% male) at the Cleveland VA Medical Center, the authors reported that the most frequent reason for medical hospitalization in their schizophrenia patients was cardiovascular or pulmonary disease; however, the study did not include comparisons with nonpsychiatric patients. Sheline (1990) reported that cardiovascular disease was the most prevalent physical illness seen in geriatric psychiatric inpatients. This study consisted of 95 patients (57 women and 38 men) between the ages of 60 and 85 years. Although persons with schizophrenia accounted for 20% of the study population, the data for the study were not broken down further to examine medical diagnoses in schizophrenic subjects. Lacro and Jeste (1994) compared elderly schizophrenia patients with other elderly psychiatric patients and found that the schizophrenia patients had the lowest prevalence of hypertension, coronary artery disease, and congestive heart failure. Finally, the New York City study of older outpatients with schizophrenia cited earlier (C.I. Cohen, unpublished data) found that rates of self-reported heart conditions were lower than rates in a community comparison group (20% vs. 26%) and that hypertension was dramatically lower in the schizophrenia group than in the community group (29% vs. 57%).

High rates of excess mortality from cardiovascular diseases have been reported in schizophrenia patients. For example, Allebeck (1989) found that 37% of deaths in the schizophrenic population in the Stockholm County register were due to cardiovascular disease. Unfortunately, his results were not further broken down by age. Numerous authors (Alstrom 1942; Baldwin 1979; Odegaard 1951, 1967) have contended that the risk of death from cardiovascular disease is higher in persons with schizophrenia than in persons in the general population but apparently lower than in those with other mental illnesses. Moreover, the relative risk of mortality from cardiovascular disease is greater in younger than in older schizophrenia patients (Baldwin 1979).

Controversial data have been published in regard to antipsychotic treatment and cardiovascular morbidity/mortality. Studies such as those of Hollister and Kosek (1965) and Saugstad and Odegaard (1985) suggest a causal relationship, whereas studies by Craig and Lin (1981) and Risch et al. (1981) report no evidence linking the two. Phillipson et al. (1990) reported that the cardiac conduction abnormalities observed with antipsychotic use may be due to the anticholinergic properties of these drugs, and Allebeck (1989) proposed that the sedating effects of antipsychotic medications may predispose patients to cardiovascular disorders by immobilizing and slowing them down. On the other hand, Lacro and Jeste (1994) proposed that antipsychotics have a protective effect on cardiovascular function.

Respiratory Disorders

Historically, during the first half of the twentieth century, respiratory diseases such as pneumonia and tuberculosis accounted for much of the high mortality rates among institutionalized patients with schizophrenia (Alstrom 1942; Baldwin 1979; Odegaard 1952). It should be pointed out that these findings were not specific to schizophrenia patients, but rather were observed among all institutionalized psychiatric patients. Recent studies, however, continue to point to disproportionately higher rates of respiratory morbidity and mortality in schizophrenic populations, although the usual proviso about lack of data among older persons with schizophrenia applies here as well.

Among more recent reports, respiratory disease was found to be one of the most frequent causes of medical hospitalization (18% versus 22% for cardiovascular disease) in the previously cited study of veterans by Sajatovic et al. (1996), and bronchopneumonia was found to be a common cause of death in a 13-year follow-up study by Brown et al. (2000) of 370 schizophrenia patients ranging in age from 16 to 65 years. A study by Saku et al. (1995) using the Koseki register in Japan followed 4,980 male and female schizophrenia patients (ranging in age from 4 to >80 years) and determined that pneumonia and tuberculosis followed suicide as the leading causes of death.

Immune Dysfunction

Hypotheses about the link between immune dysfunction and schizophrenia date back to the early twentieth century, and in the 1960s an autoimmune-mediated process was implicated in the etiology of schizophrenia (Rappaport and Delrahim 2001). A resurgence of interest in immune dysfunction occurred in the 1980s as numerous observations documented associations between various autoimmune diseases (e.g., systemic lupus erythematosus, HIV) and neuropsychiatric symptoms. Recent data suggest that activation of the inflammatory response system, the cellular immune system, and the humoral immune system may be present in some people with schizophrenia (Rappaport and Delrahim 2001). Some support exists for the hypothesis that minor levels of immune activation may be associated with psychotic exacerbations and that some individuals with schizophrenia may have a chronic immune dysregulation characterized by activation of T helper cells.

Paradoxically, however, studies of specific immunological disorders have generally supported lower prevalence rates among schizophrenic populations. For example, Ehrentheil (1957) and Lipper and Werman (1977) noted a decreased incidence of asthma, hay fever, and other allergic reactions in schizophrenia patients. Other studies, such as that of Sabbath and Luce (1952), showed an alternating pattern of coexisting psychosis and allergies. Matthysse and Lipinski (1975) cautioned that histamine could not specifically be examined as an allergen instigator without first controlling for the effects of phenothiazine medications.

The strongest evidence for a negative association between schizophrenia and a disease comes from rheumatoid arthritis. Eaton et al. (1992) reviewed 14 epidemiological studies conducted between 1934 and 1985 and concluded that, despite various methodological shortcomings, there was ample evidence supporting the negative association between these two disorders. For example, Tsuang et al. (1983) reported that the rate of rheumatoid arthritis in schizophrenia patients was less than one-fifth that in other psychiatric patients. Similarly, when Allebeck et al. (1985) compared persons with schizophrenia and persons with affective psychosis and neuroses, they found that the former group had one-half the number of rheumatoid arthritis cases as the other groups. Their schizophrenia sample consisted of 572 men (13% ≥ 60 years) and 618 women (24% ≥ 60 years). Mors et al. (1999) suggested that there may be a genetic link between the two diseases. One hypothesis proposes that genes that promote resistance to rheumatoid arthritis may produce an increased susceptibility to schizophrenia, and vice versa, although the diseases are not mutually exclusive. However, underdiagnosis also has been proposed as an alternative explanation for the negative association observed between the two disorders (Mors et al. 1999).

Cancer

A wide variety of increased and decreased prevalence rates of different types of cancer among schizophrenic populations have been reported in the literature. In addition, comparisons are made more difficult because some studies focused on death rates and others focused on disease rates. In general, relative to the overall population, there seems to be a pattern of lower rates of lung cancer and higher rates of digestive and breast cancers among schizophrenic populations. For example, data from the ORLS (Baldwin 1979) indicated that among schizophrenia patients as a whole, there were no significant differences in incidence of the most common cancers seen in the general population. However, they did observe a significant excess of esophageal cancer in their schizophrenia population. Subsequently, several studies (Baldwin 1987; Dupont et al. 1986; Wood et al. 1985) confirmed higher rates of digestive system cancers, with some suggestion that rates for women may exceed those for men. The studies by Craig and Lin (1981) and Mortensen (1989) are examples of research that found an increased incidence of breast cancer. Many studies (Craig and Lin 1981; Dupont et al. 1986; Mortensen 1989; Newman and Bland 1991; Parfitt 1981; Soni and Gill 1979) have found a decreased risk of lung cancer in schizophrenic populations, even among persons who were heavy smokers (Parfitt 1981). The apparent lower prevalence of lung cancer in schizophrenia patients is surprising, considering the high number of smokers in this population (Jeste et al. 1996). However, a more recent British study of 370 schizophrenia patients ages 16–66 years (Brown et al. 2000) found lung cancer mortality rates among persons with schizophrenia to be twice the expected values.

In examining age-specific trends, Mortensen and Juel (1993) proposed that although no significant increase in cancer mortality is seen in any age group, there is a trend toward decreased mortality in older patients. In a schizophrenic study population consisting of 555 women (65% ≥ 60 years) and 389 men (81% ≥ 60 years), Malzberg (1950) found increased cancer mortality in young patients but significantly decreased rates in elderly patients, with lower rates in males than in females. Several studies found excess cancer mortality in mental patients as a whole when hospital stays were short, whereas cancer mortality rates were diminished in these patients relative to the general population when hospital stays were long, especially among those 65 years and older (Baldwin 1979; Fox and Howell 1974). However, although these studies included schizophrenia patients, their focus was not specifically on schizophrenia. Baldwin (1979) suggested two possible explanations for the increase in mortality rates among short-stay patients: their older age, and the reasons for their admission (i.e., selective processes). Lower cancer mortality rates among longer-stay older persons has led some authors to propose that it may be the environment of the hospital, rather than the fact of having schizophrenia, that protects elderly persons with schizophrenia from some cancers (Tsuang et al. 1983).

The data are controversial with respect to antipsychotic use and cancer morbidity/mortality. Mortensen (1986) proposed that phenothiazine treatment may be an environmental factor that protects against malignant neoplasia. High-dose antipsychotics have been associated with a reduced incidence of bladder and prostate cancer, and nonphenothiazine antipsychotics with a decrease in lung and breast cancer (Mortensen 1989, 1992; Mortensen and Juel 1990). This has been supported by several animal studies that found malignant tumors were inhibited by chlorpromazine (Saku et al. 1995). However, on the opposite side, Ettigi et al. (1973) observed that breast cancer may be more common with phenothiazine treatment. Apropos of this finding, Goode et al. (1981) suggested that antipsychotics may potentially increase the incidence of breast cancer by elevating prolactin levels.

Hyponatremia

Older persons in general are at greater risk for developing hyponatremia, and some data suggest that older persons with schizophrenia may be at even greater risk. Kushnir et al. (1990) proposed that some of the mortality labeled as "undetermined cause of death" in the schizophrenic population may in fact be due to undiagnosed polydipsia. A study by de Leon et al. (1994) suggested that up to 20% of chronically institutionalized schizophrenia patients may have polydipsia. A study conducted by Gleadhill et al. (1982) focused on the incidence of hyponatremia—defined as a serum sodium concentration of less than 125 mEq/L—among hospital admissions. During a 3.5-year period, the schizophrenia patients had an incidence rate of 5.80%, compared with a rate of 0.36% for all other patients combined. The mean age of the hyponatremic patients was 50 years. Eighty percent of these patients were also noted to be excessive water drinkers. The authors postulated that persons with schizophrenia may produce an inappropriate amount of antidiuretic hormone (ADH) release or may somehow reset their body's osmostat, resulting in hyponatremia. This theory would be supported by the work of Raskind et al. (1978), who found higher ADH levels in acutely psychotic patients than in a control group. A second possible explanation for the elevated incidence of hyponatremia in this population is that antipsychotic medications may also affect ADH release. Gleadhill and colleagues also noted that because 70% of the hyponatremic schizophrenic patients (vs. 8% of the normonatremic schizophrenic patients) were taking anticholinergic drugs, their excessive thirst might have been attributable to the drying of the mucous membranes that occurs as a side effect. A third explanation is based on the stimulating effects of nicotine on ADH release. Because many schizophrenia patients are heavy smokers, nicotine may likewise play a role in the etiology of hyponatremia (Gleadhill et al. 1982).

Mortality Rates

Several questions must be addressed with respect to mortality rates and schizophrenia. First, are mortality rates higher in schizophrenia patients than in their same-age peers in the general population? Second, do mortality rates change with age? Third, what are the relative mortality rates from different disorders in schizophrenic populations? And finally, what variables affect mortality rates in schizophrenic populations?

The standard mortality ratio (SMR) is a tool used to examine death rates in a population and can be broken down to examine rates due to specific causes. The SMR is the rate of observed deaths divided by the rate of expected deaths, which is based on rates of death seen in the general population. Therefore, an SMR greater than 1 would indicate a mortality rate in the study group that is greater than the rate in the general population, whereas an SMR less than 1 would signify a mortality rate lower than that in the general population.

Allebeck (1989) concluded that schizophrenia patients in general are 8 times more likely than the general population to die as a result of injuries and 14 times more likely to have an "undetermined" cause of death on the autopsy. Thus, suicides, injuries, and accidental deaths account for the majority of deaths, although in this chapter our focus is natural causes of mortality. Whether there is increased mortality from natural causes among persons with schizophrenia is uncertain. It has been widely observed that schizophrenia patients appear to have a mortality rate two to four times that of the general population, or a life-span reduction of approximately 10–15 years (i.e., nearly 20%) in comparison with people without schizophrenia (Jeste et al. 1996; Newman and Bland 1991). However, most of this increased mortality occurs in younger patients and decreases with age (Newman and Bland 1991; Simpson and Tsuang 1996). For example, on the basis of data from a 10-year study of 1,190 patients (age range=younger than 10 to older than 80 years) in Stockholm, Sweden, Allebeck and Wistedt (1986) and Allebeck (1989) reported a high mortality rate in younger age groups but a mortality rate equal to or lower than expected in those 60 years and older; the SMR was nearly equal in the two sexes. Several reports from the United Kingdom have likewise found higher SMRs in younger populations and lower SMRs in older schizophrenic populations (Brown et al. 2000; Herrman et al. 1983). On the other hand, although Newman and Bland (1991) reported a clear trend for a declining SMR with age, they noted that even in the 70+ age group, the SMR for all causes of death combined was greater than 1. These results were based on a cohort study of 3,623 subjects in Alberta, Canada, with an age range of 9 to 88 years (mean age=37 years).

With respect to causes of death, Brown et al. (2000) determined that 80% of natural deaths in persons with schizophrenia were from neoplastic, circulatory, or respiratory disease, which is similar to the distribution in the general population. Despite this similar distribution, persons with schizophrenia have been found to have elevated rates of death from cardiovascular disease; tuberculosis; and lung, kidney, and digestive diseases in comparison with their same-age peers (Dixon et al. 1999). For example, in the large Canadian study conducted by Newman and Bland (1991), death rates in persons with schizophrenia were found to be significantly elevated over those in the general population for respiratory, digestive, circulatory, and genitourinary disorders. Although mortality rates for infectious disease were not significantly elevated, the SMR for infectious disease was greater than 1. Disorders with nonsignificant SMRs included neoplasias, except for digestive cancer, which was significant with an SMR of 1.7 for both sexes combined. By contrast, several other studies did not find evidence of increased risk of cardiovascular mortality in schizophrenia patients (Black et al. 1985; Eastwood et al. 1982; Martin et al. 1985; Tsuang et al. 1980). Craig and Lin (1981) found that in men the cancer mortality rates tended to peak in the 60- to 69-year-old group and then taper off, whereas in women the cancer mortality rates continued to rise past age 70.

The aforementioned studies included a wide range of age groups with only minimal focus on the elderly age group. A few studies have looked more specifically at older persons with schizophrenia. A study by Giel et al. (1978) showed lower SMRs in the 65+ age group (both males and females) in the categories of malignancies, cardiovascular illness, and cerebrovascular disease. However, both men and women had increased mortality from pneumonia, roughly three and six times more than expected. Herrman et al. (1983) reported that ischemic heart disease was the most common cause of death in both sexes after the age of 54 years. They further noted that the number of deaths from this cause was more pronounced among the elderly females in comparison to the elderly males. Lovett Doust (1980) hypothesized that the increased mortality from cardiovascular disorders in persons with schizophrenia was related to abnormal cardiac rate variation. He found that significantly more schizophrenia patients than healthy age-matched control subjects exhibited bradycardia between phases of tachycardia and that this association was unrelated to sex and medication. Some investigators (Hollister and Kosek 1965; Saugstad and Odegaard 1985) believe that the higher rates of cardiovascular mortality in the schizophrenia population may be due to antipsychotic use, although others (Craig and Lin 1981; Risch et al. 1981) have found no evidence of increased cardiovascular mortality associated with such use. Finally, cardiovascular death rates may be misleading, because the pronouncement of death due to cardiovascular reasons appears to be a diagnosis that is "given in the absence of more solid evidence for the underlying cause of death" (Allebeck 1989, p. 86).

Most studies (Wood et al. 1985) agree that older schizophrenia patients have lower mortality relative to other psychiatric patients but increased mortality in comparison with the general population. This finding is consistent with Lacro and Jeste's (1994) data indicating that older patients with schizophrenia had a decreased prevalence of physical illness compared with other older psychiatric patients. Possible explanations for these findings include a different sort of lifestyle (environment) for schizophrenia patients, a possible protective mechanism of antipsychotics on cardiovascular function, and that elderly patients with schizophrenia are in some way particularly resilient in that they have survived a weeding-out process that other physically ill schizophrenia patients have not survived. The lower mortality in persons with schizophrenia is observed for nearly all causes, with the exceptions being heart disease and cancer. Cancer mortality in schizophrenia patients is higher than that in other psychiatric patients but lower than that in the general population (Wood et al. 1985).

Several variables have been implicated in the higher mortality rates in schizophrenic populations. As in the general population, gender has a very strong effect on death rates. The SMR for men with schizophrenia has been found to be twice that for women, whereas relative risk (i.e., age-specific SMR) is increased in women, especially at younger ages (Mortensen and Juel 1993). Black (1988) reported that the increased mortality risk in persons with schizophrenia relative to the general population persists after age 40 years for women but not for men, which suggests that this may be due to the average older onset age observed in female schizophrenia patients. Consistent with these findings, Tsuang and Woolson (1978) found both men and women to have excess mortality in the first decade of follow-up, with men having increased mortality in the second decade of follow-up and women having increased mortality in the third and fourth decades of follow-up. Finally, Segal and Kotler (1991) found that low income was an independent risk factor for mortality among community-dwelling persons with schizophrenia and that the SMR dropped from 2.85 to 1.82 when income was controlled.

Health Habits

Poverty, unstable living situations, and lower-than-expected educational attainment have been linked with schizophrenia, and these variables are thought to be associated with unhealthy lifestyles and to increase the risk of medical disorders (Dixon et al. 2001). Brown et al. (1999) evaluated 102 middle-aged persons with schizophrenia residing in the community and found that patients exercised less, smoked more, and ate less healthy diets than did control subjects. McCreadie et al. (1998) likewise found that many schizophrenia patients eat poor diets and are obese.

Numerous studies (Dixon et al. 2000; Lyon 1999) have shown that persons with schizophrenia smoke cigarettes at almost double the rate of the general population. Brown et al. (2000) conducted a 13-year follow-up of 370 schizophrenia patients (both male and female) in Southampton, United Kingdom, with ages ranging from 16 to 65 years. They concluded that most of the excess natural mortality of modern community samples is attributable to cigarette smoking.

Use of alcohol may be lower among older schizophrenic outpatients than among their same-age peers in the general population. In the New York City sample of older persons with schizophrenia (C.I. Cohen, unpublished data), only 3% of the sample reported consuming three or more drinks daily, and only 10% of the sample reported any alcohol consumption. Many had apparently reduced their consumption, with 10% and 11% reporting moderate and heavy drinking patterns, respectively, when they were younger. Although current use of drugs is very low in older schizophrenic populations, projections based on usage patterns in early and middle adulthood (Patterson and Jeste 1999) indicate that levels of substance abuse will increase dramatically in the upcoming generation of aging persons with schizophrenia.

Subjective Health Status

Self-rated health status is an important measure of subjective well-being. Although it tends to correlate with more objective measures of health, it is based on personal perception and judgments. Because such judgments may be colored by the subject's past health problems, the health levels of other persons in the subject's social sphere, and the subject's aspirations for the future, individuals may underestimate the severity of their illnesses and postpone seeking treatment. Only a few studies have examined this issue in aging persons with schizophrenia.

Krach (1993), using the Older Americans Resources Survey to obtain information from 20 female schizophrenia patients (mean age=61 years) with long institutionalization histories, found that 60% and 40% of the sample rated their health as excellent/good and fair/poor, respectively. Mental health ratings were similar, with 70% and 30% reporting excellent/good and fair/poor mental health, respectively. On the basis of the level of physical disorders and reports of impairment in daily living (e.g., 35% had moderate or severe impairment in activities of daily living), Krach (1993) concluded that these patients overrated their physical heath status and underreported their medical symptoms, although she provided no objective measures of physical health. Indeed, in contrast to Krach's conclusions, the authors of the PORT study (Dixon et al. 1999) maintained "that persons with schizophrenia have the capacity for reasonable appraisal of their medical conditions that can be a useful tool to promote positive health behaviors" (p. 502). This conclusion was based on their finding of a significant association between number of medical conditions and self-rated health.

In the PORT survey, lower educational level and greater number of comorbid medical disorders were the only variables associated with poorer self-rated physical health. Other variables, such as gender, race, age, comorbid alcohol or drug disorder, geographic location, and patient setting, were not associated with self-rated health, although there was a trend for older subjects to perceive their health as better.

The study of older persons with schizophrenia in New York City cited previously (C.I. Cohen, unpublished data) found that despite equal or greater prevalence rates of physical disorders among the schizophrenic persons versus older community residents, self-reported health differed between the two aging samples. Self-ratings of good or excellent health were reported by 43% of persons with schizophrenia and by 54% of community control subjects. When the entire schizophrenia sample was examined (i.e., including Hispanic subjects), the percentage reporting excellent/good health dropped to 38%. In bivariate analyses, the factors associated with more negative self-ratings of health were Hispanic ethnicity, depression, higher levels of activity limitation, diminished life satisfaction, and lower education; there was also a trend ($P<0.10$) associated with positive symptoms, lower income, and number of physical disorders. However, in multivariate analyses, only activity limitations and depression remained significant predictors of negative self-ratings of health. Compared with an older community sample, older persons with schizophrenia had higher scores on the depression (7.5 vs. 5.5) and activity limitations (6.0 vs. 5.0) scales; scores on the latter scale can be affected by limitations from mental as well as physical causes. Thus, the results of the multivariate analysis indicated that self-ratings of health may primarily reflect psychological rather than physical factors. Moreover, findings suggest that older persons with schizophrenia do not overestimate their physical well-being relative to their same-age peers in the community and that, if anything, they may even underrate their physical well-being.

Health Care

Findings from the PORT study indicated that with the exception of diabetes and hypertension, more than 30% of the patients who reported current physical problems were not receiving treatment for them. With respect to patient-related reasons for receiving inadequate medical care, schizophrenia patients may not report physical problems to their doctors, possibly because of lack of insight or because of a decreased sensitivity to pain (Jeste et al. 1996). Both Munjas (1986) and Lima and Pai (1987) noted that persons with schizophrenia are more likely than psychiatrically healthy persons to exhibit physical illness through behavioral changes and/or by exacerbation of their psychiatric symptoms. Many researchers have observed that schizophrenia patients often do not verbalize pain or discomfort (Andreasen 1987). Authors have variously attributed this finding to patients' resistance to pain and inflammation (Horrobin 1977), a greater tolerance for pain in comparison with control subjects (Dworkin 1994), cognitive problems in recalling symptoms (Pary and Barton 1988), and communication difficulties and/or thought disorder in which the schizophrenic illness modified the description or explanation of pain (Watson et al. 1981). Krach (1993) observed that because of negative symptoms, nonspecific behaviors and mood changes are frequently patients' only symptoms of physical illness. She theorized that the older person with schizophrenia seldom will verbalize pain or discomfort but instead will exhibit an exacerbation of psychiatric manifestations, such as confusion. Patt et al. (1994) speculated that schizophrenia patients' greater tolerance of pain may be due to antipsychotic medication. Antipsychotics such as haloperidol may also enhance analgesia, which may further complicate medical diagnosis (Maltbie et al. 1979). Fishbain (1982) noted that because schizophrenia patients may experience relative pain insensitivity, physicians may be more apt to make erroneous assessments and to believe that an illness has not progressed as rapidly as it has. Ruskin (1985) found that the subtle thought disorders (e.g., suspiciousness, mistrust) of many persons with schizophrenia made it difficult for them to cooperate rationally in the planning and execution of their medical treatment.

Compelling evidence indicates that physical illness is underdiagnosed and untreated because of physician variables. In studying how well physicians at a psychiatric clinic were able to detect physical illnesses, Koranyi (1979) found that nonpsychiatric physicians missed one-third and that psychiatrists missed one-half of their patients' comorbid medical conditions. Similarly, Koran et al. (1989), examining the California public health system, found that only 47% of patients' physical illnesses were recognized by the mental health staff.

Sternberg (1986) concluded that part of the reason that psychiatric patients may receive inadequate medical care is that any medical problem that presents in association with psychiatric symptoms is likely to be primarily treated as psychiatric in origin. Even the more common complaints can be thought of as purely psychiatric and consequently dismissed—for example, a complaint of hearing noise, which medically could be tinnitus, could be dismissed as auditory hallucinations. The behavioral or emotional problems of psychiatric patients may also produce a strong negative countertransference reaction in physicians, thus undermining the quality of treatment. In particular, cognitively impaired and suicidal patients have been shown to elicit the most dislike from physicians (Felker et al. 1996).

McIntyre and Romano's (1977) survey of 118 psychiatrists and residents indicated that although a great number of them claimed that the physical examination is important, only 8% would actually conduct such an examination for their outpatients. One-third of the 92% of psychiatrists who did not perform physical examinations stated that they did not feel competent in their ability to conduct an examination. Only 6% of the psychiatrists believed that the therapeutic relationship would be negatively affected by conducting physical examinations; by contrast, 52% felt that doing so had no influence and 42% felt that this practice had a positive effect on the therapeutic relationship. Notably, Felker et al.'s (1996) review cited several studies showing that physical examinations do not interfere with the therapeutic relationship.

Further barriers to care may stem from prejudice against elderly patients, particularly those with severe and persistent mental illness. Many older persons with schizophrenia receive Medicaid, either alone or with Medicare. However, Medicaid reimbursement, eligibility requirements, and coverage vary widely across the nation, and Medicaid generally lacks the flexibility in choice of provider that may be available with Medicare alone. Medicaid patients are often relegated to public-sector health programs that are overcrowded and not well equipped to deal with older persons with psychiatric problems. Finally, other impediments to receiving optimal health care may result from lack of transportation or an inadequate social network to assist the patient in getting to treatment. In summing up the state of health care for persons with schizophrenia, Goldman (1999) concluded, "A fragmented health care system, lack of access to care, patient inability to clearly appreciate or describe a medical problem, and patient reluctance to discuss such problems all contribute to the lack of attention to medical problems in patients with schizophrenia" (p. 98).

Finally, despite the critical concerns about inadequate health care for persons with schizophrenia, data from a study of older persons with schizophrenia in New York City (C.I. Cohen, unpublished data) suggested that the situation may not be so bleak for the geriatric population. Ninety-three percent of this sample of 117 outpatients had seen a physician other than a psychiatrist in the past year, and nearly three-quarters had seen their doctor in the past month. The number of visits to nonpsychiatric health providers was actually somewhat greater than in the community comparison group. In addition, one-third of the sample had seen a dentist in the past year, and among women, 28% and 44% reported that in the past year they had received a pap smear and breast examination, respectively. Moreover, the percentages who reported receiving medication for a heart disorder, hypertension, and diabetes were 77%, 81%, and 85%, respectively. A combination of factors played a role in patients' likelihood of seeking out and complying with medical treatment; these included the availability of health insurance (Medicare and Medicaid in most instances), easier access to public transportation and ambulette services, a wider availability of home attendant services to assist patients and to accompany them to medical visits, and participation in programs that encouraged physical assessments.

Summary and Conclusions

The paucity of literature specifically examining the health of older persons with schizophrenia necessitated that we extrapolate from studies of schizophrenic persons in general. Therefore, our conclusions must be viewed as provisional and will be subject to revision as more studies are conducted of the aging population with schizophrenia.

Schizophrenic persons in general are thought to have worse physical health than their same-age peers. However, a small body of data suggest that older outpatients with schizophrenia do not have more physical problems than their same-age peers, although the severity of their medical conditions may be slightly greater. An important caveat when interpreting data about health and mortality is that older schizophrenic populations are even more a group of survivors than are their same-age peers in the general population. This is because the risk of dying is much higher in the schizophrenic population, and life span is reduced by about 10–15 years on average.

With respect to specific disorders, there has been a fairly consistent association between NIDDM and schizophrenia, although this association has been confounded by the use of antipsychotic agents. However, several authors have noted that an association existed even before the introduction of antipsychotic agents. Cardiovascular disease and mortality appear to be higher among persons with schizophrenia than in the general population but lower than in people with other psychiatric disorders. Moreover, the relative risk of cardiovascular mortality is higher in younger than in older individuals with schizophrenia. Respiratory disease and mortality appear to be higher in schizophrenia patients, in general, which may reflect the proportionately higher rates of smoking in this population. Despite recent data suggesting an immune dysregulation in schizophrenia, lower risk rates have been found for rheumatoid arthritis, asthma, and allergies. Data concerning cancer have been inconsistent. The preponderance of the evidence indicates that persons with schizophrenia have higher rates of cancer of the breast, the digestive system, and the lung, although the data for lung cancer are more equivocal. Risk rates for cancer mortality seem to be highest among younger persons with schizophrenia, and there is some evidence that antipsychotics may protect against cancer. Finally, with respect to overall mortality rates, schizophrenic populations have two to four times the rates of the general population. However, virtually every study has found a decline in mortality rates among older schizophrenic populations, although their rates may still exceed those of their same-age peers. Excess mortality rates are higher among older women than among older men, and mortality rates for older schizophrenia patients of both genders are lower than those of older persons with other psychiatric disorders.

With respect to health care, the PORT study found that for the schizophrenic population in general, with the exception of those with hypertension and diabetes, approximately 30% of patients who reported a physical problem were not receiving treatment. Nevertheless, data from a study that specifically examined older outpatients with schizophrenia found that a greater proportion were receiving treatment than had been found in the PORT study—that is, 93% of the patients had seen a nonpsychiatric physician in the past year. Thus, treatment may have been enhanced by the combination of better health insurance available to seniors (Medicare as well as Medicaid) and participation in programs that encouraged physical assessments.

Several key issues must be addressed in future research:

- To provide for the health requirements of the growing number of aging individuals with schizophrenia, a critical need exists for longitudinal studies involving large samples of older persons with schizophrenia from the diverse socioeconomic and cultural backgrounds that reflect the heterogeneity of the general population.
- Testable theoretical models of various aspects of health need to be developed. All such models must include variables that have been shown to affect the health of older persons in general, such as gender, age, class, race, and ethnicity. It may be advantageous to begin with existing models that have been developed for the general geriatric population and adapt these for use with older schizophrenic populations. One place to start, for example, is with Krause (1990), who proposed a model of illness behavior in older persons that could be tested for older persons with schizophrenia. This model evaluates the role of stressors, social supports, physical health, health perceptions and beliefs, tangible aid to obtain medical care, and the interactions of self-care, informal care, and formal care. Elements of this model were operationalized and tested by the San Diego research group (Shaw et al. 2000). Similarly, Berkman and Gurland (1993) developed a model of health perceptions (or self-rated health) based on their study of older persons in the community. They view health perception as one aspect of quality of life, and their model conceptualizes health perceptions as arising in a pathway influ-

enced by sociodemographic characteristics, health impairment, and functional impairment. When Cohen and Talavera (2000) adapted this model for use in a study of older persons with schizophrenia, they found that their operationalized model was statistically significant in predicting functional impairment and that the latter variable was, in turn, able to significantly predict self-rated health. Thus, both of these models can offer a useful point of departure for future studies.

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P•A•R•T III

Gender and Sociocultural Aspects

CHAPTER 8

Gender Differences in Schizophrenia Across the Life Span

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In this chapter I discuss gender differences in the expression of schizophrenia across the life span. For example, the strength of the connection between fetal insults and later schizophrenia is sex dependent. Infections during the second trimester of pregnancy are associated with later schizophrenia in female offspring. The association between the severity of obstetric complications and schizophrenia is even stronger but, in this case, holds true for male offspring. These observations, when better understood, may lead to a clearer grasp of the pathophysiology involved and eventually to more effective healing. Another example of gender differences in schizophrenia is that whereas premorbid functioning and quality of life during the first decade of illness are relatively superior in women, the opposite is true in subsequent decades. Aging women with schizophrenia are disadvantaged to a greater degree than men. Here I review what is known about such differences to better assess and better treat both men and women.

Etiology

The causes of schizophrenia are largely unknown. Its expression and course vary from person to person, for reasons that are rarely apparent. We do know, however, that age and sex play a role. Schizophrenia is currently conceptualized as a complex genetic disease, with many genes contributing to its etiology and probably also to its onset age, specificity of symptoms, evolution, and response to treatment. Because the symptoms of schizophrenia do not usually begin in early childhood and, as we are starting to realize, may sometimes not begin until old age, it is a safe assumption that as-yet-unknown epigenetic factors either silence or activate the expression of the requisite genes and regulate their transcription and their translation into the proteins that build brain structure and result in brain function. Given that the peak of schizophrenia incidence is postpubertal, it is tempting to think that at least one of these unknown epigenetic factors might be hormonal. *Epigenetic* refers to the impact of nongenetic factors on the regulation, timing, and cell specificity of gene expression. An integrative model of schizophrenia needs to encompass the interplay among genes, epigenetic phenomena such as hormonal gene regulation, and social environment.

Hormones Regulate Genes

As a preamble to an examination of sex and age differences in schizophrenia, it is important to understand how steroid hormones (glucocorticoids and gonadal steroids) exert their effects. They permeate nerve cell membranes and attach themselves, through a cascade of intracellular and intranuclear events, to the regulatory regions of target genes. Stress is a generally acknowledged trigger of episodes of psychosis. The experience of psychological stress releases glucocorticoids from the adrenal glands. These hormones, along with immune factors and neurosecretors, set off a chain of events that culminates in gene activation. Developmental transitions such as adrenarche, puberty, the postpartum period, menopause, and adrenopause—periods in the life span at which marked hormonal changes occur—are strikingly associated with peaks of schizophrenia incidence. Gonadal steroids, therefore, as well as glucosteroids, may turn out to play a major role in the modulation of relevant schizophrenia genes—perhaps in opposing directions. Estrogen response elements, for instance, exist in the promoter regions of at least 100 known genes. It may emerge that one or more of these genes is involved in the pathophysiology of schizophrenia, which would partially explain male–female schizophrenia differences (Table 8–1).

TABLE 8–1. Summary of sex differences in schizophrenia

Women experience more mood symptoms
Men experience more deficit symptoms
Women present as more socially appropriate
Delusional themes differ between the two sexes
Men engage in more substance abuse
Women have more comorbid problems (allergies, endocrine disturbances, eating disorders, posttraumatic stress disorders, psychophysiological disorders)

Sex Differences in Schizophrenia Over the Life Span

Male and Female Fetal Life Problems

The developing fetus shows sex-specific vulnerability to a variety of environmental insults that may increase the risk for schizophrenia. It has been hypothesized that infection, malnutrition, anoxia, or chemical insult during pregnancy interferes with normal fetal brain development. Studies that have detected a correlation between infection in second-trimester pregnancy and schizophrenia in offspring, have found it—puzzlingly—to be significant only for daughters (Kunugi et al. 1995). An even greater puzzle is why it takes at least two decades (from fetal life to schizophrenia onset) before a putative prenatal insult manifests as illness. Given that redundancy abounds in neural circuits, it is presumed that symptoms emerge only after normal postpubertal neuronal pruning has taken place, and then only in response to an increased cognitive demand. This hypothesis is supported by the subtlety of the varied neuropathology found in schizophrenia (Table 8–2). In postmortem tissue, diminished neuronal growth, sidetracked neuronal migration, and faulty neuronal differentiation have been reported. Computed tomography scanning and magnetic resonance imaging reveal decreased gray matter, especially in the hippocampus; widened cerebral sulci; and enlarged ventricular spaces. Although the bulk of these abnormalities have been reported in males, they may yet prove to be equally prevalent in the two sexes.

Obstetric Complications Affecting Male and Female Offspring

Brain abnormalities in schizophrenia may originate in or be intensified by obstetric complications during labor and delivery. In the general population, male births are more likely than female births to be associated with

TABLE 8–2. Schizophrenia neuropathology

Cortical volume ⇓
Ventricle size ⇑
Hippocampal and cortical neuron size ⇑
Gliosis absent
Hippocampal neuron density ⇓
Disarray of laminar neurons in temporal cortex
Perfusion and metabolism in frontal regions ⇓
Striatal D_2 receptors ⇑
Dopamine content and metabolism ⇑
5-HT_{2A} receptors ⇓
Synaptic and neuronal marker genes and proteins ⇓

Note. ⇓ = decrease; ⇑ = increase; D_2 = dopamine type 2 receptor; 5-HT_{2A} = 5-hydroxytryptamine (serotonin) type 2A receptor.

obstetric difficulties, and this is true in the schizophrenia population as well (Dalman et al. 1999). One reason might be H-Y antigen antibody formation—mothers develop antibodies to their sons' H-Y antigen (present on the Y chromosome), and these antibodies subsequently mount an attack on the fetal brain. Another possibility is that male infants reach term with larger heads than female infants, which slows down labor and increases anoxic stress. Preterm male infants are known to fare less well than preterm female infants of the same weight, presumably because the pace of brain development is faster in girls, so that they are more mature at birth. The relative maturity of girls at birth may explain why the connection between obstetric complications (including short gestation) and schizophrenia is statistically stronger in men than in women.

Premorbid Functioning in Male and Female Adolescents

Premorbidly, young men and women show differences in motor, social, and academic development (Seeman and Fitzgerald 2000). Schizophrenia starts later in women than in men and is relatively less debilitating during the first decade following onset. These two facts can be explained by gender differences in neurodevelopment. For instance, for the first three decades of life, females show significantly more myelin staining in temporal lobe white matter than do males of the same age. This myelin sheath protects neural circuits against the potentially toxic effects of corticosteroids produced in the wake of stress. Estrogen hormones are considered to play a key role in the pace and extent of the myelination process, thus potentially buffering the impact of stressful events. The duration between the first nonspecific symptom and the first psychotic symptom is almost twice as long in women as it is in men, pointing to a major protective influence operating in the female sex (Cohen et al. 2000). Early puberty in girls has been associated with a later onset of schizophrenia (Cohen et al. 1999), suggesting that this protective influence could be hormonal.

The protective factor could be mediated via social vectors. For instance, whereas social support is associated with better general health in both sexes, it is known to play a more important role in the health of women than in men (Denton and Walters 1999). This knowledge may help to design preventive interventions.

Early Adulthood in Men and Women

In incident cases of adolescent or early adult schizophrenia, onset in men precedes that in women by at least 2–3 years. Earlier male onset can be explained by hormones, by differential social supports, or by the greater prevalence of substance abuse in males. The discrepancy in onset age means that at the onset of illness, young women may have already finished school, acquired work experience, and established bonds of intimacy, whereas men may not have. The later start of schizophrenia in women confers an early advantage that is apparent in different domains of illness.

Symptoms

Women experience more depressive symptoms, less substance abuse, and fewer negative symptoms (Seeman and Fitzgerald 2000). The initial acute episodes in women tend to be shorter than those in men. Women present as more socially appropriate. Whereas these differences make the problems of the early years less painful for women, they also make schizophrenia relatively more difficult to diagnose in women. As a group, women are more prone to thyroid disorders, eating disorders, posttraumatic stress disorders, and certain kinds of personality disorders that include psychotic symptoms in their presentation. The inclusion of such mainly female and better-outcome syndromes under the rubric of schizophrenia means that outcome statistics favor women. At the same time, it may mean that diagnosis-specific treatment is delayed in women and that women may pay for that delay later.

Occupation

Initially, more women than men with schizophrenia are gainfully employed, probably because of the later onset of illness and the greater probability of premorbid job experience. Later on, however, the ratio evens out, with 70% of both sexes registered as unemployed. A major source of stress, particularly for women, is conflict between obligations of work and home. Such conflicts are especially acute for women who are single parents, have few outside supports, or live in poverty. The convergence of these circumstances is unfortunately present in many women living with schizophrenia. Despite this, women's economic situations are often better than men's, at least while marriages last and parents survive. In other words, more women than men are financially supported by family members.

Cognition

Problems of a cognitive nature—difficulty in filtering and sorting sensory experience, or in correctly attributing meaning to events and to the intentions of others—may represent a more fundamental, if less striking, impairment in schizophrenia than the symptoms of schizophrenia per se (Lewis and Lieberman 2000). Schizophrenia is associated with global intellectual impairment and deficits in executive functioning, memory, and attention. The pattern of cognitive deficit differs in the two sexes, and it is possible that cognition is affected more severely in men. At least at the start of illness, men appear to be more impaired (Weiser et al. 2000).

Intimacy

Although women with schizophrenia enter into relationships more readily than do men, both sexes experience obstacles to intimacy. Those affected may hear voices that prohibit sexual relations or comment negatively on desires, motives, and behaviors. Tactile or olfactory hallucinations may make intimacy unpleasant or even frightening. The detachment and general anhedonia that accompany schizophrenia may induce a lack of interest in sexuality and an inability to experience arousal. High rates of sexual dysfunction and also of unsafe sexual behavior (Miller and Finnerty 1998) have been reported in schizophrenia. Some of these problems are specific to women in that they may disproportionately experience the effects of unsafe sex. A high percentage of women with schizophrenia have a history of physical and sexual abuse (Goodman et al. 1997), a circumstance that must be taken into account in the design of psychiatric services (e.g., special care taken to avoid retraumatization).

Schizophrenia treatment has adverse effects on sexual function in both men and women. The older antipsychotics and risperidone, by increasing prolactin levels, interfere with fertility, reduce libido, and contribute to anorgasmia, oligomenorrhea or amenorrhea, and galactorrhea. These problems are that much worse in women, whose baseline prolactin levels are already higher than men's.

Pregnancy and Breast-Feeding

As a corollary to relatively increased intimacy, women with schizophrenia become parents more often than do men with the illness, and childbearing has become even more common with the advent of prolactin-sparing antipsychotics, which do not interfere with a woman's fertility (Currier and Simpson 1998). Continuation of antipsychotic treatment during pregnancy is a dilemma for women with schizophrenia who are afraid to expose their fetus to potentially hazardous substances. It presents a dilemma for their physicians as well. On the one hand, the pregnant mother is under severe stress and may require more, rather than less, medication. On the other hand, because of increasing titers of sex steroids acting on neurotransmitter receptors, some pregnant women may not require high drug levels to stay symptom-free.

Potential teratogenic effects of antipsychotic drugs are both dose and time dependent, the fetus being at greatest risk during the first 3 months of gestation. Besides organ malformation, potential risks to the fetus are spontaneous abortion, growth retardation, and immediate neonatal effects such as extrapyramidal and withdrawal symptoms, although long-lasting behavioral teratogenesis has not been demonstrated. A recent review acknowledged a relative lack of data for the safety of antipsychotic and antiparkinsonian drug use during pregnancy and breast-feeding (Llewellyn and Stowe 1998). This knowledge gap places additional burdens of uncertainty on pregnant and lactating women.

Stress, poverty, abusive relationships, and the added guilt of being unable to stop smoking or to discontinue use of alcohol, street drugs, or over-the-counter medications makes pregnancy a very difficult time for many young women with schizophrenia.

Gender Differences in Antipsychotic Treatment Response

Women have been reported to show higher antipsychotic plasma levels than men after receiving the same drug dosage (Pollock 1997). This may partially explain the superior treatment response of women both in time to remission and in dosage required to achieve remission (Szymanski et al. 1995), an advantage that may be limited to younger (premenopausal) women. Many more recent studies, however, have failed to find differences in treatment responsiveness between women and men (Magharious et al. 1998).

Treatment Side Effects

As with response, the incidence and severity of antipsychotic side effects is confounded by many variables and is heavily dependent on both prescribed dose and patient adherence to treatment. At the same dose level, acute dystonia, long thought to be more prevalent among men, has been shown to occur preferentially in women treated for a first episode of illness (Casey 1991). Earlier clinical studies had not taken into account the fact that young male patients were commonly prescribed higher doses than were women, probably because men were more aggressive when psychotic. More than 80% of drug reactions are known to be dose related; despite this, most adverse effects occur in women (Martin et al. 1998).

Side effects of antipsychotic medications have different implications for men and women. On the whole, men are most disturbed by interference with performance, especially sexual performance; women tend to be more distressed by side effects that affect appearance, weight gain being of special importance because it has become so prevalent with the new generation of antipsychotic drugs (Devlin et al. 2000). Two-thirds of those who develop agranulocytosis secondary to clozapine are women, an effect related not to dose but rather to immunological factors.

Later Adulthood in Men and Women

Subjective Experience

A recent study that used focus groups concluded that the experience of women living with schizophrenia was one of isolation and fear of rejection (Chernomas et al. 2000). These women both sought and fled from men, perceiving themselves as “easy prey.” They reported enjoying the benefits of motherhood (someone to love, a purpose, an identity, a source of emotional support), but these benefits were offset by the added stress and exhaustion, the inevitable financial drain, the fear of their children’s being apprehended by child welfare agencies, and also the fear of their children’s inheriting schizophrenia. Those who lost children to foster care or adoption reported continuing grief and anger. The women expressed needs for support, information, and treatment programs that focused on areas of special importance to them: social activities, exercise classes, substance abuse programs, relationship and assertiveness groups, family planning, and antistigma and antipoverty strategies. The results of similar focus groups in men have not yet been reported.

Parenting

Rates of child*bearing* (but not child *rearing*) in women with schizophrenia approximate those in the general population; half of the children are born prior to the diagnosis being made (Barkla et al. 2000). About half of the pregnancies are unplanned, a figure similar to the U.S. average for unplanned pregnancy. A quarter of unplanned pregnancies are terminated

(Barkla et al. 2000). Only half of mothers retain custody of their child (Miller and Finnerty 1998). The experience of parenting in men with schizophrenia has not been reported.

Mothers' Experience

Mothers with schizophrenia are concerned about the impact of stress and role strain in their lives. Because of the fear of losing custody of their children, they may try to minimize the extent of their stress. Stigma about mental illness ranks high as a concern for mothers. Managing illness in addition to the stress of parenting is experienced as a difficult burden, and personal needs are neglected. When these women get ill, they often delay seeking help because they have no one to look after their children. They fear losing custody, and in their minds this fear contributes to an increase in symptoms. When their children are in foster care, some mothers report losing all motivation to get better. The grief of permanent custody loss can last a lifetime (Nicholson et al. 1998).

Consequences of Antipsychotic Treatment

Common side effects of antipsychotic medication, such as sedation and orthostatic hypotension, are equally prevalent in men and women, but their impact in women who have child care responsibilities is more serious than most clinicians realize. Sleepiness and dizziness interfere with adequate parenting and may contribute to loss of child custody (Seeman and Cohen 1998).

Menopause

Women, but not men, have a second peak of incidence of schizophrenia at the time of menopause (Castle 2000); preexisting symptoms also worsen at this time. At a time point roughly approximating menopause, women's comparative outcome advantage wanes. Although it occurs at the time of menopause, this change is not necessarily hormone dependent. It corresponds to a time in the lives of women when parents die and social supports fade. From the evidence of personal narratives, psychosocial issues play a larger part in worsening symptoms than do declining estrogen levels (Seeman 1998).

It is interesting that, parallel to the increasing severity of women's symptoms relative to men's, the incidence of new-onset schizophrenia at midlife is much higher in women. One could speculate about factors conferring protection on men during this life period. From a biological standpoint, at the age when the ovaries stop producing estrogens, the protective effects of estrogens in the brain (Table 8–3) are still operative in men, testosterone still being converted to estradiol.

TABLE 8–3. Actions of estrogens in the central nervous system

Modulate blood–brain barrier
Selectively increase cerebral blood flow
Increase neuronal supply of glucose and oxygen
Increase myelination
Improve connectivity and circuitry
Regulate calcium and other electrolyte channels
Decrease seizure threshold
Stimulate growth of synapses and dendrites
Modulate most neurotransmitters
Modulate signal transduction intracellularly
Protect against oxidative, amyloid, and glutaminergic stress
Protect against corticoid stress
Decrease apoptosis

From a psychosocial standpoint, factors that predispose to psychosis, such as social isolation, poverty, and physical illness (Burnett et al. 1999), are more prevalent among women at menopausal age than among men. Chronic physical illness is more prevalent among women of all ages, and isolation and poverty are more prominent among older women, especially those who are single, separated, or widowed. The incidence of schizophrenia in persons older than 65 years has been reported as 12.6 per 100,000 population per year (Copeland et al. 1998), with a female:male ratio of 3:1. Although the female:male ratio appears to be less pronounced in African- and Caribbean-born elderly persons living in south London, the total incidence rate is higher in this subpopulation than in the general population (Reeves et al. 2001). This failure to find an increased female:male ratio in schizophrenia incidence in the over-65 age group may be the result of social factors such as isolation, exclusion, and low socioeconomic status being highly prevalent among both women and men.

Aging in Women and Men

Health

Aging and the progress of schizophrenia occur side by side, making it impossible to disentangle the sex-specific effects of age from those of disease progression. Women live longer than men, so women's needs are more visible at this time. Poverty and, often, cognitive dysfunction interfere with disease prevention. Hypothetically, the withdrawal of estrogen in women may make their cognitive deficiency worse than that in men, who continue to produce testosterone well into old age. Regardless of sex, however, individuals with schizophrenia eat a diet higher in fat and lower in fiber compared with the general population. They exercise little, smoke heavily, and are reported to use more substances. This unhealthy lifestyle contributes to ill health and could be a major focus of helpful intervention. Bone and joint disease, respiratory ailments, cardiovascular disease, diabetes, and dementia are frequently seen. Breast and gynecological malignancy is often considerably advanced in this population before it is diagnosed.

Such evidence as exists suggests that aging diminishes the disability attributable to schizophrenia symptoms, although negative symptoms tend to persist. Dementia occurs in about one-quarter of patients, a rate similar to or only slightly higher than that in the over-65 population as a whole. An extensive review of the literature found no clear association between neurological abnormalities and age or duration of illness in those with schizophrenia (Heinrichs and Buchanan 1988).

The quality of relationships tends to improve in old age, although the number of social contacts decreases and dependence on others increases. Social deterioration at this age seems most closely correlated with three (perhaps interdependent) factors: substance abuse, loss of previous valued supports, and a family history of schizophrenia (Seeman 1998). Key social supports may disappear with age, perhaps to different degrees in women and men. The presence and the quality of social ties affect both physical and mental health in complex, profound ways.

Response to Antipsychotic Treatment

Aging means decreases in intracellular water, protein binding, and tissue mass. These decreases, plus an increase in total body fat, mean that concentrations of antipsychotics in the brain rise and that the body reservoir is increased, allowing drugs to accumulate. Drug metabolism decreases because of relative enzymatic inactivity, decreased blood flow to the liver, and decreased liver mass. Renal excretion is progressively impaired. These factors act synergistically to increase the effects of antipsychotic medications in old age in both sexes. Women may be most at risk from high drug doses because of their relatively greater lipid–lean ratio—that is, they have more storage space for drug accumulation (Pollock 1997).

Side Effects of Antipsychotic Medication

Tardive dyskinesia, still frequently cited as most commonly affecting elderly women, has been shown in a cohort (as distinct from a cross-sectional) study to be more of a risk factor for elderly *men*, although its *severity* may be relatively greater in women in their later years.

Chronically high prolactin levels secondary to a lifetime of antipsychotic medication reduce gonadal steroid secretion and predispose the elderly with schizophrenia, especially women, to osteoporosis. The combination of osteoporosis, sedation, and hypotension increases the risk of falls and hip fractures in older women. The weight gain secondary to antipsychotic treatment increases the relative risk of diabetes mellitus and lipid abnormalities in older age for both sexes.

Mortality

Mortality in young adults with schizophrenia is approximately two times higher than that in the general population, with suicide being the major cause (Brown 1997). Suicide accounts for 50% of the deaths in men and 35% of those in women, rates 20 times higher than those in the general population for both sexes. The absolute suicide rates are higher among men in all age groups, but—relative to the general population—the risk of suicide for women is *higher* than that for men until age 60. The overall mortality in schizophrenia caused by unnatural factors (suicide, accident, homicide) is significantly higher in males than in females throughout the life cycle (Brown 1997). Although the excess mortality attributable to schizophrenia decreases with age, death from natural causes, especially cardiovascular causes, remains excessively high, particularly in women (Osby et al. 2000). Women with schizophrenia also show increased mortality from all forms of cancer, including breast cancer. These findings are important for prevention and improved care.

Conclusions

This chapter has used a life-span approach to explore what is known about gender differences in schizophrenia. The experience of schizophrenia and individual treatment needs are very much embedded in the broader context of culture, socioeconomics, age, and sex. Optimal treatment for a man with schizophrenia is different from optimal treatment for a woman. Sex will often dictate how assessments need to be carried out, how difficult the diagnosis is to make, how treatments are delivered, and what constitutes risk and optimal intervention.

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CHAPTER 9

Social Vicissitudes of Schizophrenia in Later Life

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The aim of this chapter is to address the following questions:

1. How do various social dimensions differ between a) older persons with schizophrenia and their same-age peers in the general population and b) older and younger persons with schizophrenia?
2. How does the aging process affect various social dimensions?
3. What are the best strategies for developing a conceptual model for studying the social world of older persons with schizophrenia?

The human social world can be conceptualized in various ways. Although aspects of the "social" inhere within the biological and psychological realms, for the sake of analysis it is necessary to abstract out the social realm from the other two realms. By "social," I mean aspects of the life, welfare, and relations of persons in a community. This is in contrast to the "biological," which refers to aspects of living organisms such as structure and physiological processes, and the "psychological," which pertains to human behavior and mental states and processes.

There are essentially two ways to approach the topic of this chapter. One way is to assume that the various indicators of social life are relatively autonomous and should be examined separately. These variables include social networks, social competence, and coping (the latter variable being a borderline variable between social and psychological realms). These variables typically are used as independent variables to predict mental or physical symptoms or quality-of-life measures. They are also thought to have buffering effects (i.e., they may reduce the impact of stress on the outcome measures) and consequently may be examined for their interactive effects with stress variables.

An alternative approach is to identify a unifying concept to draw the disparate measures together. One potential unifying concept is quality of life. The attraction of this omnibus term is that it typically incorporates "objective" (socionormative) and subjective terms along a continuum from positive to negative; also, it allows for global measures such as "life satisfaction" or "adaptive functioning" as well as ratings of specific domains (e.g., finances, health, social relations, leisure activities, living situation, personal safety).

To use global indices, it is critical that the domain-specific measures can appreciably predict global measures. There is evidence from the life satisfaction literature that this is so; for example, George (1981) concluded that domain-specific satisfactions account for 50%–60% of the variance in global life satisfaction. A related concern is how global measures, which typically are based on subjective ratings, are related to objective measures of life quality. George (1981) pointed to considerable accumulated evidence that global measures are related to numerous objective variables.

In this chapter, I argue that the use of more global indicators such as quality of life can serve as the linchpin for models of the social dimension in schizophrenia. However, the use of these global indices also necessitates that other social variables be examined as potential predictors of these global indices. Thus, I have organized this chapter into two initial sections on two key predictor variables, social networks and coping, followed by an examination of quality of life as a global measure.

Social Networks

Social networks can provide specific types of support (e.g., information, emotional, material) and can help buffer stress. In older persons in general, social networks seem to have a positive impact on emotional factors such as morale, notions of self-worth, and life satisfaction, as well as on behaviors such as use of health and social services (Litwin 2001). Aging research in general has recognized that changes in social networks as persons grow older do not involve simple depletion; instead, the composition and content of networks depend on context and personal attributes. Thus, persons in stable neighborhoods or those with better health and mobility are more apt to maintain a higher level of social supports. The "convoy" model of social networks posits that individuals enter and leave their social spheres over the life course (Antonucci and Akiyama 1987). Ties with close family members and friends are likely to be the most stable, whereas those with neighbors, coworkers, and distant family tend to be more vulnerable to severance based on role and life changes.

In the general aging population, larger social networks have been associated with higher educational levels, higher income, being married, being in the "young-old" group, and having fewer physical impairments (Litwin 2001). There appear to be only minimal racial differences in the overall size of networks, although older African Americans have larger family networks and whites have larger friendship networks. Older African Americans are involved in more exchange of material support, but there are no racial differences in emotional support (Mendes de Leon et al. 2001). The Duke Established Populations for the Epidemiologic Studies of the Elderly project found that among persons 65 years and older, with the exception of material (instrumental) support, all types of network support (e.g., network size, frequency of social interactions, emotional support) are longitudinally associated with lower levels of disability as measured by impairment in activities of daily living (Mendes de Leon et al. 2001). The authors speculated that the absence of an association with material support may have reflected the fact that persons seek material assistance before disabilities become more overt.

Similarly, in examining the social networks of older schizophrenic persons, it is important to contextualize these with respect to age, race, social class, and functional ability. A disproportionate number of persons with schizophrenia are in the lowest income quartile; roughly two-fifths have never married, and about one-fourth have been divorced; nearly two-fifths have had no children; they tend to have more cognitive deficits and to have more physical and activity limitations (Cohen et al. 2000). Hence, older persons with schizophrenia possess attributes that place them at risk of having smaller networks than do most of their same-age peers. Of course, many of the aforementioned attributes may be secondary to their having had schizophrenia. Nevertheless, in older age, when many of the positive and perhaps also the negative symptoms are less prominent and personally troublesome, many persons are unfortunately left with economic, social, and health sequelae that may affect their ability to strengthen existing ties or develop new ones.

Some of these issues become apparent in comparing older schizophrenic persons with their same-age peers in the general population as well as with younger persons with schizophrenia. For example, Cohen and

Kochanowicz (1989) found that social networks were 27% smaller in older relative to younger persons with schizophrenia, with the significant difference being in the kin network. In support of the notion that older persons may have the potential to better manage social relationships, Cohen and Kochanowicz (1989) found that older individuals reported significantly fewer "critical" or "bossy linkages" and tended to perceive a greater proportion of their ties as important, as good or best friendships, and as satisfying. This finding is consistent with the general life-span perspective of the emotion literature. For example, Magai (2001) found a trend of decreased anger with age. This decrease may result from diminished energy resources, a need to preserve close relationships, or better use of emotion-regulating strategies. Nevertheless, relationships may not be without discord. Semple et al. (1997) found that 30% of middle-aged and older persons with schizophrenia reported having difficulty with a parent.

It is noteworthy that Cohen and Kochanowicz (1989) found an association between older age and fewer exchanges per linkage, particularly among nonfamily networks, as well as a trend toward fewer "sustenance" linkages (i.e., those involving money, food, or health). This suggested that there was less material dependence on informal linkages and perhaps enhancement of emotional bonds. Nevertheless, it is unclear how much of this diminished material exchange is voluntary and desired, and whether these needs are being adequately fulfilled elsewhere. Indeed, there was no age-associated increase in the number or content of formal linkages, thus suggesting that the formal network was not compensating for these changes.

It should be emphasized that despite some normalization of social relationships in older age, older schizophrenic persons' social networks still tend to more closely resemble the networks of their younger counterparts with schizophrenia than they do the networks of their same-age peers without schizophrenia. Thus, our group found that, compared with the networks of racially matched non–psychiatrically ill same-age peers, the networks of schizophrenic individuals were smaller (e.g., 10.0 vs. 11.5 members), included substantially more relationships involving sustenance support (59% vs. 15%), had a smaller proportion of "intimate" linkages (44% vs. 67%), and were much denser (52% vs. 23%), often concentrated on remaining kin members or persons in supportive housing (Cohen et al. 1996). On the other hand, older persons with schizophrenia are more apt to use formal services (85% vs. 36%), including individual/family counseling, senior centers, and churches. Finally, 82% of older persons with schizophrenia said that their linkages "could be counted on," which was slightly less than the proportion endorsing this factor among their same-age peers.

The limited research in this area yields some positive findings with respect to older persons with schizophrenia. They are not isolated, they have intimate relationships, their relationships are probably less strained, and they feel that their relationships can be counted on. On the other hand, given the economic and increasing health needs of schizophrenia patients as they age, it is not certain whether patients' networks can provide adequate material assistance, a problem that may worsen as members of their social networks also grow old.

The structural and functional features of social networks may play an important role in survival and morale. Typically, among older persons in general, family members are relied on to provide material support and to serve as caregivers. If older persons with schizophrenia have small family networks, their ability to obtain assistance with health problems and daily functioning may be limited. If many of these persons have greater potential for sociability as they age, social structures need to be in place that will facilitate their social ties. At the same time, resources will be needed to provide formal supports—such as help with household tasks, errands, and the like—that typically may be provided by family networks. However, service providers must be mindful of promoting a collaboration of formal and informal supports that complement each other in order and that do not attenuate extant informal systems. Litwak's (1985) Theory of Complementary Roles has addressed this issue for aging persons in general.

On the other hand, for older persons in general, frequency of interaction with nonfamily networks is correlated with morale, life satisfaction, happiness, and lower levels of disability, whereas interaction with family is not (Litwin 2001). This may be due in part to the fact that family relationships may become increasingly dependent and unequal in power, which may conflict with the cultural ethos of self-reliance. Indeed, issues of self-reliance may be especially acute within certain cultural groups. In a study conducted in New York City among older adults in general, lower-income whites and African Americans had attachment styles that tended to value independence and interpersonal avoidance under stress, with African Americans especially prone to this style (Magai and Cohen 1998). It is not clear what the impact of this style will be on older persons who become more infirm and require increased assistance from others. Thus, older persons with schizophrenia who may have acquired through social and cultural circumstances greater autonomy may be more negative and hostile about receiving assistance as physical infirmities arise in old age (Magai and Cohen 1998).

Finally, consideration must be given to network characteristics such as density and number of clusters. In younger persons with schizophrenia, both excessively high-density and excessively low-density networks were associated with a greater number of days in the hospital over a 12-month period (Dozier et. al. 1987). Emotional support—which is often needed in crises—is often best provided by strong ties such as family or close friends, whereas informational or material support—which is often needed in transitional periods or long-standing demand situations, respectively—may be provided by a more widely diverse set of supports. Crises or more acute problems may be best handled by a small, dense network, whereas a more diffuse network may be better at handling long-standing problems. Thus, in theory, the older schizophrenic person's social networks may be adequate for crisis type situations (if the close relationships are positive) but less able to deal with long-standing demands.

Pescosolido's (1992) Network-Episode Model theorizes that service utilization can be explained by a combination of service system factors (e.g., treatment efficacy, accessibility) and social network variables (e.g., size, density, network composition and content). The shift from institutional to community-based treatment has made these social network factors—particularly those in the informal sector—much more relevant to health care.

Coping and Interpersonal Competence

The literature is a bit murky with respect to coping and interpersonal competence. The latter is often subsumed under functional adaptation, particularly that of social skills. However, Semple et al. (1999) have distinguished between social skills and interpersonal competence. *Social skills* are defined as "the person's abilities to respond appropriately to unfamiliar social situations," although Bartels et al. (1997), in their study of elderly patients with schizophrenia, operationalized the term as "accepting and initiating contact with others, group participation, friendships" (p. 49). Thus, social skill is a borderline concept somewhere between concrete social linkages and presumed social abilities. *Interpersonal competence* refers to "the individual's ability or capacity to solve life problems and to achieve effective human interactions" (Semple et al. 1999, p. 127). Buhrmester et al. (1988) identified five domains of interpersonal competence: initiation of social interactions, negative assertion (i.e., ability to say no), self-disclosure, provision of emotional support to others, and conflict management. Thus, there is an overlap between the terms *social supports*, *coping*, *social skills*, and *social competencies*. It would seem that social skills and social competency are pivotal to attracting and maintaining social supports. Nevertheless, several researchers have contended that the poor social skills and social withdrawal seen among persons with schizophrenia are expressions of coping behavior designed to avoid stressful life situations (Hoffman and Brenner 1995, cited by Semple et al. 1999).

The definition of coping likewise deserves some comment. *Coping* refers to the various ways in which people try to meet environmental demands or deal with emotions created by the pressure of the demands. Often, coping is tied to environmental stress so that it is conceptualized as a process of executing responses to various environmental threats. Moreover, coping has been broadly dichotomized into "problem focused"—i.e., doing something to alter the source of stress, removing the threatening event, or altering its impact—and "emotion focused"—i.e., aimed at reducing or managing the negative feelings that arise in response to the threat or loss (Carver 1996).

In practice, the two coping categories may overlap. Moreover, these categories lack specificity, and "emotion focused" can include diverse strategies such as use of social support, positive reframing of a situation, wishful thinking, escapism, and religiosity. Typically, if a situation is one that can be changed, problem-focused coping predominates. If the situation is one that must be endured, emotion-focused coping tends to predominate.

Despite these conceptual complexities, as a practical matter only a few studies have examined coping, social competence, or social skills in older schizophrenia patients. Cohen (1993a) looked at coping strategies used to control symptoms of schizophrenia. About three-fourths of patients were found to use symptom management techniques, which can be divided into four styles: cognitive (e.g., thought suppression, shifting attention), increases in behavior (e.g., socializing, performing tasks), decreases in behavior (e.g., social withdrawal, alcohol consumption), and medical (e.g., medication, contact with a clinician). Although hard data are lacking, it is assumed that patients with effective coping styles have a better prognosis and that failure in these compensatory attempts brings about manifestations of relapse of illness (Cohen 1993a). It is also assumed that coping is a long process in which those who are best able to cope have learned what seems to help them through trial and error.

Cohen (1993a), using cross-sectional data, found that the cognitive strategy of "fighting back" to overcome unwanted thoughts was negatively associated with age (r=–.14), whereas cognitive strategies of "acceptance" of symptoms and learning to live with them were positively correlated with age (r=.16). A behavior strategy, "social diversion" (i.e., increasing social contacts by calling a friend or talking to someone), was the one most strongly associated with age (r=.19). Although social diversion was used more commonly by older persons, the three most commonly used strategies in all age groups were "fighting back," "acceptance," and "isolated diversions" such as watching television, listening to the radio, and reading.

Although limited by the cross-sectional nature of the sample, the data indicated that coping styles may change over time. The finding that social diversion is more commonly used among older persons is consistent with findings that the quality of social relations, especially with family members, often improves with age. Similarly, the tendency of older persons to more often accept symptoms and not fight back may reflect enhanced tolerance of the illness and of themselves. As British psychiatrist John Wing observed, persons with schizophrenia, like most other people, learn to live with themselves as they grow older. Cohen (1993a) conjectured that modification in coping styles with age represent trial-and-error procedures—unique to the disorder intertwined with life-span changes common to most aging individuals.

Researchers in San Diego (Semple et al. 1999) have looked at social competence. They found that middle-aged and older persons with schizophrenia were significantly less likely than a psychiatrically healthy comparison group to perceive themselves as being competent, initiating interactions, providing emotional support, or managing conflict.

Finally, Bartels et al. (1997) examined social skills of community-dwelling persons 60 years and older with primary diagnoses of schizophrenia or schizoaffective disorder, major depression, and bipolar disorder. They found that persons with schizophrenia were significantly impaired on all seven social skills items of the Specific Level of Function scale (Schneider and Struening 1983). These included items relating to accepting and initiating contacts, communicating effectively, engaging in activities and groups, forming friendships, and asking for help.

How do coping variables relate to each other and to other variables? Provisional data indicate that coping can affect social competence and social functioning, whereas its effect on symptoms seems to be less compelling. For example, the San Diego group (Semple et al. 1999) found that a global measure of self-perceived social competence was positively related to one coping variable (positive reappraisal) and one social network measure (perceived emotional support from others). There were also significant positive associations with three other coping variables (planful problem solving, seeking social support, and being confrontive), but these did not attain significance in multivariate analysis. The authors also found that presence of negative symptoms, but not of positive or depressive symptoms, was significantly related to lower levels of self-perceived interpersonal competence.

In a second study that employed path analysis, the San Diego group (Patterson et al. 1997) found use of avoidant coping strategies (e.g., distancing, escape, self-control, accepting responsibility) to be a predictor of "social maladjustment," which is a measure of six areas of social functioning (e.g., work, leisure activities, social relationships). Social maladjustment was in turn a predictor of health-related quality of life, the latter being a hybrid measure of functional health status (e.g., mobility, physical and social activity) and subjective symptoms.

Cohen et al. (1997) found that coping (i.e., "relying on oneself for emotional support") was significantly associated with higher levels of life satisfaction and lower levels of depression. However, in multivariate analysis, coping no longer attained significance for either of these outcome values.

Finally, coping and adaptation must be understood within a life-span perspective. Aging for persons with schizophrenia, like aging for persons in general, is no longer viewed as a decremental process but instead is seen as a process of adaptation, compensation, and plasticity.

Sociodemographic Factors

Variability in psychopathology seems in part to reflect sociodemographic and contextual factors. Although research has been hampered by methodological problems due to sample heterogeneity, inclusion of confounding variables, and lack of sophistication of instruments, there is evidence that positive symptoms may be affected by poverty, unemployment, male gender, and living in industrialized rather than developing nations (Cohen et al. 2000). Similarly, negative symptoms in part may reflect long-term institutionalization, poverty, and demoralization (Cohen et al. 2000). Depression among older persons with schizophrenia has been linked to low income, older age, female gender, and Hispanic ethnicity, although the latter two variables did not remain significant in multivariate analysis (Cohen et al. 1996; Zisook et al. 1999). Thus, a New York City study of persons with schizophrenia 55 years and older found a difference of $117 in mean income ($611 vs. $494) between nondepressed and depressed individuals, respectively (Cohen et al. 1996).

Given the disproportionately high levels of poverty and substandard income found among persons with schizophrenia—for example, data from the Epidemiologic Catchment Area study (Holzer et al. 1986) of adult institutional and household resident populations indicated that individuals with schizophrenia are eight times more likely to be in the lowest quartile of income—it seems likely that poverty would affect persons with schizophrenia at least to the extent that it affects persons in the general population. Cohen (1993b) postulated three ways in which poverty potentially may interact with the course and outcome of schizophrenia: 1) additively, in which the effects of poverty add to the explained variance of outcomes such as psychopathology and adaptive functioning; 2) interactively, in which poverty interacts in a nonlinear fashion, so that those in the lowest classes have geometrically poorer outcomes; and 3) dialectically, in which poverty and the disorder mutually transform or refashion each other. Thus, for example, schizophrenia in poor persons may be structurally different from schizophrenia in nonpoor persons, and conversely, poor persons with schizophrenia may differ from other poor persons.

Functional Impairment

Another aspect of social adaptation concerns impaired functioning in daily activities. The original long-term studies using global measures of social functioning yielded inconclusive results, in part because of differences in instruments and in the demography and histories of the subjects. Thus, two studies (Harding et al. 1987; Huber et al. 1980) found generally good social outcomes, whereas two other studies (Ciompi 1980; Tsuang and Winokur 1975) found poor social outcomes after several decades of illness. Moreover, it is unclear when the social deficits arise. Hafner et al. (1995) contended that social deficits arise in the prodromal period or the earlier stages of the illness and eventually stabilize, whereas Ogawa et al. (1987) proposed that social functioning evolves in one of two directions: either into "self-supportive" or into "chronically institutionalized" status.

With respect to predictors of impaired functioning, several studies of samples of older persons with schizophrenia (age range=45–86 years) from the University of California at San Diego linked functional impairment to greater cognitive deficits, greater severity of extrapyramidal symptoms, longer duration of psychosis, more negative symptoms, lower level of formal education, and older age. In one of these studies, when the investigators entered variables into a multivariate analysis, only the Mini-Mental State Examination (Folstein et al. 1975) score remained a significant predictor of functioning. This corresponded to the work by Bartels et al. (1997), who likewise found a strong relationship between cognitive functioning and adaptive functioning among 188 elderly schizophrenia and bipolar disorder patients living in nursing homes and in the community in New Hampshire.

On the other hand, in a multivariate analysis of 111 chronic mentally ill persons 60 years and older living in the community, Meeks and Walker (1990) found that level of social support, severity of negative symptoms, years of antipsychotic treatment, number of hospital admissions, and years of hospitalization were all significant predictors of functioning. Positive symptoms did not attain significance, and cognition was not assessed.

Thus, although there are some differences across studies, cognitive dysfunction, when measured, has been the most consistent predictor of daily functioning in older persons with schizophrenia.

However, more recently, a report by Cohen and Talavera (2000) of persons with schizophrenia 55 years and older in New York City indicated that cognitive functioning was not related to functional impairment, nor was the latter significantly associated with the physical health measure. The authors speculated that the absence of such associations may reflect regional differences in long-term care placement policy for those with cognitive or physical illness and schizophrenia. Cohen and Talavera did confirm earlier findings that negative symptoms and movement disorders are significantly associated with functional impairment. They further speculated that an underlying abnormality in the prefrontal–basal ganglia system may be present that could account for the triad of cognitive impairment, negative symptoms, and movement abnormalities.

Comparatively less is known about the consequences of impaired daily functioning, although Bartels et al. (1997) found that impairments in basic and instrumental activities were the two strongest predictors of nursing home placement among aging persons with schizophrenia. Cohen and Talavera (2000) reported that functional impairment had a direct effect on two of seven quality-of-life variables—community activities and self-perceived health—and indirect effects on depression and life satisfaction, the latter two being mediated through self-health. Functional impairment did not affect health service utilization or residential status (i.e., living independently vs. supported living).

Subjective Well-Being and Life Satisfaction

Very little has been published about subjective well-being. The San Diego research group (Patterson et al. 1996) reported on what they called “health-related well-being.” The schizophrenia patients were more impaired than psychiatrically healthy comparison groups on the Quality of Well Being (QWB; Kaplan et al. 1989) scale. The QWB score was predicted by positive symptoms but not by negative or depressed symptoms, demographic variables, or movement disorders.

Cohen et al. (1997) have been the only researchers to examine life satisfaction—that is, subjective well-being (SWB)—in older persons with schizophrenia. In bivariate analyses, 12 variables were found to be significantly related to life satisfaction. In contrast to persons in the not-satisfied group, members of the satisfied group were significantly more likely to be male, to be older, to be non-Hispanic, to have more “reliable” network members (i.e., those who could be counted on), to have greater interconnectivity among network members (i.e., higher density of contacts), to deny loneliness, to have fewer activity limitations, to not have clinical depression, to have fewer negative symptoms, to rely on themselves for emotional support, to perceive themselves as having better health, and to report fewer "difficulties" in their lives. Multivariate analyses indicated that five of these variables—male gender, absence of loneliness, older age, reliable social contacts, and fewer perceived life difficulties—were significant predictors of life satisfaction. Although a comparison with their same-age peers in the general population indicated that the sample was worse off in regard to several objective indicators of well-being (i.e., income, clinical depression, physical limitations, and social network size), none of these variables was predictive of SWB. The data largely supported the "judgment" theory of SWB, which proposes that SWB is based on how one compares oneself with other people (i.e., being better or worse off) or with oneself (i.e., one's current life conditions versus the past) or one's aspirations to certain levels of attainment. Subjective quality of life is thought to depend on the narrowness of the gap between a person's expectations and achievements. Because people cannot easily change their lives to fulfill their goals, they most commonly lower their expectations to maintain psychological equilibrium. Indeed, three of the five significant variables—loneliness, life difficulties, and perceived social support—are based on self-comparisons of one sort or another.

Personal Identity, Culture, and the Older Person With Schizophrenia

What role a person assumes in life and how he or she feels about that role can have a substantial impact on well-being. For persons with schizophrenia, economic and sociocultural factors reinforce the mental patient role. By accepting the role of a mental patient, which includes behaving and thinking like a mental patient, persons with schizophrenia can be excused from obligations to work and support themselves and can instead receive public assistance for their survival (Estroff 1981). That is, being mentally disturbed enables persons with schizophrenia to secure money and goods, much as other persons use their skills to earn a living. In many instances, these persons have little choice, because they have a "spoiled identity"—that is, society has stripped them of alternative identities. However, by acceding to this identity, they give up considerable autonomy to professionals who control the treatment system, the social service system, and other resources.

Estroff (1981) pointed out that the process of accepting oneself as a mental patient occurs after a long period of trial and testing. Typically, mentally ill persons receive conflicting messages about their capabilities and their potential to lead "normal" lives. However, if the values, meanings, and rewards of the mental patient role are comfortable and real enough, then prospects for change become diminished. Thus, by accepting the identity of a mental patient, the person may lose in the world at large. Nonetheless, he or she receives security in remaining with other mental patients, who will not threaten to change, reject, or alter their selves, but instead confirm and share a sense of selves with them.

In recent years, several biological and sociocultural elements have coalesced to undermine—at least in part—this singular identity of mental patient. These factors include 1) new medications that reduce the overt, stigmatizing side effects (particularly the severe movement disorders) that had accompanied earlier treatments; 2) expanded opportunities for work in a more robust economy and the growth of federal volunteer programs, especially for older persons; 3) prolonged periods outside institutions that have afforded opportunities for schooling, marriage, childbearing, and work and consequently allowed for the development of other identities; and 4) a postmodern zeitgeist that more fully appreciates the provisional nature and multiple forms of "self" and that recognizes that the classic notions of a singular human essence are incomplete. Over the forthcoming decades, the interlacing of these various forces no doubt will have a profound effect on the life patterns and well-being of persons with schizophrenia as they grow old.

Quality of Life

Quality of life can be conceptualized as involving two dimensions: adaptive functioning (including self-care and social roles) and life satisfaction or subjective well-being (Katschnig 2000). Some authors add a third dimension, "external resources," which includes material variables such as standard of living and social support, although the diverse nature of the elements comprising this dimension makes a single global indicator less practical statistically as well as conceptually. The first two dimensions are generally used as outcome (dependent) variables, and other variables are examined to determine how they affect the outcome.

Clipp (2001) concluded that the breadth of the framework for quality of life, which can include global measures as well as numerous specific domains, underscores the fact that a lack of consensus exists as to what constitutes quality of life and that no unified approach has been identified for its measurement. She further stated that it is the object of study and the questions posed that largely dictate the degree of generality or specificity needed in a framework to examine quality of life. Finally, more sophisticated computer programs now allow for structural equation modeling in which researchers are not limited to one composite measure but instead can use multiple measures of theoretical concepts.

Because model testing has not been done with older persons with schizophrenia, we can conceptualize at least three possible candidates: Model 1 posits that quality of life represents a single theoretical construct with multiple, measurable indicators (Figure 9–1). Model 2 posits that quality of life is a multidimensional theoretical construct consisting of functional adaptation and life satisfaction, which can be further subdivided into objective and subjective theoretical elements with measurable indicators (Figure 9–2). Model 3 expands on Model 2 and posits that quality of life can be conceived as two measurable global indicators that are determined by various subjective and objective indicators of well-being, which in turn may be influenced by demographic and stress variables (Figure 9–3). Finally, various stress-buffering variables (e.g., coping strategies, social network variables) may also affect the outcome variables. A problem with Model 3 is that it is not clear in which data set certain variables belong. For example, should social network variables be categorized as objective indicators, buffers, or both? Such questions need to be addressed in future research.

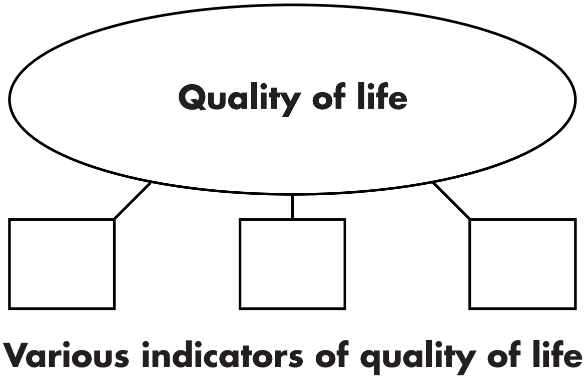

FIGURE 9–1. Model 1: Quality of life is a single theoretical construct with multiple, measurable indicators.

Moreover, no consensus exists regarding what contributes to quality of life and how it should be measured; ultimately, the dimensions and items selected depend on the research questions—that is, what aspects of life one hopes to improve. Thus, the research questions determine the degree of generality or specificity in a framework to examine quality of life. Nevertheless, at a minimum, Clipp (2001) believes that quality of life should comprise physical, psychological, social, and spiritual items. Furthermore,

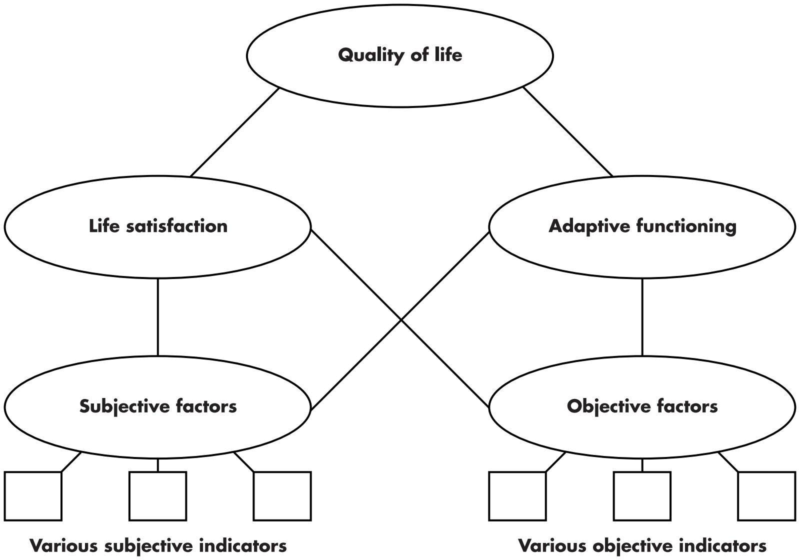

FIGURE 9–2. Model 2: Quality of life is a multidimensional construct consisting of functional adaptation and life satisfaction, which can be further subdivided into objective and subjective elements with multiple measureable indicators.

although quality of life almost invariably involves a subjective dimension for these items, many authors believe that there should be an objective dimension to complement the subjective one. Thus, for example, within aging research, subjective well-being, which is one aspect of quality of life, has been linked to various objective and subjective variables, such as demographics, material and social resources, personality, self-concept, motivation, coping, social support, religiosity, volunteering, and wisdom (George 1981; Okun 2001).

At the risk of oversimplification, I believe that the literature has tended to support Quality of Life Model 3. That is, quality of life is conceptualized as comprising adaptive functioning and life satisfaction. The data provisionally indicate that subjective measures more strongly predict life satisfaction and that objective measures more strongly predict functional impairment. Thus, variables such as social competence, perceived social support, and perceived life difficulties more strongly affect life satisfaction, whereas physical illness, cognitive deficits, negative and positive symptoms, movement disorders, and type and size of social networks more strongly affect functional impairment. However, subjective and objective measures may have weaker effects on functional impairment and life satisfaction,

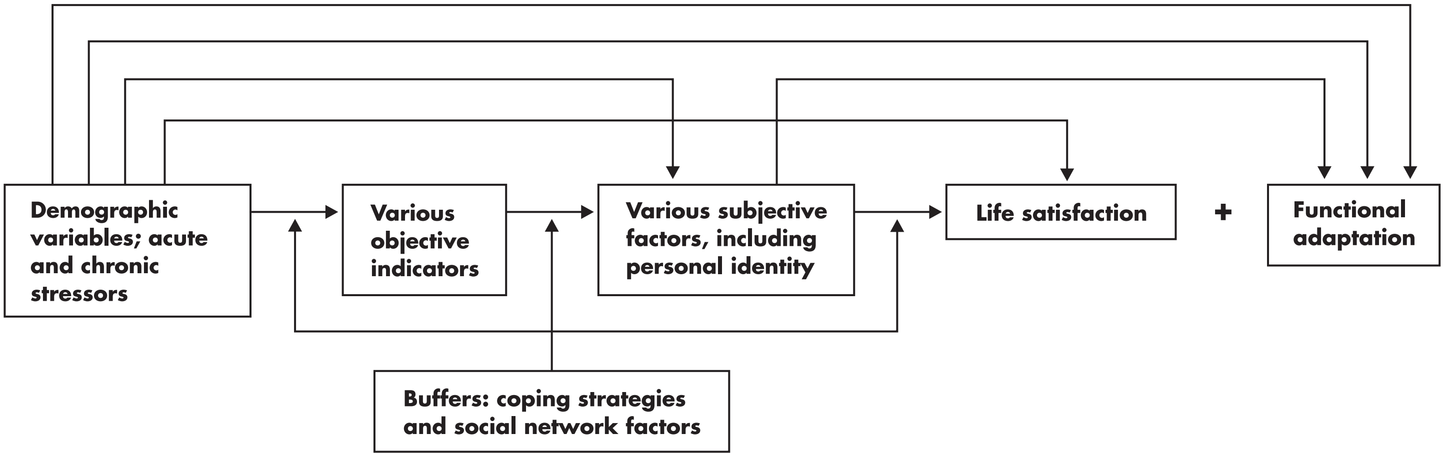

FIGURE 9–3. *Model 3:* Quality of life is composed of two global measures that are determined by various subjective and objective indicators of well-being, which may in turn be influenced by demographic and stress variables (both stress-inducing and stress-buffering).

respectively. Among demographic variables, gender, age, and perhaps race affect subjective as well as objective measures. Finally, various stressors (chronic and acute) may affect subjective and objective measures and in turn affect well-being and adaptive functioning. From the aging literature in general, coping strategies and social supports have been found to buffer these effects (Pearlin et al. 1990).

The model presented in Figure 9–3 suggests a variety of points for clinical intervention. For example, improving social competence through social skills training may increase life satisfaction as well as indirectly affect functional adaptation by improving the size and content of social networks. Moreover, social networks can also be strengthened through various interventions with families, natural community helpers, and formal agencies. Coping skills can be enhanced through cognitive-behavioral techniques and group methods. Cognitive-behavioral strategies may also serve to enhance cognitive deficits. Liberman (Chapter 13) in this volume addresses strategies to enhance social skills and cognition.

Newer pharmacological agents may be more effective than older agents in reducing positive and negative symptoms because of their better compliance records as well as their direct therapeutic effects. Compliance has been helped by these agents' more favorable side effect profile, including a diminished incidence of movement disorders. Depressive symptoms, which are common in older persons with schizophrenia, may be relieved by antidepressants. Thus, the newer antipsychotic and antidepressant agents may help improve adaptive functioning in a variety of ways.

As noted by Schoos and Cohen (Chapter 7) in this volume, older persons with schizophrenia may not receive adequate health care and may have more severe levels of physical disorders. Ensuring that adequate health care is available and working to reduce health risks (e.g., quitting cigarette smoking, losing weight) will improve physical well-being, which in turn may enhance adaptive functioning.

Finally, attention must be paid to material factors that affect quality of life, even when they do not seem to strongly correlate with subjective well-being. Katschnig (2000) argued that such correlations are often attenuated by the schizophrenic person's lower expectations; he concluded that "we are obliged to help them find an appropriate balance between lowering their expectations and increasing their achievements" (p. 36).

Summary and Conclusions

Conclusions about the extent to which various social dimensions differ among older persons with schizophrenia, older persons in general, and younger persons with schizophrenia must be viewed as provisional because of the paucity of studies, especially with respect to settings and to socioeconomic and cultural diversity. There appear to be two groups: 1) a larger group of persons with schizophrenia who mostly improve with age and whose various social parameters occupy an intermediate position between younger persons with schizophrenia and older persons in the general population, and 2) a smaller group (perhaps about 20%) who remain institutionalized or quasi-institutionalized and whose social parameters are the same as—or frequently worse than—those of younger persons with schizophrenia.

Thus, for most persons with schizophrenia there is evidence of adaptation and compensation with aging. Nevertheless, it is unclear how the effects of low income, substandard housing with risk for homelessness, and long periods of unemployment may affect the course of symptoms of the disorder. Moreover, in later life, despite a trend toward improvement, countervailing factors such as cognitive deficits, physical health, and movement disorders can worsen adaptive functioning.

Finally, in looking at potential models for conceptualizing the social domain, I have argued for using quality of life as a linchpin for such a comprehensive model. This is because it encompasses functional adaptation, which focuses on more objective parameters, and life satisfaction, which focuses on subjective features of living. A variety of objective and subjective variables can be used to predict functional adaptation and life satisfaction. The literature has indicated that whereas subjective variables are more predictive of life satisfaction, objective variables are more predictive of functional adaptation. Clinicians and policymakers therefore must develop strategies to address both objective factors—such as physical illness, cognitive deficits, negative and positive symptoms, movement disorders, and social network function and size—and subjective elements—such as perceived life difficulties, perceived social support, coping mechanisms, and sense of social competence.

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PART IV

Treatment and Service Issues

C•H•A•P•T•E•R 10

What Are the Service Needs of Aging People With Schizophrenia?

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Colin A. Depp, M.A.

As will be evident from many of the chapters in this book, much of what we have recently learned about schizophrenia in late life comes from studies of inpatient populations (see also Meeks 2000). These studies, and the few that have focused also on outpatients, have in the past decade greatly improved our knowledge about schizophrenia in the latter half of the life span. However, inpatient studies are limited in their ability to inform us about the service needs of elderly people with schizophrenia. Inpatients are to some extent homogeneous in their service needs: they are all experiencing severe enough symptoms to disrupt their community functioning and usually are in need of medication and support sufficient to restore a base level of functioning so that they can be discharged. What symptoms continue to be problematic after discharge? To where, to whom, and to what kind of ongoing treatment are they discharged? What are the factors that maintain them in their community residences? What factors contribute to the most positive quality of life? These are the broad questions that seem most pertinent to ascertaining the service needs of this population. For this reason, we focus in this chapter on outpatients, using what we know from our own data and from our review of other published work. In the absence of formal needs assessment, we examine what is known about the characteristics of older people with schizophrenia and the needs that are implied by these characteristics. We then examine current data about service utilization and, finally, examine possible models for service structure and delivery.

Psychiatric Characteristics and Implied Service Needs

Naturally, the first question we ask with regard to service delivery is "What are the psychiatric symptoms and secondary characteristics that must be treated?" Long-term follow-up studies examining the natural history of schizophrenia have suggested that there may be a general improvement in the condition of affected persons in later life (e.g., see Chapter 2 [Harding] in this volume for a review). However, there is also considerable heterogeneity in late life among people diagnosed with schizophrenia, both in terms of long-term course of the disorder and in terms of late-life functioning (e.g., Ciompi 1980; Meeks and Murrell 1997; Meeks et al. 1990). Thus, it is unclear what general trends toward improvement may mean in terms of treatment needs.

Despite the possibility of improvement with age, our data suggest that it is relatively unusual for elderly individuals with schizophrenia, including those who are not currently in continuous contact with treatment centers, to be symptom-free (Meeks and Murrell 1997; Meeks et al. 1990). In our most recent data set of older and middle-aged adults with severe mental illness (see Meeks and Murrell 1997 for a description of the full study), we had 124 participants who met Research Diagnostic Criteria (RDC; Spitzer et al. 1978) for schizophrenia (48%) or schizoaffective disorder, mostly schizophrenic (52%).[1] Of these, only 15, or 12%, were without significant symptoms or impairment in the 4-month period preceding our interview. The majority (73%) were experiencing symptoms of disorder (including residual symptoms) that had been chronic or fluctuating for 5 or more years. Sixty-five percent manifested at least one clearly identifiable psychotic symptom (delusions, hallucinations, thought disorder), most commonly delusions. This finding is particularly striking given that nearly 90%

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[1] The RDC divides schizoaffective disorder into four categories, according to polarity and the prominence of affective symptoms. Those patients with the "mostly affective" designation (bipolar and unipolar) would most frequently be diagnosed with psychotic affective disorders in DSM-IV-TR (American Psychiatric Association 2000). Those designated "mostly schizophrenic" would mostly be diagnosed with DSM-IV-TR schizoaffective disorder.

of the sample was taking antipsychotic medication. In other words, a majority of this outpatient sample were experiencing psychotic symptoms that were at best only partially controlled by medication. It is important to note that this study was conducted before the atypical antipsychotic medications were widely available, and none of the participants was taking these medications.

Negative symptoms, which typically are not alleviated and indeed are often exacerbated by antipsychotics (e.g., Jibson and Tandon 1998), were also prevalent, occurring at clinically significant levels in just under half of the sample. Approximately 15% of the sample showed significant to severe negative symptoms in the absence of any positive symptoms; 18% had two or more psychotic symptoms with no negative symptoms, so the largest number had a combination of positive and negative symptoms. Data on inpatients also suggest that although a shift in relative emphasis from positive to negative symptoms may occur in late life, positive symptoms are still clinically significant (e.g., Davidson et al. 1995). However, in outpatients negative symptoms may be more strongly related to functioning than positive symptoms (Cohen and Talavera 2000; Meeks et al. 1990). Negative symptoms appear to be related to the presence of cognitive dysfunction in older people with schizophrenia (Harvey et al. 1998), and both negative symptoms and cognitive deficits are characteristic of poor outcome in schizophrenia (see Chapter 6 [Harvey and Friedman] in this volume). Indeed, Bartels and Mueser (1999) have argued that cognitive impairment is one of the most important indicators of a high need for care and low level of function.

In addition to the typical symptoms of schizophrenia, evidence from several studies suggests that depressive symptoms are also common among older patients with schizophrenia (e.g., Cohen et al. 1996; Meeks and Murrell 1997). The evidence is somewhat conflicting regarding the impact of depressive symptoms on outcomes in schizophrenia, but work by Cohen et al. (1996) suggests that depression in older people with schizophrenia is similar to depression among other older adults. Our work also suggests that outpatients with the combination of psychosis and depressive symptoms are unlikely to receive medication for the depressive symptoms.

In our experience, from both formal data analysis and the anecdotal accounts we have collected from lengthy interviews with more than a hundred older patients with schizophrenia, mental health treatment too often has been limited to routine prescriptions for treating positive symptoms and infrequent follow-up visits. Our review above implies that this approach is limited for three reasons. First, at least with traditional antipsychotics, treatment of the positive symptoms is only partially successful. It remains to be seen whether atypical antipsychotics, particularly those other than clozapine, can do better than conventional antipsychotics have done (see Chapter 11 [Kasckow et al.] in this volume), but unless they can do much better, many patients will still be left to cope with the disruption or distraction of chronic psychotic symptoms. Second, negative symptoms may have a more profound impact on daily functioning than do positive symptoms. We currently have no clearly effective pharmacological treatment for either negative symptoms or the concomitant cognitive impairment associated with poor outcome schizophrenia, so in addition to pursuing the potential of the atypical antipsychotics in this regard, we also need to consider other interventions for maximizing functioning. A third and final problem with treating only positive symptoms is that depressive symptoms are often overlooked. Thus, a principal need of older patients is access to care in a system that permits sufficient contact for periodic and systematic reassessment of positive, negative, and affective symptoms, along with an evaluation of the effectiveness of medications and the impact of residual symptoms on functioning. Furthermore, the system must include integrated access to nonpharmacological interventions that specifically target management of, or coping with, residual positive symptoms, negative symptoms, and depression.

Medical Needs

A critical issue for treatment of older adults with any condition is the importance of integrating psychiatric care with medical services. Because the risk of medical illness, particularly chronic illnesses that require ongoing medical management, increases with age, the likelihood of comorbidity between schizophrenia and one or more chronic illnesses also increases. Some types of medical events may trigger conditions that might mimic schizophrenia, so medical evaluation is critical when new onset cases are seen. Even when managing long-term cases, however, regular assessment of physical condition will be important. Elderly Medicare beneficiaries with schizophrenia have been found to incur roughly twice the health care costs of elderly people with no mental illness (Husaini et al. 2000). Two types of escalating problems can occur (see Bartels and Mueser 1999; Meeks 2000; also see Chapter 7 [Schoos and Cohen] in this volume). An uncontrolled medical problem such as poor blood sugar regulation may lead to exacerbation of psychosis, which may lead to increased antipsychotic medication, the side effects of which may worsen the medical condition. Conversely, psychosis may lead to poor medication management, resulting in a medical crisis. In either case, close coordination between mental health and medical providers is critical. At minimum, each provider must be aware of medications prescribed by the other and their potential side effects, and they must have a means for communicating with one another.

Social and Economic Resources and Implied Service Needs

The availability of social and economic resources will influence service needs, because to the extent that resources are lacking or insufficient, there may be a need for formal services to substitute for or augment those resources. Financial and educational resources will affect access to and utilization of services, whereas social supports may affect medication adherence, transportation, and emotional and functional needs.

The availability of economic and social resources will differ according to the developmental history of the individual, and in determining individual service needs, it might be useful to consider aspects of that history. For older adults in general, achieving a higher educational level can be an important protective factor for late-life health and adjustment. Early onset of schizophrenia will likely disrupt educational and occupational attainment. In our representative outpatient sample from the public mental health sector, the mean educational level was 11 years, and 88% had annual incomes of less than $10,000. Fewer than 20% were working or had retired from sustained employment; the rest had rarely if ever worked outside the home and of those who had worked, most had worked only in unskilled labor. Clearly, then, schizophrenia is a lifelong debilitating illness, and the majority of older adults seen for public mental health services will have few financial resources at their disposal. This means that the cost of medications will be a significant issue in the management of their symptoms, and the willingness of third party payers such as Medicare and Medicaid to pay for the newer antipsychotics may be an important service consideration. Access to transportation will also be a consideration; services that require costly cab or public transportation rides will not be appealing to this population, particularly among those older individuals whose functional capabilities are in decline due to medical illnesses.

The majority of older adults with schizophrenia are likely to be living in family-owned or rented homes in the community, and nearly a third are living alone, but as many as 35% may be in institutional settings, including hospitals, nursing homes, and personal care or board-and-care homes (Meeks et al. 1990). In our 1990 study, about 74% of these institutionalized participants were in nursing homes, and 22.8% were in hospitals. Recent policy changes concerning nursing home placement for mentally ill persons may have reduced the rates of nursing home placement somewhat since the late 1980s when that study was conducted, but it is clear that a significant proportion of older adults with schizophrenia will be living in nonpsychiatric institutional settings, and the needs of those individuals may be different than those who are living more independently or in family care. Thus, mental health services must be sufficiently broad to meet the needs of patients in a variety of settings. To further complicate matters, these older adults are more likely to change residences than older adults without mental illness (Meeks and Murrell 1997), making continuity of services difficult.

Social impoverishment may also be an important vulnerability factor for older people with schizophrenia. Research on factors such as social skills (e.g., Hoffmann et al. 1998) suggests that people with schizophrenia often experience difficulties with the necessary cognitive, behavioral, and emotional skills for developing adequate social resources. There is substantial evidence that the social networks of younger individuals with schizophrenia are smaller and less reciprocal than those of other adults with or without other psychiatric illness (Cohen and Sokolovsky 1978; Meeks and Murrell 1994). For older adults in general, the increased burden of care associated with aging typically falls on family caregivers, particularly spouses and adult daughters. Of the older adults with schizophrenia that we studied, 40% had never been married, and 45% had no living children. Only 20% were married at the time of participation in our study. Even in late middle age many rely on parents or siblings for support, and so risk losing their primary supports as they age (Bartels and Mueser 1999).

Several other characteristics of older people with schizophrenia may interact to increase the vulnerability of their social networks. Early illness onset and, relatedly, lower educational attainment may have a particular impact on the development of friendship networks, resulting in larger relative reliance on kin. People with prominent negative symptoms are at greater risk for smaller, more poorly developed networks (Meeks and Hammond 2001). People with schizophrenia are at greater risk for small networks overall, and may compensate by developing more service sector links (Meeks and Hammond 2001; Meeks and Murrell 1994).

Despite the vulnerability of their networks, older people with schizophrenia typically are embedded in social networks that provide significant instrumental and emotional support (Cohen and Sokolovsky 1978; Meeks and Hammond 2001). Their networks are dominated by female relatives, and they rely more heavily on these relatives for emotional support than do their same-aged peers (Meeks and Hammond 2001). This arrangement may strain the mental health of both patients and caregivers, particularly when the relationship with the caregiver includes hostility or criticism (see, e.g., Leff and Vaughn 1985). In the ideal, then, mental health services should incorporate assessment of, and coordination with, indigenous social networks as well as assessment of individual differences that may be related to network impoverishment. Our research suggests the need for supplemental services to target family members, particularly spouses and female kin, for support and intervention.

Summary of Service Needs

This brief review of the characteristics of older people with schizophrenia has pointed out a number of implied needs for services related to the vulnerabilities associated with the combination of schizophrenia and old age. These needs are summarized below.

1. Medication management of positive symptoms of schizophrenia that minimizes secondary negative symptoms and optimizes functioning; financial considerations may influence the availability of the most recently developed antipsychotic medications for this purpose.
2. Assessment of and treatments for negative symptoms and cognitive deficits.
3. Assessment and management of depressive symptoms.
4. Coordination of care between mental health and other medical service providers.
5. Treatment available in accessible locations, including within institutional settings such as nursing and board and care homes.
6. Emotional and instrumental support in the absence of a strong friendship and kin network, possibly also opportunities for leisure activities.
7. Support for family and other indigenous caregivers.

In the sections below, we examine the extent to which current services appear to meet these needs and what models of service provision seem most promising for the future.

Service Utilization

Answering the question “where and how do older persons with schizophrenia receive help?” is surprisingly difficult, given the paucity of research in the area. The broad range of service settings that provide services to this population (e.g., nursing homes, personal care homes, community mental health centers) makes estimates of service utilization encompassing all of these settings challenging. Epidemiological surveys of service utilization, including the Epidemiologic Catchment Area data (Regier et al. 1988), often fail to sample from institutionalized older adults. Furthermore, data on service utilization, by definition, omit those who do not use services, so that the number of those who "fall through the cracks" remains unknown. Beyond use of services, even less empirical research has addressed whether and to what degree these services are meeting the needs of older adults with schizophrenia. From available data, it is clear that aging individuals with schizophrenia are high users of services, both compared with psychiatrically healthy older adults and compared with those with other serious mental illnesses (Bartels et al. 1999; Meeks et al. 1990; Shaw et al. 2000). Moreover, there is a widely held belief that community services to this population are not nearly sufficient. In a recent survey by the Group for the Advancement of Psychiatry committee on aging, the majority of 13 leaders in community psychiatry reported that mental health services for older adults were highly inadequate in their communities (Cohen 2000). These services will need to contend with the coming bubble of aging individuals with schizophrenia who are of the baby-boom generation. The number of older adults with severe mental illness is projected to double in the next 30 years (Bartels et al. 1999).

Service Use by Community Residents

It is estimated that 65%–85% of older people with schizophrenia reside in the community, and most of these use some form of mental health care (Cohen 2000; Meeks et al. 1990). Data suggest that these individuals are frequent users of a wide range of services, including medical care, outpatient mental health services, and acute inpatient hospitalization. In our sample of 124 aging individuals with schizophrenia, 97% stated that they were receiving mental health services at least twice a year at the time of the interview, and the majority (63%) included a service provider in their self-reported social network. Most saw a psychiatrist, and the most common frequency of contact was between two and six visits per year. Contact with other mental health professionals was much less frequent: the rates of seeing a psychologist, social worker, or nurse were all under 50%. In contrast, approximately 72% visited a general practitioner at least once a year. Rates of contact with service providers appear to vary according to the sample population. In a study of 89 elderly and middle-aged veterans with schizophrenia, Shaw et al. (2000) found that participants averaged two contacts per week with some type of community support services (from among psychological, social, and daily living services) and that very few participants in their sample reported receiving no services at all.

Aging individuals with schizophrenia appear to display different service utilization patterns than younger cohorts. In an analysis of the San Diego County Mental Health System (fiscal years 1986 and 1990), Cuffel et al. (1996) found that those diagnosed with schizophrenia and over age 75 were less likely to receive psychotherapy and medication management. However, they were significantly more likely to receive hospital services. The authors surmised that these age-related increases in service cost could be due to increased medical morbidity in older patients, tardive dyskinesia, and/or the effect of cognitive impairment. From our experience, the reduced dependence on outpatient visits to mental health professionals may also reflect patients' acceptance of their mental illness coupled with greater treatment compliance. That is, as they take their medications more consistently, they may be less likely to have illness fluctuations that lead them to seek additional services. Aging is likely to make medical and functional setbacks a greater focus in coping with daily life.

For every aging individual with schizophrenia who receives community mental health services, there may be an approximately equal proportion who receive no mental health care. In a study of residents of public housing developments in Baltimore, Maryland, Black et al. (1997) found that among residents diagnosed with a DSM-III-R (American Psychiatric Association 1987) psychotic disorder (4.5% of the total sample), 53% received no mental health services. Public housing residents with psychotic disorders were the least likely to receive services, which implies that the disorder itself may disenable access to treatment.

Failure to link these individuals with appropriate services may arise from several factors. Consumers may not believe that they require services, a perception that may be due to age, psychosis, or both variables working in concert (Black et al. 1997). On the service side, providers may fail to locate these individuals because of limited outreach. Even when elderly people with schizophrenia enter a service arena, linkage with appropriate treatment may fail to occur. In their review, Cuffel et al. (1996) noted that the elderly use fewer specialty mental health services than younger cohorts, instead relying more heavily on emergency services. The authors cite evidence that elderly individuals with schizophrenia may be more likely to receive diagnoses of dementia in the emergency setting. Therefore, evaluating the adequacy of services to aging people with schizophrenia is hampered by the lack of accuracy in identifying those with the diagnosis.

The risk that aging people with schizophrenia will fail to find access to appropriate treatment will likely increase as a greater proportion maintain residence in the community. Decreased mortality rates among those with severe mental illness as well as patient preference to remain in the community have increased the number of older adults with schizophrenia who do not reside in institutions. The closure of state hospitals and the Ominibus Budget Reconciliation Act of 1987 have limited the availability of inpatient treatment for severely mentally ill individuals in psychiatric and nursing home facilities, respectively. At the national level, adults over the age of 75 demonstrated the highest increase in use of ambulatory mental health services and the highest decrease in inpatient services (Demmler 1998). Therefore, the burden of care for older adults with schizophrenia will likely fall increasingly on community services (Bartels et al. 1999).

Services in Institutions

Of the 15%–30% of elderly persons with schizophrenia who reside in institutions, the vast majority resides in nursing homes. In general, among those with serious and persistent mental illness who reside in institutions, 89% reside in nursing homes, and most of these individuals are diagnosed with schizophrenia (Bartels et al. 1999). Data from the National Nursing Home Survey (circa 1985; Burns et al. 1993) indicated that although they were more likely to receive mental health care than those with other diagnoses, only one of six residents with schizophrenia received mental health care.

The data regarding current utilization of inpatient psychiatric hospitals by community-residing individuals with schizophrenia are somewhat unclear. In our sample, the median number of hospitalizations was about 4.5 across the entire life span (mean=9.38, mode=2, SD=15.50), and 32% reported spending 5 or more years in a psychiatric hospital over the course of their lives. However, during the year that we observed these individuals, very few were hospitalized. In a chart review study of community-residing veterans older than 65 years and diagnosed with either bipolar disorder or schizophrenia in the early 1990s, Sajatovic et al. (1996) found that both groups were high users of inpatient services. Those with either diagnosis averaged four hospitalizations in a 10-year period, but for those with schizophrenia hospital stays were longer (mean=56 days). In an analysis of state hospital utilization in Washington State over a 5-year period, Semke and Jensen (1997) found a trend for inpatients with schizophrenia older than 60 years to experience longer stays in the hospital, whereas a reverse trend was found for younger individuals. Very little is known about the aftercare received by older adults after discharge. In an interview study of 60 older individuals 1 month after discharge from a state hospital, Proctor et al. (1999) found that contact with mental health services was infrequent (median of one contact). Although most service contacts were related to a mental disorder, study participants showed a greater reliance on medical providers, suggesting that mental health providers often fail to provide continuity in services in aftercare.

Differences in Patient Characteristics Across Settings

As our review so far suggests, there is considerable diversity among elderly persons with schizophrenia in terms of functional and medical needs, just as there is among nonpsychiatric elderly groups, many of whom have chronic medical illnesses. Shaw et al. (2000) found that utilization of community support services was comparable to utilization by community-residing individuals diagnosed with Alzheimer's disease. Utilization may be predicted more by functional status than by psychiatric symptoms. A mixed-diagnosis study performed by Bartels et al. (1997) assessed 188 elderly individuals diagnosed with either bipolar disorder or schizophrenia residing either in the community or in nursing homes. Although there were diagnostic differences with regard to symptoms, functional differences were related to setting rather than diagnosis. For both diagnoses, the most significant predictors of nursing home placement were impairment in activities of daily living and community living skills. Those diagnosed with schizophrenia and residing in nursing homes were more likely to be male and unmarried. Neither positive nor negative symptoms of schizophrenia, nor cognitive functioning, was significantly predictive of nursing home placement. Harvey et al. (1998) compared three groups of patients with lifelong schizophrenia: an acutely ill group, a chronically hospitalized group, and group of nursing home residents. Nursing home placement was particularly associated with adaptive skill deficits, and cognitive impairment significantly predicted adaptive skills for those in all three settings. Placement in a nursing home does not appear to be associated with positive or negative symptoms but rather with dependence on assistance due to the effects of cognitive impairment and adaptive skill deficits. Those with fewer social resources are at greater risk for entering the nursing home level of care. These studies highlight the need for interventions that target cognitive functioning, social resources, and survival skills in an effort to sustain community residence.

Even among outpatient groups, there is likely to be diversity in terms of need for care and differences among those who use different types of care. The Shaw et al. (2000) study included a comparison among high users of psychological, social, and daily living services. Users of psychological services were younger and more symptomatic. Social service users were more likely to be female and to have cognitive deficits. Those who used daily living services were older and had greater functional deficits. These findings imply that community-based treatment must accommodate differing levels of intensity and modes of service.

Consumer Evaluation of Services

Very little attention has been paid to perceived or actual barriers to accessing services, or to patients' own evaluation of what help they receive. In our sample, participants responded to a questionnaire about a wide range of services, including medical care, social activities, mental health care, transportation services, and personal care homes. The majority of respondents (71%) felt that it would be "very easy" to receive services at a community mental health center. In contrast, only 45% felt that it would be "very easy" to receive help from a state mental health hospital. In terms of actual difficulty, only 15% felt they had ever experienced any difficulty in obtaining mental health services. The participants in our sample most frequently cited practical barriers to receiving services. Cost, lack of transportation, and lack of knowledge about services were felt to be much more prohibitive than feeling too sick or not trusting service providers. In terms of satisfaction with mental health services received, 89.2% felt that services were "Average," "Very Good," or "Excellent." In general, participants were pleased with other services they used. However, we should interpret these findings with a few caveats in mind. First, the respondents were highly dependent upon the services they received and appeared very reluctant to say anything negative about them. Second, the sample itself was biased in favor of long-term users of outpatient services. Those individuals who were noncompliant with medication, or who were not utilizing outpatient services, may have been either in inpatient settings or unknown to the system and therefore excluded from the sample. Finally, on average these participants were poorly educated and impoverished and were not well-informed or sophisticated consumers of services. They frequently showed a willingness to be satisfied with very little, whether with regard to medical or mental health services, or with regard to their social networks, and in this sense they were not significantly different than their same-aged peers who do not have psychiatric disorders (Meeks and Murrell 1997).

Suggestions for Future Research on Needs and Service Utilization

Clearly, we still have very few empirical data about service utilization patterns and needs among older people with schizophrenia. Therefore, effort should be made to garner samples of aging individuals with schizophrenia that represent the range of clinical, functional, and placement diversity within the population. The use of managed care databases (see Semke and Jensen 1997) may be a potential resource for such information. Studies based in dwellings where disabled elderly individuals are likely to reside will help to identify those who are not already linked to services (Black et al. 1997). As suggested by Palmer et al. (1999), multisite data on the characteristics of these individuals should be pooled, and recommendations that arise from these data could be assimilated in a manner similar to the Schizophrenia Patient Outcomes Research Team client survey (Lehman and Steinwachs 1998). Such an undertaking would require closer collaboration among researchers, clinicians, government, and industry.

Suggestions for Improving Services

As should be clear from the first portion of the chapter, the challenge of meeting the many needs of this population is a difficult one. From our review of service utilization, it appears that the current system of community care is underequipped at best, haphazard at worst, and certainly unprepared to deal with the coming increase in the number of elderly people with schizophrenia. Several innovative models of community care have the potential to be applied in this population. For example, the Program for Assertive Community Treatment (PACT) model has enjoyed great success in keeping younger people with schizophrenia in contact with services and reducing hospital admissions (see Marshall and Lockwood 2002 for a review). PACT emphasizes 24-hour availability, small caseloads, assertive outreach, and services that remain continuous across settings (Lachance and Santos 1995). Although intensive models of case management would appear to better address the complexity of needs in this population, little empirical study has focused on application of these programs to the chronically mentally ill elderly (see Chapter 12 [Mohamed et al.] in this volume for a detailed discussion of such models). Based on our review of service utilization, the following are suggestions for what we feel would be important ingredients of novel community care models.

1. ***Identify needs.*** Research and clinical attention should address the causes for the apparent underutilization of services by older adults with schizophrenia. First, comprehensive assessment should assist in reducing the frequency of misdiagnosis. Education of general practitioners on the nature and symptoms of late-life schizophrenia should occur, given the propensity of this group to seek services from the medical sector. Development of a reliable screening instrument to differentiate between dementia and schizophrenia may also assist in reducing misdiagnosis. Once the population is better identified, research should delineate predisposing characteristics that place affected individuals at risk either for failing to link with services or for institutionalization, which may indeed be the same subgroup. For example, we know that lack of social resources (Meeks and Murrell 1997), minority status (Black et al. 1997), and male gender are risk factors for poor outcome. Targeting services to the neediest of elderly individuals with schizophrenia would seem imperative. Granted, there may be a subgroup of individuals who have refused to seek treatment for many years and will likely continue to do so." Research should strive to identify what proportion of unmet need stems from resident preference versus lack of outreach by service providers.

   Even among those who are already receiving services, there is a need to improve routine or periodic assessment so that specific needs are addressed, such as depression, changes in medical conditions, or gaps in support due to social network changes. Assessment must be more comprehensive than a screen for active psychosis and medication side effects.
2. ***Address barriers to services.*** At least from our data, the consumers' perceived barriers to service access appeared to be practical and remediable. For instance, one of the most frequently cited barriers was lack of knowledge of services, which can be addressed through informational materials and through active case management. Transportation, or neighborhood accessibility, is also a critical component of service delivery.
3. ***Integrate medical and psychiatric health services.*** In accordance with the complexity of needs of this population, novel programs should emphasize collaboration between mental health services and primary care. Approaches to this end include psychogeriatric assessment teams that offer community outreach (Black et al. 1997), which may offer services such as home-based care and intensive case management (Bartels et al. 1999). Other ways to bridge mental and medical services include offering psychiatric and medical care at the same site (Bartels et al. 1999) and forming multidisciplinary treatment teams with cross-trained professionals.

4. ***Broaden emphases of treatment.*** Interventions that focus on cognitive functioning and adaptive skills should be held in the same regard as treatments for psychotic symptoms. Data reviewed here indicate that maintaining in the community is largely a function of having skills to remain at least partially self-sufficient, and individuals can remain in the community even with active and enduring psychotic symptoms. Cognitive rehabilitation (see Liberman [Chapter 13] in this volume) and the atypical antipsychotics may help in this regard, as will interventions that include direct instruction on "survival skills" for self-care. Iatrogenic deficits in functioning, such as tardive dyskinesia, should be addressed in treatment. Treatment plans should represent "total care" of the individual, with attention paid to factors beyond psychiatric symptoms to include family burden, legal, medical, and financial concerns. From research we reviewed, individualization of treatment plans is essential in light of the diversity in this population.

Conclusions

The service needs of elderly people with schizophrenia are complex and, at present, poorly understood. Aging people with schizophrenia commonly face, in addition to persistent symptoms, increasing medical morbidity, limited financial resources, and social impoverishment. Cognitive impairment, negative symptoms, and social isolation, rather than psychosis, appear to predict the level of care needed. In spite of considerable ongoing disability, most elderly individuals with schizophrenia continue to function in the community. The current system of community care for aging people with schizophrenia will be placed under increasing strain as the number of affected individuals doubles in the coming decades. Current mental health services for people with schizophrenia are often not tailored to the special needs of aging individuals and are fragmented from medical and other providers. Model services to meet the growing needs of elderly people with schizophrenia, as well as those with other severe and persistent mental illnesses, will require a multidisciplinary approach to treatment, encompassing both the traditional modes of psychiatric treatment and treatments that focus on medical, cognitive, and social arenas.

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CHAPTER 11

Use of Novel Antipsychotics in Older Patients With Schizophrenia

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The treatment of older patients with schizophrenia involves numerous challenges (Tariot 1999). It is expected that the older patient population will increase appreciably in the coming years, with concomitantly greater numbers of patients requiring treatment. Chronic illnesses also increase with age; thus, the use of multiple medications is more common in the elderly. As a result, the appropriate choice of psychopharmacological agents is important in treatment of these patients. In this chapter we discuss the use of atypical antipsychotics in elderly patients with schizophrenia in the context of the problems associated with aging.

In treating the older patient with schizophrenia, clinicians need to be aware of the fact that older patients are more sensitive to a variety of side effects; side effects are important factors that can influence compliance and tolerability of medications. The elderly also exhibit heterogeneity of response, and they can range from "physically fit" to "frail." Thus, older patients' physiological status can widely influence their response to medications.

Physiological changes associated with aging include pharmacokinetic and pharmacodynamic factors. Pharmacokinetic factors can influence concentrations of drugs in tissue compartments over time. Psychotropic drugs are well absorbed from the gastrointestinal tract by diffusion. Theoretical evidence suggests that aging-associated physiological changes decrease drug absorption. However, there is no evidence that a clinically significant decrease in total absorption of psychotropic drugs occurs with normal aging (Israili and Wenger 1981).

The liver is the principal site for metabolic transformation of lipid-soluble psychotropic drugs. Metabolites can be pharmacologically active or inactive. Some metabolic pathways (e.g., demethylation) may be influenced by age. These effects can contribute to increased plasma concentrations of numerous drugs in elderly patients (e.g., tertiary amine tricyclic antidepressants [Nies et al. 1977], benzodiazepines with active metabolites [Greenblatt and Shader 1981]). Hydroxylation, however, tends not to be affected by age (Pollock et al. 1992).

In terms of distribution, an increase in the proportion of body fat to water is notable with aging (Hollister 1981). This change in body fat–to–water ratio increases the volume of distribution for lipid-soluble psychotropic agents in elderly patients. Renal excretion of lipid-soluble drugs occurs mainly as hydrophilic forms that are glucuronidated, either conjugated or unconjugated. For tricyclic antidepressants, hepatic hydroxylation followed by renal excretion is the major elimination pathway. The decrease in glomerular filtration that is associated with aging accounts for part of the increased accumulation of hydrophilic metabolites in some elderly patients (Nelson et al. 1988). This age-related decrease also leads to decreased clearance of lithium in elderly patients (Hardy et al. 1987). The net effect of these pharmacokinetic changes is a need for lower starting and target doses of psychotropic drugs.

In addition to the pharmacokinetic changes associated with aging, pharmacodynamic changes also occur (Cantillon et al. 1994). These result from changes in various transmitter systems at various levels in cellular processing (i.e., at the receptor level or at the level of reuptake). The net effect of these age-associated pharmacodynamic changes, like that of the pharmacokinetic changes associated with aging, is increased sensitivity to antipsychotic medications.

Conventional Antipsychotic Drugs

Antipsychotic drugs used in the elderly include conventional antipsychotic drugs and atypical agents. Conventional antipsychotics are less optimal treatments than the newer atypical antipsychotics. Conventional antipsychotics have been available for almost 50 years. All of these agents share the common property of dopamine blockade (particularly blockade of the D_2 subtype of receptors). The conventional agents help considerably with positive symptoms but have little effect on negative symptoms. In addition, the low-potency conventional antipsychotics are particularly troublesome for the elderly population because they have side effects that can lead to serious adverse events (e.g., falls resulting from orthostatic hypotension). In addition, delirium, urinary retention, constipation, and dry mouth can result from the anticholinergic side effects. Furthermore, the high-potency conventional antipsychotic agents have various adverse effects such as extrapyramidal symptoms (EPS; Tariot 1999).

Although all antipsychotic agents can cause tardive dyskinesia (TD), the conventional agents are associated with higher incidence rates of this side effect. For younger individuals taking antipsychotics, the annual cumulative incidence of TD is 4%–5% (Kane et al. 1988b). In middle-aged and older adults, Jeste et al. (1999) determined that the cumulative incidence rate is much higher. After 1 year, the rate was 29%; after 2 years, it was 50%; and after 3 years, it was 63% (Jeste et al. 1999). TD is often an irreversible syndrome, although this is not always the case. In patients with schizophrenia, discontinuing antipsychotics in order to reduce manifestations of TD is often difficult. Rates of symptom relapse are high after withdrawal; for example, relapse rates of 53% over 9.7 months were reported following drug withdrawal, compared with rates of 16% in individuals maintained on the medications (Gilbert et al. 1995). Relapse rates observed after withdrawal in elderly and younger patients also appear to be similar (Jeste et al. 1993). Thus, with conventional antipsychotic medications, patients need to be maintained on flexible, individualized low dosages to control psychotic symptoms as well as to minimize side effects. An alternative approach is to use the newer atypical antipsychotics, which have fewer side effects than the conventional agents (Jeste et al. 1999).

Atypical Antipsychotic Medications

Five newer antipsychotic drugs have been approved for use in the United States—clozapine, risperidone, olanzapine, quetiapine, and ziprasidone.

The atypical antipsychotic medications are strong antagonists of serotonin receptors in addition to possessing central dopamine antagonism. Serotonin dopamine antagonists help alleviate the positive and negative symptoms of schizophrenia (Kane et al. 1988a). These drugs have lower rates of EPS as well as lower rates of TD (Jeste et al. 1999). Table 11–1 presents common side effects of atypical antipsychotics and their dosage ranges in the elderly. Table 11–2 summarizes the key studies using these atypical agents in older patients with schizophrenia.

Clozapine

Clozapine, an atypical antipsychotic that is a tricyclic dibenzodiazepine derivative, has been widely used and researched. It is superior in efficacy to numerous conventional antipsychotics in patients with treatment-resistant illness and significantly improves quality of life and social functioning (Kane et al. 1988a; Wagstaff and Bryson 1995).

Clozapine is helpful for controlling treatment-resistant psychotic symptoms and managing patients with severe TD (Chengappa et al. 1995). However, because of its side effects, clozapine's use in elderly patients has been limited. These side effects are troublesome in young adults and are much worse in the elderly. The increased risk for agranulocytosis dictates frequent blood monitoring. In addition, clozapine is associated with a higher risk of seizures, sedation, and confusion. The anticholinergic side effects can also be a problem in elderly men with prostate problems as well as in patients with compromised cognition.

Clozapine has been recommended for elderly patients with movement disorders and psychosis. This includes patients with Parkinson's disease and psychotic symptoms as well as treatment-resistant elderly patients or those patients with severe TD (Factor and Brown 1992). The starting dosage recommended for elderly patients is lower than that recommended for younger patients: 6.25–12.50 mg/day. Increases of 6.25–12.50 mg once or twice a week are recommended. Final target doses of clozapine in this population are also recommended to be in the range of 50–100 mg/day.

Risperidone

Risperidone, a member of the benzisoxazole class of compounds, has been shown to be superior to haloperidol in efficacy and tolerability. Studies examining risperidone's safety and efficacy in patients ages 45–100 years have been performed (Jeste et al. 1999; Madhusoodanan et al. 1999). These studies included patients with schizophrenia and related psychosis as well as dementia associated with psychosis. Improvements were noted in this

TABLE 11–1. Atypical antipsychotic side effects and dosage ranges in elderly patients

	Clozapine (6.25–200.00 mg)	**Risperidone (0.5–4.0 mg)**	**Olanzapine (5–20 mg)**	**Quetiapine (25–250 mg)**
Orthostasis	++++	++++	+++	++
Sedation	+++++	++	+++	++
Prolactin increase	0	+++	+	0
Weight gain	++++	+	+++	+
Extrapyramidal symptoms	0/+	++	+	0/+
Tardive dyskinesia	0	+	+	?
Anticholinergic effects	++++	+	+	0
Seizure risk	+++	+	+	+
Hematological effects	+++	+	+	+

Note. +=minimal; ++=mild; +++=moderate; ++++=moderately severe; +++++=severe; 0=no effect; ?=not certain. Ziprasidone dosage and side effects in the elderly have not yet been determined.

Source. Data from Casey 1997 and Pickar 1995.

TABLE 11–2. Studies examining atypical antipsychotics in elderly patients with psychotic disorders

	Total, *N*	Design
Clozapine		
Chengappa et al. 1995	12	Retrospective chart analysis
Factor and Brown 1992		Open label
Risperidone		
Jeste et al. 1999	53	Open label
Madhusoodanan et al. 1999	100	Open label
Olanzapine		
Madhusoodanan et al. 2000b	10	Open label
Sajatovic et al. 1998	27	Open label
Quetiapine		
Arvantis and Rak 1997	152	Open label
Madhusoodanan et al. 2000a	7	Open label

Note. Includes patients with schizophrenia.

patient population with low dosages, generally less than 3 mg/day. Whereas positive symptoms improved after only 6 weeks of treatment, negative symptoms required 6–10 weeks of treatment to show improvement.

Side effects of risperidone commonly seen in elderly patients include postural hypotension, sedation, and EPS. These effects are dose related. Starting dosages of risperidone in the elderly are lower than those recommended for younger adults—that is, 0.25–0.50 mg/day with dosage increases of no more than 0.25–0.50 mg once or twice per week. The maximum dose used is generally less than 3 mg (Madhusoodanan et al. 1999). Patients with Parkinson's disease or with significant hypotension usually should not receive more than 1 mg of risperidone per day.

Olanzapine

Olanzapine is in the thienobenzodiazepine class of psychotropic agents, which is structurally related to clozapine. In vitro studies indicate that olanzapine has a high affinity for dopaminergic (D_4, D_3, D_1), serotonergic ($5\text{-HT}_{2A/2C}$, 5-HT_3, 5-HT_6), muscarinic, histaminic, and α-adrenergic receptors. Its affinity for $5\text{-HT}_{2A/2C}$ is higher than that for D_1. In addition, the affinity for $5\text{-HT}_{2A/2C}$ is also higher for D_4 than for D_2 receptors (Bymaster et al. 1996; Seeman et al. 1993). Unlike clozapine, olanzapine is associated with no seizure risk or hematological liability. Olanzapine has a low rate of EPS (Tollefson et al. 1997). In addition, olanzapine's side effects include sedation, orthostasis, and weight gain.

The effects of olanzapine in older patients with schizophrenia were examined in open-label fashion by Madhusoodanan et al. (2000b) and Sajatovic et al. (1998). In the study by Madhusoodanan and colleagues, 11 hospitalized patients (ages 60–85 years) with schizophrenia or schizoaffective disorder were treated with 5–20 mg of olanzapine per day. Treatment was discontinued in 2 patients in whom symptoms either failed to improve or worsened. Rating scales examining Clinical Global Improvement (CGI) indicated that 9 patients were better. CGI scores remained the same in 1 patient and actually worsened in another patient. Scores from the Extrapyramidal Symptom Rating Scale (Ghadirian et al. 1996) showed significant reductions from baseline to final visit. No significant changes were noted in laboratory tests, which included monitoring of prolactin levels and electrocardiogram.

The study by Sajatovic et al. (1998) examined 27 patients 65 years or older who were given olanzapine as add-on therapy to their antipsychotic medication. The other antipsychotic medications were gradually discontinued. The mean dosage of olanzapine was 8.4 (±4.2) mg/day. Changes in Brief Psychiatric Rating Scale (BPRS; Marder 1995) scores were not significantly different; however, substantial changes were seen in Simpson-Angus Neurological Rating Scale (Simpson and Angus 1970) scores, Barnes Akathisia Scale (Barnes 1989) scores, and Abnormal Involuntary Movement Scale (Marder 1995) scores.

Quetiapine

Quetiapine is a dibenzothiazepine derivative that has activity at histaminic and α_1- and α_2-adrenergic receptors. It has relatively low activity at dopamine and serotonin receptors (Allen et al. 1994) and minimal EPS. One trial examined 151 men and women over age 65 years. At 12 weeks there were statistically significant improvements in BPRS and CGI Severity of Illness scores. The mean dosage of quetiapine in patients with idiopathic psychosis was 87.5 mg/day (Arvantis and Rak 1997). Changes in EPS were measured with the Simpson-Angus Scale, and akathisia was assessed with the Barnes Akathisia Scale. Improvements or no changes were noted in all but 10%–15% of patients (Borison et al. 1996). The most common side effects were somnolence (30%), dizziness (12%), and postural hypotension (12%). Another study evaluated in open-label fashion elderly patients with schizophrenia, schizoaffective disorder, or bipolar disorder (Madhusoodanan et al. 2000a). Patients ranged in age from 61 to 72 years. Four patients responded to treatment and three did not. Preexisting EPS diminished in three of the patients, whereas transient hypotension, dizziness, and somnolence occurred in two. Quetiapine is more sedating than olanzapine (Janicak et al. 1997).

Ziprasidone

Ziprasidone is an atypical antipsychotic agent that is chemically unrelated to phenothiazine or butyrophenone antipsychotics. It exhibits high in vitro binding affinity for dopamine D_2 and D_3 and serotonin 5-HT_{2A}, $_{2C}$, $_{1A}$, and $_{1D}$ receptors. In addition, it has affinity for the α_1-adrenergic and histamine H_1 receptors (*Physicians Desk Reference* 2002)

Ziprasidone has been recently marketed by Pfizer. In young adults, dosages of 40–160 mg/day have been demonstrated to lead to improvement in both positive and negative symptoms (Harrigan and Reeves 1996). No data are yet available on ziprasidone's use in the elderly.

Conclusions

The development of atypical antipsychotics has been one of the greatest recent advances in clinical psychopharmacology. Atypical antipsychotics offer benefit in the treatment of both positive and negative symptoms of schizophrenia. They have tremendous advantages over older drugs in terms of side effects. Their greater safety and tolerability makes them especially appropriate for elderly patients who are more susceptible to EPS and TD, problems generally associated with older antipsychotics.

Clinicians who prescribe antipsychotics for elderly patients need to start with a low dosage and raise it gradually until the lowest effective dose is reached. In addition, drugs with strong anticholinergic or sedative effects should be avoided in this population. Antipsychotics do indeed provide symptomatic relief for older patients with schizophrenia; however, they do not completely cure the underlying illness. Thus, a comprehensive treatment approach for schizophrenia should combine drug therapy with appropriate psychosocial interventions.

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CHAPTER 12

Community-Based Treatment of Schizophrenia and Other Severe Mental Illnesses

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Research on the effects of community-based treatments for schizophrenia has been expanding rapidly in the past two decades. An emerging body of evidence now demonstrates that community interventions can indeed improve the long-term outcome of schizophrenia in younger patients. However, research in this area in older patients has been scarce. Clinically, as Meeks and Depp (Chapter 10 in this volume) point out from both formal data analysis and the anecdotal accounts that they collected from lengthy interviews with more than 100 older patients with schizophrenia, mental health treatment too often has been limited to routine prescriptions for treating positive symptoms and infrequent follow-up visits. In this review we provide an update on research on community-based treatment for schizophrenia and other severe psychiatric disorders. Community treatments to be addressed in this review include assertive community treatment, case management, vocational rehabilitation, supported housing, day treatment, and patient clubhouses. Our review here focuses only on studies with true-experimental or quasi-experimental designs. *True-experimental designs* include randomized pretest–posttest control group designs and randomized posttest-only control group designs. *Quasi-experimental designs* encompass nonrandomized pretest–posttest control group designs and nonrandomized posttest-only control group designs. Only a few studies of these community-based treatments have focused specifically on older persons with schizophrenia. However, when available, we include the age ranges or means and standard deviations, thereby enabling speculation in some instances as to whether the programs might be effective with older populations. Moreover, we have extrapolated from studies of similar programs for nonschizophrenic older persons in the community.

Assertive Community Treatment

The Assertive Community Treatment (ACT) model was originally developed at the Mendota Mental Health Institute in Madison, Wisconsin, and has since been replicated and studied in a wide variety of settings, both in the United States and abroad. This model evolved from the observation that many clients with severe mental illness are noncompliant with treatment and that skills learned in hospital settings are not generalized to the community (Stein and Test 1980). These clients are at increased risk for high utilization of costly psychiatric services, such as inpatient hospitalization and emergency department treatment. The pioneering work of Stein and Test led to the development of ACT programs. These programs were designed to provide psychiatric services to clients in their natural living environments rather than in clinics and were characterized by multidisciplinary treatment teams with a low client:case manager ratio (10:1); shared caseloads among clinicians rather than individual caseloads; direct provision of services rather than brokering of services; 24-hour coverage, including emergencies; attention to illness management; provision of most services in the client's natural environment; high frequency of contact with clients (several times a week at the beginning of treatment, with decreases as the client's level of functioning increases); and assistance with practical problems in living such as housing.

To summarize studies of ACT programs for the schizophrenic population in general, the data fairly consistently show an overall positive effect on symptoms and service use patterns. These programs decrease recidivism and the use of emergency mental health services and improve medication adherence and involvement in treatment. The continuous support and close monitoring obtained through frequent home visits are most likely responsible for these positive effects. ACT programs have not been shown to improve global functioning and have had mixed effects on quality of life. This is surprising, given that the philosophy underlying ACT involves providing clients assistance in meeting their basic living needs.

A possible explanation for the observed lack of improvement in functioning could be the extent of services provided to the control group. Another possible explanation could be that skill learning either may be subject to a plateau effect or may perhaps be a result of the adjustment in the intensity of services delivered to clients. Because ACT provides services on an "as needed" basis, the frequency of services may decrease slowly over time as clients become more stable and functional. Furthermore, in these studies researchers did not separate global functioning into subareas (e.g., hygiene, transportation, budgeting), and thus it is difficult to determine precisely the areas where functioning consistently does or does not improve. Despite the fact that ACT programs do not have an overall positive impact on psychological well-being and community adjustment outcomes, ACT programs nevertheless have positive effects on social functioning and on satisfaction with services.

Finally, ACT programs usually result in a reduction in costs associated with the delivery of services, an effect that may be related to these programs' impact on recidivism. A significant improvement in the quality of work functioning also has been reported (Marks et al. 1994). Those findings suggest that ACT reduced the financial burden of severe mental illness on patients and society as a whole.

With respect to the utility of ACT in older persons with schizophrenia, as shown in Table 12–1, 6 of the 16 studies listed in the table had a sufficient proportion of persons 50 years and older to allow for some provisional assessments. Of the 6 studies, 5 showed favorable outcomes for ACT and 1 showed mixed results. Of course, none of these studies analyzed outcome by age; however, there was no mention of older persons doing worse than younger persons. Thus, these studies suggest that ACT is a useful modality for older persons with schizophrenia.

Case Management

The case management (CM) model was developed after the era of deinstitutionalization. CM is defined as support provided to patients as they negotiate for the different services they desire. Unlike programs designed on

TABLE 12–1. Assertive community training

Study	**Outcome**	**Ages cited, years**	**Relevant to persons age 50+**
Aberg-Wisledt et al. 1995	+	Mean=39	No
Arana et al. 1991	+	38 ±10	No
Audini et al. 1994	+	Range=18–64	Yes
Bond et al. 1988	±	Not stated	Possibly
Bond et al. 1990	±	Mean=33	No
Bond et al. 1991	+	Not stated	Possibly
Borland et al. 1989	+	20–57 (11% 45+)	Yes
Bush et al. 1990	+	Not stated	Possibly
Essock and Kontos 1995	+	Mean=41	Possibly
Lafave et al. 1996	±	Range=16–65	Yes
Marks et al. 1994	±	Mean=34	No
Muijen et al. 1994	+	Mean=38 ±12	Yes
Sands and Coraan 1994	±	Mean=47	Possibly
Solomon and Draine 1995a	–	Mean=35 ±9	No
Stein and Test 1980	+	18–62	Yes
Wood and Anderson 1995	+	Range=18–65	Yes

Note. Studies with an age range that includes persons 50 years or older in which 1 standard deviation above the mean includes age 50+ are considered relevant to older persons and are noted by "Yes." Studies with a mean age range that includes persons 40 years or older with no standard deviations reported are considered possibly relevant and are noted by "Possibly." + = positive; – = negative; ± = results not significant.

the basis of a specific treatment model (e.g., ACT, social skills training), CM programs are organized around specific sets of services: 1) connecting with clients, 2) planning for services, 3) linking clients with services, and 4) advocating for service improvements. Other services, such as rehabilitation assessments, crisis intervention, outreach services, and skills teaching, may also be offered. Unlike ACT, case managers are not the direct providers of services. Contact between clients and case managers usually occurs in community mental health centers. Frequency of contact and client:staff ratios are highly variable. CM is considered intensive if the client:staff ratio is no more than 20:1, the frequency of contact is at least once a week, and outreach services are provided. If all three of these conditions are not met, the CM program is described as regular.

With respect to outcome research, most programs increase the use of mental health services to allow patients to maintain functioning in the community setting. This is an anticipated result, given that the purpose of CM is to coordinate and link existing services and to facilitate their access to the client. CM services appear to have an impact on the use of emergency services. Intensive CM tends to decrease the use of emergency services, whereas regular CM increases their use. CM has a positive impact on outcomes assessing psychological well-being. When socialization and teaching of social skills were integrated into CM services, increases in global and social functioning as well as in quality of life were noted (Bigelow and Young 1991). Most of the CM programs reviewed here included skills teaching, and their positive effects on certain outcome variables—such as residential and occupational status—likely resulted from the teaching of specific skills directly associated with these variables.

CM services were also associated with mixed findings in cost outcomes. Cost outcomes are directly related to recidivism and to use of mental health services. These findings were anticipated, because CM programs increase use of maintenance services and do not consistently decrease recidivism. Therefore, although CM does not allow an individual to increase the amount of time spent in the community, it increases the quality of that time.

In reviewing the impact of CM programs, different models were lumped together, and this may have contributed to some of the discrepancies in findings. For example, some models, such as the Strengths perspective (Modrcin et al. 1988) and rehabilitation-oriented CM programs (Macias et al. 1994), have a stronger rehabilitation component and thus should have a larger impact on community adjustment. However, the lack of detail provided about interventions and the paucity of replication studies of clearly defined and well-implemented programs prevented such distinctions and associated conclusions.

With respect to the utility of CM for older persons with schizophrenia, as can be seen in Table 12–2, of the 20 CM studies listed in the table, we identified 8 that included persons 50 years and older. Of these 8 studies, 4 reported positive outcomes for CM, 2 reported mixed results, and 2 found no advantages for CM. Importantly, when we looked at all 20 studies, only 7 had positive outcomes, 9 had mixed results, and 4 showed no advantages for CM. Thus, studies that included older persons were proportionately more likely to have positive outcomes. In sum, although CM does not seem as overwhelmingly beneficial as ACT for older persons with schizophrenia, the data still suggest that CM may be profitably used with this population.

Although evaluative data on the utility of CM with older schizophrenic populations are sparse, use of case management has become especially popular with other aging populations. In fact, CM interventions have proliferated in all types of health and social services settings, especially in programs serving long-term care populations. Nevertheless, two major demonstration programs, the Channeling Project (Kemper 1988) and the Medicare

TABLE 12–2. Case management

Study	**Outcome**	**Ages cited (years)**	**Relevant to persons age 50+**
Bigelow and Young 1991	±	Mean=36 ±13	No
Bond et al. 1988	±	Not stated	No
Carter and Van Vleet 1995	+	Not stated	No
Curtis et al. 1992	–	Mean=36 ±12	No
Ford et al. 1995	+	Mean=48 ±15	Yes
Franklin et al. 1987	–	20% >50	Yes
Goering et al. 1988	±	Not stated	Possibly
Hornstra et al. 1993	+	Mean=39 ±13	Yes
Jerrell and Ridgely 1995	+	Range=18–33	No
Lehman et al. 1993	±	Mean=31	No
Macias et al. 1994	+	35% ≥45	Yes
Modrcin et al. 1988	±	Mean=26	No
Muijen et al. 1994	±	Not stated	Possibly
Quinlaven et al. 1995	–	7%–17% 51+	Yes
Rossler et al. 1992	±	26% 45–64, 8% ≥60	Yes
Rossler et al. 1995	±	27% 45–64, 8% ≥60	Yes
Ryan et al. 1994	+	Mean=37 ±10	No
Rydman et al. 1999	±	Mean=32	No
Solomon and Draine 1995b	–	Mean=41	Possibly
Urlson et al. 1995	+	Mean=32 (range=18–54)	Yes

Note. Studies with an age range that includes persons 50 years or older in which 1 standard deviation above the mean includes age 50+ are considered relevant to older persons and are noted by "Yes." Studies with a mean age range that includes persons 40 years or older with no standard deviations reported are considered possibly relevant and are noted by "Possibly." +=positive; −=negative; ±=results not significant.

Alzheimer's Demonstration Evaluation (Miller et al. 1999), failed to find that the increased costs of CM interventions were offset by reduced nursing home costs, although both programs did reduce nursing home placement in treatment versus control groups (Kemper 1988; Miller et al. 1999). Moreover, both programs found improved access to and use of community care and a reduction in unmet needs (Kemper 1988; Newcomer et al. 1999). Although the service system may be fragmented and confusing, Zarit and Teri (1991) noted that families are generally able to find services on their own; they speculated that CM may be more effective for older persons who lack involved caregivers. This suggests that older persons with schizophrenia living alone in the community should be the primary targets of CM interventions.

Vocational Rehabilitation

Vocational rehabilitation (VR) interventions are based on the assumption that employment not only improves the activities, social contacts, and remuneration of individuals but also may promote self-esteem, illness self-management, community tenure, and quality of life (Drake et al. 1994). VR also aims to help the individual to become—and to perceive him- or herself as being—an active member of the community. The major goal of VR programs is to help the client to obtain and maintain employment. The most frequently used vocational model is supported employment (SE), defined as competitive employment in an integrated community setting for an average of 20 hours per week in circumstances in which long-term ongoing support is available. In this model, clients receive assistance in vocational planning in which individual vocational profiles based on competencies and job interests are developed. Issues also addressed include selection of appropriate job choices and preparation for job entry. Preparation for job entry usually involves 1) teaching of general work and 2) training in interpersonal and communication skills necessary for the acquisition of good working habits. Interviewing skills are taught and practiced. Job matching, job placement, training and support by coaches at job sites, and follow-up services are also offered in SE programs.

Participation in SE programs has been associated with increases in the ability to find and keep employment. The entry criteria of most SE programs include clinical stability, compliance with medication regimens, housing stability, and willingness to participate in vocational training and to find employment. Meeting these criteria requires a higher-functioning subgroup of patients. Patients with diagnoses of schizophrenia and related disorders were less likely than those with depressive or personality disorders to remain employed (Fabian 1992). It is possible that SE programs are more effective with less severely disabled clients. This issue needs to be considered when comparing the effects of SE with those of other rehabilitation models. Overall, research studies have revealed positive impacts on family atmosphere as a consequence of the increases in financial independence associated with the working status condition. However, the fact that some of the studies that evaluated level of functioning and residential status also offered social and life skills teaching targeted toward these outcome variables makes it difficult to attribute the positive effects resulting from these variables to the VR intervention.

The experimental designs used in studies reviewed here do not permit evaluation of the impact of VR programs on nonvocational domains of functioning. Considering that many patients who participate in these programs do not obtain jobs, comparing patients who participate in programs with those who do not may not be a good test of the effects of employment on nonvocational domains of functioning. Furthermore, as with ACT and CM, the effect of VR programs on outcomes in elderly patients with mental illness has not yet been evaluated systematically and clearly needs to be studied. VR has not been shown to have any enduring impact on independent competitive employment. VR programs targeting elderly persons should be designed to address the unique needs of this population. Meeks and Depp (Chapter 10) in this volume noted that in their outpatient sample of older patients with schizophrenia, fewer than 20% were working or had retired from sustained employment; the rest had rarely if ever worked outside the home, and of those who had worked, most had worked only in unskilled labor. A potentially useful alternative to VR is volunteer work. Indeed, over the past three decades there has been a growth of elderly participation in volunteer activities. Such activities may be attractive to older persons with schizophrenia and may serve to more fully integrate them with other senior citizens in the community.

It is difficult to assess the utility of VR with respect to older persons with schizophrenia, because few of the reported studies have been methodologically rigorous. Of note, the study by Drake et al. (1994) had experimental and comparison groups with a mean age in the late 40s, and roughly one-sixth of the subjects were older than 60 years. This study found few if any advantages for VR.

Volunteerism is another option for higher-functioning older persons with schizophrenia. The proportion of persons 65 years and older who volunteer has increased roughly fourfold since the 1960s (Chambre 1993). Moreover, one in three people over the age of 75 had volunteered in the past year. Differences in volunteerism by age group have been nearly obliterated. Reasons for the surging interest in volunteerism among older persons has been the emphasis on activity in later life, the changing demographics (e.g., better education, more affluence, more native born) of the population, social factors such as the need for more volunteers as women have entered the labor force, and government and private-sector initiatives for volunteers.

Public funding may also serve as an impetus for older persons to volunteer. Most of the publicly funded volunteer programs in the United States are administered under Title V of the Older Americans Act or under the Corporation for National Community Services. Some of the services relevant to older persons with schizophrenia include 1) the Retired Seniors Volunteer Program, which recruits volunteers 60 years and older to work in hospitals, nursing homes, and senior centers; 2) Foster Grandparents, which provides a small stipend to low-income individuals 60 years and older to work with youths in need of supportive and affectionate adults; 3) Senior Companions, which provides a stipend for low-income persons 60 years and older to visit other elderly individuals in nursing homes, hospitals, and private homes; 4) Green Thumb, which employs low-income rural residents 55 years and older to work part-time in parks and other beautification programs; and 5) Senior Aides, which offers small stipends for part-time work in community service jobs as homemakers, home health aides, and food program assistants.

Although to our knowledge there have been no systematic assessments of volunteerism among aging persons with schizophrenia, studies of older volunteers in general have demonstrated that these persons derive substantial benefits in terms of life satisfaction, self-esteem, and mood (Cutler 1976; Hunter and Linn 1980–1981). Stevens (1991) found four factors that predicted satisfaction and increased the likelihood that volunteers would stay on the job longer: 1) a pattern of providing community service throughout adulthood, 2) congruence between the volunteer's role expectations and his or her actual experiences on the job, 3) social contact on the job, and 4) perceived recognition and appreciation for volunteer work.

Supported Housing

Following the deinstitutionalization movement in the 1960s and 1970s, public and private housing alternatives were very limited, and the few available placements in private facilities were based on patients' financial means rather than on functional needs. Additionally, housing options were primarily facility based and transitional. The deinstitutionalization process and its associated changes resulted in frequent displacement, lack of opportunity to apply learned living skills, isolation from others in the community, and lack of assistance in obtaining permanent housing in an open market (Carling 1990).

The concept of "supported housing," which has received a great deal of attention in the past several years, emphasizes the importance of providing non-facility-based, permanent housing options and a level of support services determined by the individual patient's functional ability and preference. The success of supported housing requires an understanding of the type and level of support services needed to maintain individuals in their environment, taking into account the client's preference for professional support, and a creative ability to negotiate arrangements in the open housing market.

Following deinstitutionalization, chronically mentally ill elderly patients were discharged from state mental hospitals to nursing homes.

Within 30 years, nursing home care accounted for 29% of national expenditures on behalf of the mentally ill (Frisman and McGuire 1989). The elderly mentally ill usually did not benefit from these changes. The nursing home setting was less appropriate than state hospitals (Goldman et al. 1986), primarily because the typical nursing home staff lacks training in psychiatry and therapeutic care. It is well documented that most providers in nursing homes lack the skills to understand and manage behavioral symptoms (Burns et al. 1988; Cohen 1995; Strome 1989). Many chronically mentally ill elderly nursing home residents are overmedicated (Semla et al. 1994) and inadequately and inappropriately cared for (Bootzin et al. 1989). Some studies have found that providing care in a way that fosters dependency may lead to a downward spiral of "learned helplessness," depression, and increased disease and mortality (Langer and Rodin 1976). In fact, Langer and Rodin (1976) found that simply emphasizing the possibility of choices among a group of nursing home residents led to increased morale, socializing, and survival rates in comparison with a group where staff fostered dependency (Rodin and Langer 1980).

As Meeks and Depp (Chapter 10 in this volume) point out, in 1990 about 74% of institutionalized participants were in nursing homes. Because the needs of these individuals may differ from the needs of those who are living more independently or in family care, mental health services must be sufficiently broad to address the needs of patients in a variety of settings.

Mental health services targeting elderly mentally ill persons living in public housing could reduce suffering and delay institutionalization. However, little research has examined the specific mental health needs of this population, how these needs might be met, and the costs and effectiveness of providing these services. Roca et al. (1990) described a mobile treatment service program of psychogeriatric assessment, treatment, and teaching directed toward residents of public housing. The program demonstrated that recognition of psychiatric symptoms by housing managers does not necessarily lead to eviction but instead may serve as a route of access to appropriate treatment. None of the residents who were referred were evicted, and all who required acute psychiatric hospitalization were allowed to return to the buildings from which they had come.

Roca et al. (1990) also reported that high rates of medical illness and physical dependency among elderly residents of public housing added complexity to the management of psychiatric disorders in this population. The prevalence of polypharmacy greatly complicated decisions about the use of psychotropic drugs in residents. In addition, many residents with psychiatric disorders also had disorders that limited their mobility and that seriously interfered with their ability to use traditional psychiatric facilities.

It has been noted that moderately and severely impaired persons often do not seek out community-based services, due in part to fear of exposing disability and thereby losing independence. In fact, 12% of the residents referred to the program in Roca et al.'s study (1990) had been unwilling to be seen in the psychiatric clinic setting. Strikingly, fewer than 5% of residents referred to the psychogeriatric team refused to be seen at home.

With respect to outcome studies for the general population of persons with schizophrenia, McCarthy and Nelson (1991) reported on seven supportive housing programs. When residents were interviewed at least 5 months after entering the programs, personal empowerment and instrumental role involvement were significantly improved over baseline. Residents' days of hospitalization were dramatically reduced after they entered the program.

Supportive housing has also been the focus of a multilevel evaluation of systems programs, and clients, in a 5-state, 10-site National Institute of Mental Health nationwide demonstration program (Livingston et al. 1991). This study concluded that nearly all clients who entered these programs, regardless of whether they were homeless or were referred from hospitals or residential programs, were living in integrated apartments at the end of the 3-year evaluation (Livingston et al. 1991). This national evaluation of the implementation of supportive housing found that isolation was a real problem for many consumers and that mental health agencies, with the exception of exemplary programs, were generally not yet effective in countering the problem of loneliness. With regard to costs, systematic cost data are not available to compare supportive housing with traditional approaches.

Day Programs

Day programs include day treatment programs and partial hospital programs. The American Association of Partial Hospitalization describes *partial hospitalization* as an ambulatory treatment program that includes the major diagnostic, medical, psychiatric, psychosocial, and prevocational treatment modalities designed for patients with serious mental disorders who require coordinated intensive, comprehensive and multidisciplinary treatment not provided in an outpatient clinic setting (Casarino et al. 1982). Several forms of this modality may coexist. These include true alternatives to inpatient care; a program providing transition from inpatient to outpatient aftercare; a maintenance program providing continued support for the social, psychological, and vocational well-being of persons at risk for mental illness; and an enrichment program for socially or psychologically understimulated individuals at risk of illness. The services are viewed as essential supportive and rehabilitative programs for seriously disturbed individuals who otherwise would require hospitalization. Day treatment is transitional, less intensive than 24-hour care, and more supportive than regular outpatient treatment. Most programs operate 5 days a week with a length of stay of 3–6 months. The staff:client ratio usually ranges between 1:4 and 1:6. The programs are staffed by psychiatrists, psychologists, social workers, occupational therapists, rehabilitation counselors, and nurses. Day treatment programs provide primarily group therapy within a milieu setting. They also offer medication clinics. Clients are usually patients who have recently been discharged or are at immediate risk for relapse.

The major research emphasis in partial hospitalization has involved outcome and cost-effectiveness comparisons with inpatient treatment of randomly selected psychotic patients requiring intensive treatment. Partial hospital programs have generally been shown to be at least as effective as traditional inpatient units in treating psychotic patients who do not present a risk of suicide and to be superior to outpatient treatment for persons with chronic schizophrenia. The evidence also suggests that partial hospitalization is a cost-effective treatment approach.

Measures of psychopathology have consistently failed to show the superiority of any particular treatment, except drugs, in the treatment of schizophrenia. In a well-designed Veterans Administration study comparing day treatment with drugs alone, Linn et al. (1979) found that day-hospital patients fared better on measures of psychopathology as well as on overall function over 24 months. Good outcome factors included long-term commitment, low patient turnover, and a moderate amount of stimulation. Another follow-up study of 1,410 patients in 34 day-hospital programs showed that although the programs were generally effective in promoting the well-being of patients, their effectiveness was lower with the schizophrenic persons (Davis et al. 1978).

Generally, patients with schizophrenia in partial hospital programs appear to show greater improvement in vocational and social adjustment than do those in inpatient or outpatient programs (Greene and De La Cruz 1981). Identification of patients likely to respond to partial hospital programs remains a major issue to be resolved through research. Moreover, the cost-effectiveness of partial hospitalization has been consistently demonstrated in comparison studies of partial hospital and inpatient treatment (Casarino et al. 1982; Washburn et al. 1976).

Although it appears that partial hospitalization is at least as effective as inpatient hospitalization in treating a spectrum of psychiatric disorders and is substantially more cost-effective than standard inpatient care, very few studies of this modality have included persons 50 years and older, and almost none of them reported even 17% (i.e., 1 standard deviation) of their sample in this older age range. Therefore, as with all modalities reviewed in this chapter, further studies targeting older populations must be undertaken.

Clubhouses

The clubhouse model is based on the Fountain House model (Beard et al. 1982). Clubhouses operate 7 days a week and usually have evening and weekend hours. The program is staffed by paraprofessionals and by the members themselves. Support services based on the self-help model are offered. Staff members work as a team to complete tasks that are needed to operate the clubhouse. Components of the program include work at the clubhouse, transitional employment, and active outreach. Case management and advocacy are also usually offered. Considerable emphasis is placed on addressing members' perceived needs and increasing their sense of empowerment. Clients usually remain members for life.

Warner et al. (1999) compared a group of clubhouse members with a group of matched patients who were not clubhouse members. The groups were compared in terms of quality of life, service utilization, and treatment costs over a 2-year period. The clubhouse group did better than nonclubhouse users on indices of employment status, social relationships, subjective well-being, service utilization, and cost-effectiveness. Wilkinson (1992) compared frequency of hospitalization during the period prior to clubhouse membership with that during the period of regular clubhouse membership. Hospital days, number of admissions, and average lengths of stay were all markedly reduced during the clubhouse period. The cost analysis revealed savings from reductions in lengths of stay ranging from $5,000 to $14,000 per patient. However, the study did not assess whether the use of outpatient services increased in the postclubhouse period. Earlier studies at Fountain House (Beard et al. 1978) and a recent study by Delaney (1998) similarly found positive effects of clubhouse membership on rehospitalization rates and days in the hospital; in the former study, members with the most frequent attendance had the best outcomes.

It is difficult to determine the utility of clubhouses for older persons with schizophrenia, because such populations were not included in most studies. Delaney (1998), who reported better outcomes for the clubhouse group versus a comparison group, included a range of participants with ages ranging from 22 to 60 years; however, it was not clear what proportion of the sample was over age 49.

Although no specific data are available regarding use of clubhouses and related self-help groups by older persons with schizophrenia, here, again some data about seniors in general may be instructive. Surveys indicate that older persons appear to be underrepresented in self-help groups. Whereas the overall dropout rate between midlife (ages 50–64 years) and older ages was about 30% for all professional psychosocial treatment, the rate was 72% for self-help groups (Lieberman 1989). Some of the reasons for this trend include 1) the recruiting practices of self-help groups, which typically enlist participants through peers and other informal networks; 2) older persons' attitudes, beliefs, and needs for help; and 3) the availability of alternative help-providing resources—for example, widows typically find other widows within their social networks (Lieberman 1989).

Lieberman (1989) contended that age alone does not appear to be a valid criterion for a homogeneous group component, although certain foci, such as retirees, grandparents of divorced children, and parents mourning the death of an adult child, lend themselves to more uniform age groups. However, little research data are available to indicate whether older persons would do better in homogeneous and heterogeneous groups.

Summary and Conclusions

In this chapter we have provided an overview of the principal psychosocial treatment modalities used with schizophrenic persons. With respect to older persons with schizophrenia, the best outcome data have been for ACT and CM studies. The data suggest that both of these modalities should benefit older persons, with the most favorable findings found for ACT programs. On the basis of studies with older persons in general, some support also exists for the use of CM, with the most robust findings observed for persons living alone. Considerably less evaluative data are available for the other modalities, and few studies have included older persons. The rise of voluntarism among older people in general, especially given that some programs are funded through public monies, may provide an alternative avenue for work-related activities for older persons with schizophrenia. The fact that self-help groups have been widely used with older persons in general suggests that patient clubs might be helpful for older persons with schizophrenia. However, in the general population there is drop-off in the use of self-help groups with age, and perhaps this trend might also hold for the use of patient clubs.

Our review has emphasized the lack of data available with respect to psychosocial programs and older persons. Clearly, as the population of older persons with schizophrenia grows, it becomes critical to develop assessment studies targeted to aging individuals. Most importantly, the crucial question that needs to be answered for each of these modalities is whether existing programs can be adapted to accommodate older persons or whether separate programs tailored to their specific health, cognitive, and functional adaptive abilities must be created.

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CHAPTER 13

Biobehavioral Treatment and Rehabilitation for Older Adults With Schizophrenia

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Psychosocial interventions for elderly persons with schizophrenia and related disorders have only recently become evidence based and empirically validated. These interventions are evolving into well-specified mental health techniques, whether delivered individually or in groups. Service delivery is optimized when provided by multidisciplinary teams in the context of community-based, residential, day treatment, or ambulatory programs, as well as through consultation and liaison to allied social and medical agencies and personnel (Liberman 1988). Before describing these interventions and their demonstrable impact on elderly persons, several basic attributes and assumptions of treatment must be clarified to illuminate our understanding of their process and outcome. In this chapter, the following questions about psychosocial treatments are raised in regard to older adults with schizophrenia:

1. What are the basic attributes of psychosocial interventions?
2. Can disease management and community adaptation skills be taught?
3. What environmental supports have been helpful and effective?

4. Is cognitive-behavior therapy (CBT) feasible for medication-resistant symptoms?
5. Can social learning techniques be applied in residential settings?
6. Does behavior therapy reduce the dose requirements for antipsychotics?
7. Can efficacious services be used in ordinary practice settings and systems of care?

The final section of the chapter summarizes the answers to these seven questions.

Basic Principles of Treatment

Pharmacotherapy remains the principal mode of treatment for elderly persons with schizophrenia, despite the fact that the effectiveness of psychotropic drugs is frequently attenuated in older individuals. Thus, treatment is almost always *biobehavioral*, involving a combination of medication and psychosocial services. Even when medication is given without specific additive or integrated psychosocial therapies, there is an influence on the process and outcome of treatment by virtue of the lack of such therapies. Many studies of pharmacological treatment of schizophrenia have documented the additive value of structured and well-crafted psychosocial and behavioral therapies (Corrigan et al. 1990; Liberman et al. 1984). Medication is never prescribed, administered, ingested, distributed, metabolized, and effected in a socioenvironmental vacuum; hence, the word *biobehavioral* in the title of this chapter lends emphasis to the interactions between the biological and psychosocial elements that are present in all treatment programs.

A second principle is the *outcome-specific* nature of biobehavioral therapies. Whereas medications predominantly affect the signs and symptoms of schizophrenia, psychosocial treatments have their main impact on behavior, skills, relationships, and environments. Thus, social skills training targets primarily the affiliative and instrumental role behavior and interactions of persons with schizophrenia and only secondarily or indirectly addresses signs, symptoms, relapse, and rehospitalization (Liberman et al. 1989). For example, in one study, social reinforcement, used contingently to promote rational and coherent conversations between staff and elderly schizophrenic inpatients, indirectly led to dramatic reductions in delusional speech (Liberman et al. 1973).

A third principle that is basic to the use of biobehavioral therapies comes from practitioners' grasping the concept that the illness is not the patient; rather, the patient has the signs and symptoms of an illness. It is a misnomer to refer to a person as a schizophrenic; these individuals have many of the same strivings and desires for personally relevant goals and satisfaction in life as non–psychiatrically ill persons but happen to experience the problems associated with schizophrenia. Treatment should not be based on the assumption that removal or mitigation of symptoms is the primary responsibility of the clinician; to the contrary, treatment is most likely to succeed when clinicians apprehend that their interventions are predicated on *removing or reducing the obstacles that prevent patients from achieving their personal goals and a good quality of life.* Obstacles to reaching personal goals are represented by symptoms and neurocognitive impairments. Thus, the most acceptable, tolerable, effective, and sustained treatments are those that concomitantly reduce symptoms while promoting the abilities and social supports of older persons with schizophrenia.

Symptomatic and functional recovery from schizophrenia has been well documented in elderly persons, often many years after experiencing debilitating symptoms and cognitive impairments that required long periods of hospitalization (see Chapter 2 in this volume). Recovery or optimal outcomes in older persons with schizophrenia do not come about because of the aging process, "burnout" of excessive dopamine receptors, or whatever else might be the current neuroscientific view of the etiology of the disease. Rather, recovery is facilitated by biobehavioral treatment and rehabilitation that is delivered with the key attributes of *comprehensiveness*, *continuity*, *coordination*, *collaboration*, *concern*, and *consumer orientation* (Liberman et al. 2002).

Because the optimal outcomes for the treatment and rehabilitation of older persons with schizophrenia are multidimensional—improvements in symptoms, neurocognition, social functioning, quality of life, self-esteem—and given the outcome-specific nature of treatments, it is essential that biobehavioral treatments be multimodal. Using CBT to reduce medication-refractory delusions is not sufficient in itself as treatment, nor is social skills training aimed at achieving improved conversation skills adequate as a sole therapy. Wraparound community-based services—including outreach into the patient's natural places of living, working, and recreational activity—provides the supports often required to compensate for the cognitive and skill deficits of the older person with schizophrenia.

Although combining the full spectrum of biobehavioral treatments to obtain optimal outcomes is desirable, it places a considerable burden of multiple competencies on clinicians. Therefore, comprehensiveness of services; coordination and collaboration among staff, social agencies, patient and family members; and continuity of treatment with empathic concern for the personal goals of the patient all justify the value of a multidisciplinary clinical team for achieving good outcomes (Liberman et al. 2001).

Four additional basic principles undergirding best practices for persons with schizophrenia are the 1) inextricable intertwining of treatment and rehabilitation, 2) individualization of services, 3) flexible linkage of services with the phase and type of the person's disorder, and 4) importance of providing evaluation, monitoring, and treatment of concomitant medical disorders with efforts to assure adherence to the medical regimen.

The last principle listed above has particular relevance for the elderly person with schizophrenia, requiring special efforts and competencies to diagnose comorbid medical disorders and attention to psychosocial interventions that will assure that medical services for these disorders are effectively implemented. Many older persons with schizophrenia have cognitive deficits from both their mental disorder and their aging brain. These deficits may interfere with judgment, insight, decision making, initiative, and memory—all of which are relevant to the identification and awareness of concurrent medical disorders as well as adhering to complex medical regimens in addition to their pharmacotherapy. Thus, it is incumbent on practitioners to go the extra mile to diagnose medical problems, determine how they may complicate the prevailing mental disorders, understand drug interactions, simplify treatment regimens, and educate the older patient along with his or her natural caregivers in ways to promote the effective delivery of combined services.

Because of the gradual, cumulative, yet dangerous "creep" of medications for treating the multifaceted complaints of elderly persons, clinicians must be alert to the adverse side effects and interactions that these drugs may have on the brain and cardiovascular and other systems of the vulnerable older person.

> Mr. A, an 87-year-old widower, was a bedridden nursing home resident who presented with confusion, paranoia, and agitation. Until 2 years previously, his schizophrenia had been reasonably well controlled and he had lived an active life with some assistance from his son and daughter-in-law at their home. Now he threw food from his tray on the floor and had to be given intravenous fluids because of dehydration. Five years before, Mr. A's primary care doctor had prescribed amitriptyline for apparent depression. Soon thereafter, his cardiologist prescribed a potassium supplement and a diuretic. His ophthalmologist started Mr. A on three types of eye drops for glaucoma. He became increasingly apathetic and disoriented and paced much of the night. A psychiatrist was consulted, who prescribed haloperidol and temazepam for sleep.
>
> Mr. A's diuretic and poor fluid intake, often seen in elderly persons as their perception for thirst erodes, led to a concentration of the prescribed medications in the blood. Combined with the customary lower metabolism and excretion of drugs in older adults, the side effects of Mr. A's prescribed medications were magnified. Moreover, most of his medications had anticholinergic and other effects that produced disorientation, agitation,

> confusion, difficulty sleeping, and anorexia. After having most of his medications terminated and being switched to an atypical antipsychotic (olanzapine) that stimulated his appetite and improved his sleeping, Mr. A became much more alert, clear-thinking, and socially active. He gained weight and was able to return to live with his family.

Biomedical treatment and psychosocial rehabilitation are like a hand in a glove in the management of acute exacerbations of psychosis. *Treatment and rehabilitation are two sides of the same coin and must be viewed as inseparable.* Providing medication in hospital to control symptoms is often wasted by the revolving door of rehospitalization unless psychoeducational programs are regularly utilized to acquaint patients with the value, benefits, side effects, and self-administration techniques of medication (Eckman et al. 1990). Other educational and skills-training programs should also accompany maintenance medication strategies so that patients and their natural caregivers can develop relapse prevention plans and learn appropriately assertive ways to negotiate medication issues with prescribing psychiatrists (Liberman et al. 1993). Joined together, antipsychotic medication and skills training can assist patients to make a successful transition from the acute to the stable phases of their illnesses.

Treatment and rehabilitation must be individualized and adapted to meet the requirements of the particular phase or type of the person's disorder as well as to the individual's cultural background, expectancies, and norms. The elderly person with schizophrenia faces three barriers to individualized and culturally competent psychosocial services. First, the reductionistic biological approach to contemporary treatment of schizophrenia often minimizes or even overlooks psychosocial interventions. Medications are never prescribed or administered in a social vacuum but many practitioners and caregivers adopt a patronizing and authoritarian approach to the older person with schizophrenia that fails to educate the individual with the knowledge and skills to actively collaborate with the prescribing physician. Second, most practitioners hold the common stereotype that older persons have a limited potential for learning and improvement and thus give them short shrift with regard to cognitive-behavioral services. Third, in minority subcultures, it is the elderly person with schizophrenia who is less likely to be assimilated and who is in the greatest need for competence and sensitivity in the clinician for language and cultural know-how. Even when the older person is a member of the majority culture, there is often a generational gap with the clinician that can interfere with the provision of age-appropriate services.

> Mrs. B was born in China, where she was educated through high school, worked on a collective farm, married, and had a daughter. She developed

schizophrenia shortly after migrating to the United States when she was in her late 30s but had little access to culturally appropriate services and received only intermittent medication from the public sector in a large city. By the time Mrs. B was in her late 60s, her daughter was bending under the twin burdens of supporting her mother financially and emotionally. Mrs. B was delusional and distractible, had memory problems, evidenced severe negative symptoms, was reclusive, and had poor self-care and housekeeping skills. She spent most of her time in bed.

At a clinic specializing in mental health services for Asian Americans and Pacific Islanders, Mrs. B found a psychiatrist who could speak her native language and used the Chinese translation of the Medication Management Module (see section titled "Teaching Disease Management and Community Adaptation Skills," later in this chapter) to equip her and her daughter with the knowledge and skills to collaborate with him in the use of an atypical antipsychotic. After 3 months, she had shown dramatic improvements in her psychosis and cognition and expressed interest in attending a social club for Chinese Americans. However, her social anxiety and social deficits reached the proportions of secondary negative symptoms, serving as barriers to her progress to a more stable and recovered phase of her illness.

Social skills training, targeted to the kinds of conversations she and her daughter had identified as important for interacting in the social club, was individualized, and Mrs. B was given assignments to practice the skills (e.g., starting conversations using designated topics, looking for "Go" and "No Go" signals from other people in deciding when, where, and with whom to begin a conversation, using self-disclosure appropriately) between weekly training sessions. Her daughter provided encouragement and reinforcement for her, applying the skills to her interactions at the social club, thereby promoting generalization of the skills.

After 3 months of conversation skills training, Mrs. B had established a satisfying niche for herself at the social club and was also earning money as a part-time babysitter in her neighborhood. With growing trust and mutual respect, her relationship with her psychiatrist enabled her to confide in him that she had been coughing up blood and experiencing night sweats. Medical evaluation revealed a small tuberculous lesion adjacent to one of her major bronchioles. She was rapidly treated with antituberculosis agents and fully recovered.

Current Status of Biobehavioral Treatments for Older Persons With Schizophrenia

Although a variety of evidence-based treatments integrating pharmacotherapy with behavior therapy exist for adults with schizophrenia (Heinssen et al. 2000), there have been relatively few demonstrations of their specific value and application to older persons with schizophrenia. The symptoms and neurocognitive impairments in schizophrenia are not progressive over the life span, and many studies have documented the capacity of older persons to gain a wide range of knowledge and skills—albeit more slowly and over a longer time frame than younger individuals. Thus, there is sound reason to believe that integrated biobehavioral treatments for older persons with schizophrenia would be efficacious.

As the population ages in general, we can expect to see more theory-based, empirical studies in the realm of treatment development and assessment for older individuals with schizophrenia. Another impetus for greater attention to be paid to this subgroup of persons with schizophrenia will come from fresh interest in the prospects for and factors influencing recovery from schizophrenia (Liberman et al. 2002). Nonetheless, priorities from granting agencies and academic departments of psychiatry will have to provide motivation for scientist-practitioners to identify which forms of educational, behavioral, cognitive-behavioral, environmentally supportive and integrated biological-psychosocial modalities will prove to be acceptable, tolerable, and "user friendly" to patients, their families, and their caregivers; efficacious in controlled trials; effective in the field; durable in their impact; and generalizable in terms of impacts on everyday activities, social role functioning, and subjective quality of life.

Teaching Disease Management and Community Adaptation Skills

Because elderly individuals with schizophrenia have neurocognitive deficits compounded by memory and other information processes that are adversely affected by aging, teaching them how to reliably use their medications requires specially structured educational methods. It is not enough to hold verbally mediated discussions or psychoeducational groups on the topic of psychoactive medications, because verbal memory and learning are particularly impaired in schizophrenia. Procedural or implicit memory and learning have been shown to be unimpaired in schizophrenia; hence, it makes sense to capitalize on these well-preserved cognitive domains in designing behavioral interventions that will foster reliable use of medications. Skills training, as developed by Liberman and colleagues at the University of California–Los Angeles (UCLA) Clinical Research Center for Schizophrenia and Psychiatric Rehabilitation (Liberman et al. 1993), combines a variety of learning principles that build on the patient's capacity for procedural learning and memory.

Using highly structured and organized educational programs, called *modules* because they can be readily implemented in a wide variety of already established treatment settings, practitioners of disparate training, experience, and discipline have been able to successfully overcome the cognitive and symptomatic impairments that characterize schizophrenia (Eckman et al. 1992; Liberman et al. 1998b) and that ordinarily would interfere with learning. In modules for disease management, patients participate interactionally in *learning activities* that emphasize "learning by doing," repetition, and in vivo assignments. Such learning activities enable patients with schizophrenia to acquire knowledge and skills without excessively burdening their capacities for verbal learning and memory. The very same learning activities are used to teach the educational material in each skill area across each of the modules; thus, patients are eased into a learning enterprise that is familiar and holds no surprises for them. Aided by modules that present learning in small, incremental steps associated with "coaching" and abundant positive reinforcement, the programs can serve as functional bridges from hospital to residential to day treatment and ambulatory care settings.

Skills training modules have been designed and empirically validated for medication management, symptom management, substance abuse management, and community reentry—all relevant areas of knowledge and skill with the potential to give persons with schizophrenia greater control over their disorder. Each module includes a trainer's manual, a participants' workbook, a demonstration video, and a user's guide. The overall goals for each module are subdivided into skill areas; for example, the skill areas for the Medication Management Module are titled "Identifying the Benefits of Antipsychotic Medication," "Self-Administration of Medication," "Evaluating Side Effects," "Negotiating Medication Issues With Doctors," and "Benefits of Long-Acting Depot Medication." Each of the skill areas has very specific, operationalized behavioral goals that constitute the educational objectives of the curriculum. Figure 13–1 lists the specific skills that patients are taught in learning how to negotiate medication types and dosages with their doctors and other health care providers.

Application of Skills Training Modules to Elderly Psychiatric Patients

In a controlled study of the Medication Management Module with a mixed group of geropsychiatric patients on an inpatient unit at the West Los Angeles Veterans Affairs (VA) Medical Center, knowledge about medications increased significantly among patients receiving the module training but not among patients in the control group, which experienced the same treatment milieu but received educational classes in personal hygiene and nutrition instead of medication self-management. Acceptability of the training

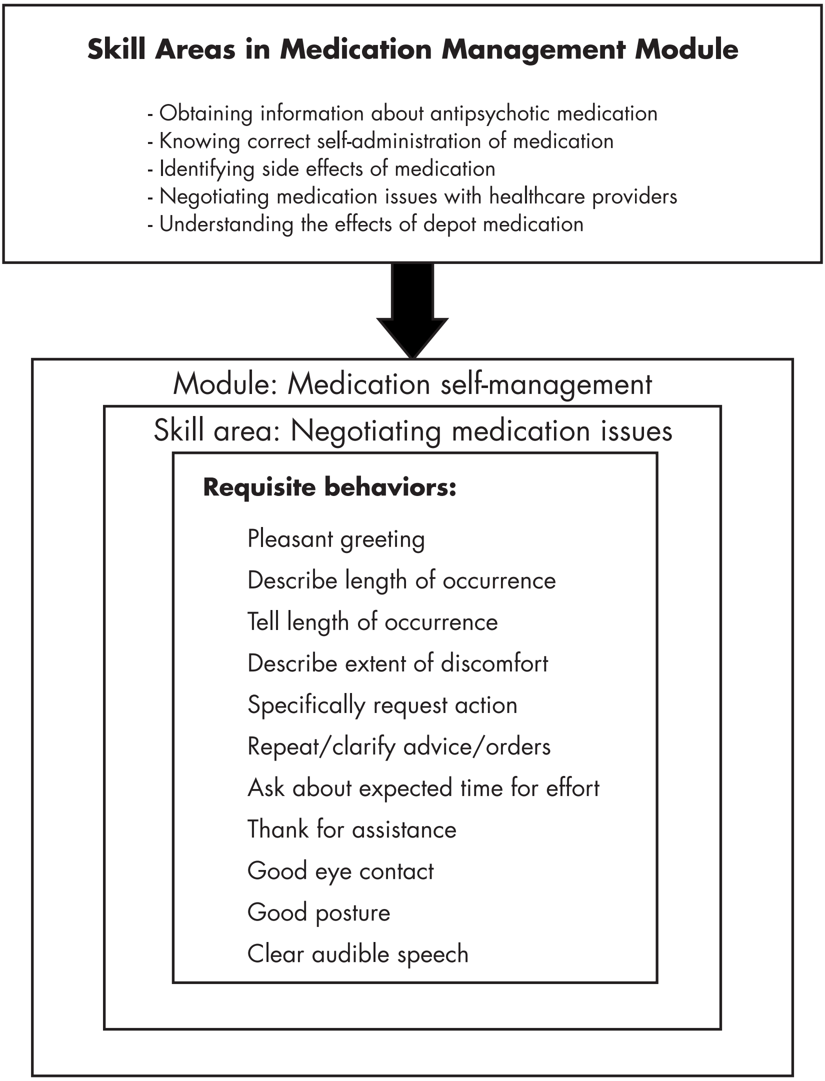

FIGURE 13–1. Organizational structure of a module for teaching disease-management skills to elderly persons with schizophrenia.

Each module consists of skill areas or topics that are further specified in the training process through behavioral or educational objectives. In the Medication Management Module, the skill area "Negotiating Medication Issues With Your Psychiatrist, Physician, or Nurse Practitioner" contains educational objectives comprising verbal and nonverbal communication skills that increase the likelihood that the patient will meet with success in managing medication problems and collaborating as a partner in the pharmacotherapy process.

program was high: patients uniformly reported enjoying the experience. Rates of adherence to medication regimens at 6-month follow-up, as measured by pill counts, were 62% for the patients who participated in the Medication Management Module versus 38% for the control patients (Wilkins et al. 1995). Attendance at outpatient aftercare appointments was also greater for the patients who received the training in medication management. Positive benefits from training elderly patients with schizophrenia in disease management have also been reported by a team at the San Diego VA Medical Center (McQuaid et al. 2000).

Training Skills for Community Adaptation

A variety of instrumental role and affiliative skills can be taught to persons with schizophrenia, using the same behavioral learning principles as were described above for teaching disease management skills. Modules developed include Recreation for Leisure, Basic Conversation, Friendship and Intimacy, Self-Esteem, and Emotion Management. The efficacy and value of these modules for the community adjustment of persons with schizophrenia, if not for elderly individuals with this disorder, have been amply documented (Heinssen et al. 2000; Liberman et al. 1993).

Environmental Supports for Disease Management and Social Functioning

Because elderly patients with schizophrenia are very likely to have comorbid psychiatric and medical problems (see Chapter 7), their medication regimens will often be quite complex. Complexity of medication regimens is a major cause of noncompliance; thus, creative planning must go into facilitating the brain–behavior–environment interactions that will promote proper use of medications.

A number of environmental modifications and ways of organizing and structuring transactions between the prescribing physician and the patient have been shown to improve adherence in persons with schizophrenia (Corrigan et al. 1990). These can be categorized according to the source of the challenges to improved management of illness: in the treatment itself, patient characteristics, family and caregiver characteristics, clinician–patient relationship, and within the system of care in which treatment is being delivered. These challenges and some corrective measures are depicted in Table 13–1.

One example of improved clinician–patient interaction that can facilitate patients' management of their illness lies in the quality of communica-

TABLE 13–1. Obstacles to clinician–patient collaboration in treatment and rehabilitation

Obstacles	Methods for overcoming obstacles
Treatment techniques	
Side effects	Use low-dose medication for maintenance.
	Prescribe medication to treat side effects.
	Titrate medication to minimum optimal dose.
	Reframe side effects as signs that the drug is working.
	Teach patient to keep a diary for tracking side effects.
	Educate patient about side effects and their management.
Complex treatment regimen	Ask patient to repeat back written and spoken instructions.
	Use simple words.
	Increase complexity of treatment in stepwise increments.
	Enlist patient participants in creating the treatment regimen.
	Use stimulus control to remind patient to take medication.
	Teach family members or caregivers to mediate in reinforcement compliance.
Long-term treatment	Institute treatment holidays.
	Administer medication intermittently, when symptoms or relapse occur.
Patient characteristics	
Cognitive disorganization	Minimize complexity of treatment regimen.
	Use pictures and cartoons to deal with illiteracy.
	Use telephone calls, compartmentalized pill boxes, and other stimuli to remind patient to take medication.
	Use large print posters and information on cards.
	Use cognitive rehabilitation techniques to improve patient thought disorder.
	Teach self-monitoring techniques to patient.
	Enlist caregivers' assistance in monitoring patient compliance.

TABLE 13–1. Obstacles to clinician–patient collaboration in treatment and rehabilitation *(continued)*

Obstacles	**Methods for overcoming obstacles**
Ignorance about illness	Teach patient about the biomedical nature of mental illness and its relation to stress. Use cognitive restructuring techniques to enhance learning. Offer destigmatizing analogies to other diseases. Use peer role models (self-help groups).
Fatalistic attitude	Teach patient about the long-term normalizing outcomes of illness. Use cognitive restructuring techniques to enhance change in attitude. Give patient increased control in goal setting, administration of medication, and psychosocial treatment. Use paradoxical interventions such as contingency contracting.
Secondary gains from psychosis	Build therapeutic relationship as a lever to change. Help the patient sample reinforcers of behaviors that compete with psychosis. Enlist significant others as mediators.
Family characteristics	
Ignorance about benefits of treatment	Encourage family participation in psychoeducation and support groups.
Unrealistic expectations	Encourage family to participate in psychoeducation, survival skills training, and training in communication and problem solving. If other strategies fail, suggest a constructive separation of patient from the family.
Indifference	Promote family education to galvanize social support for patient. Identify reinforcers, such as decreased family chaos, to motivate family involvement. Teach patient to improve relationships with family.

TABLE 13–1. Obstacles to clinician–patient collaboration in treatment and rehabilitation *(continued)*

Obstacles	Methods for overcoming obstacles
Clinician–patient relationship	
Clinician believes patient has poor prognosis	Learn about practical modes of rehabilitation. Consult professional role models. Ask the patient and family members about their aspirations.
Clinician has aversive interpersonal style	Obtain training in counseling skills.
Clinician ignores patient's dissatisfaction with treatment	Learn about the impact of side effects and how to manage them.
Treatment delivery system	
Aversive clinic setting	Improve clinic decor and ambience. Offer coffee or other refreshments. Encourage clerical staff to be pleasant.
Long waits at clinic	Maintain realistic appointment schedule. Remind patient about appointments.
Lack of coordination in treatment delivery system	Use case managers and continuous treatment to coordinate services.

tion used by the clinician. Understanding the importance of treatment and using treatments reliably will improve for patients when their clinicians simplify the treatment regimen as much as possible; use empathy and active listening skills; use verbal, nonverbal, and paralinguistic skills that convey enthusiasm and reasonable optimism for the benefits of medication and other treatments; use simple layperson's language; provide posters and illustrated handouts; and speak slowly and loudly enough for patients' comprehension.

By adapting the patient's home, hospital, or residential care environment to compensate for his or her cognitive deficiencies (such as memory problems), disease management and activities of daily living often can be improved. Nursing staff, case managers, and other outreach workers can attach signs on walls and other places in the patient's field of vision to remind the patient to engage in activities of daily living, to prepare meals, to clean the living space, to take medication on time, to call a caregiver when warning signs of relapse intrude, and to remember to attend aftercare visits (Velligan et al. 1999). In this age of electronic and wireless communication, many innovations can be crafted to compensate for attentional, memory, and learning deficits of elderly persons with schizophrenia. Examples include beepers, cell phones, palm pilots, and teleconferencing.

> Mr. C, a 72-year-old man with schizophrenia, lived alone in a rooming house and had difficulty remembering to take his antipsychotic and antihypertensive medications on a daily basis. He also neglected to take his prescribed daily walks, which were important for minimizing his osteoarthritis. Mr. C's case manager telephoned him each morning to remind him to schedule these events and again in the late afternoon for follow-up reinforcement. Even if Mr. C only "thought about" taking his meds and taking his walk, he received positive feedback. Within 3 months, he was regularly and reliably remembering his medications and taking daily walks, at which time his case manager gradually faded the phone calls to an intermittent schedule.

Making the residential or hospital environment simulate more normal community settings and introducing community visits to otherwise institutionalized patients can also improve adaptive functioning. If the *understimulation* of residential and hospital environments is countered, elderly individuals with schizophrenia will respond to the opportunities in the revamped milieu, albeit more slowly than do younger persons with schizophrenia. As an example of a modest change in the environment that brought about substantial changes in social behavior, elderly persons with schizophrenia who had undergone decades of psychiatric hospitalization were introduced to board games that elicited their responses to questions about themselves. This simple intervention more than doubled the rate of conversation. When contingent positive reinforcement was added to the games, the rate of conversation increased approximately fivefold (Liberman 1972).

With provision of a full array of community-based supports, most elderly persons with schizophrenia can be maintained in the community with better subjective quality of life and at a lower cost than in institutions (Bernstein and Hensley 1993; Trieman et al. 1996). The requisite community supports, however, are not easily mobilized and sustained over the long haul, because they require considerable coordination across different agencies; thus, it is not surprising that most studies of community supports without concurrent skills training and other interventions aimed at improving individuals' functioning levels have not resulted in significant improvements in social adjustment. Supports required to sustain elderly persons with schizophrenia in the community include medication management by psychiatrists or psychiatric nurse practitioners supervised by psychiatrists, intensive case management, social services such as housing and nutrition, transportation, general medical care, dental care, 24-hour crisis intervention, home-based mental health care, residential and family support services, caregiver training, outreach, and psychosocial rehabilitation.

Because of its investment in elderly veterans, who account for more than 40% of its patient population, the VA system has been among the leaders in developing a panoply of services for aged persons with serious and disabling mental disorders, from the inpatient and outpatient monitoring and case management functions of psychogeriatric team care to programs that connect primary care with specialized psychiatric services (Kim et al. 2001). The latter arena will become increasingly important to psychiatrists as consultants, because it is abundantly clear that elderly individuals prefer to receive mental health services from their primary care physicians and their ancillary team members.

Cognitive-Behavior Therapy for Psychotic Symptoms Refractory to Drugs

In recent years, controlled studies have documented the value of CBT for delusions and hallucinations that have been refractory to antipsychotic medications (Garety et al. 2000; Sensky et al. 2000; Tarrier et al. 1998). The techniques are similar to those that have been long known to be efficacious in depressive and anxiety disorders. Such techniques include disputing and challenging, creating dissonance, using coping statements, generating alternative explanations for symptoms, cognitive restructuring of the meaning of the symptoms, and behavioral experiments.

The acceptability and feasibility of CBT techniques was tested during 12 weekly 1-hour group sessions with nine elderly patients with schizophrenia with an average age of 62 years who had residual psychotic symptoms and functional deficits. The initial sessions emphasized thought challenging with simplified methods based on the "3 C's": **c**atch the thought (identify irrational cognitions), **c**heck it (assess whether the thought contained any distortions or interfered with functioning), and **c**hange it (develop alternative thoughts). To facilitate use of the techniques, multiple modalities were used to present the "3 C's" (posters, handouts, role plays, video feedback) and these were augmented by mnemonic aids, repetition, and weekly homework assignments.

Attendance was high, participants completed the majority of homework assignments, and the personal goals set by each patient at the outset were accomplished in most cases. A subsequent, randomized controlled study of this approach, using more role-playing and problem-solving exercises, resulted in superior outcomes for the CBT group in reduction of depressive symptoms, which are a common comorbid symptom in persons with schizophrenia.

> Ms. D, a 68-year-old woman, had a 35-year history of persecutory delusions of being injured by electromagnetic waves sent by unknown conspirators who were also attempting to poison her through the tap water. Her symptoms were only modestly responsive to a variety of antipsychotic and adjunctive medications, including clozapine. She had undergone more than 10 hospitalizations and was living in a board and care home, where she met with a psychologist twice weekly for 3 months in CBT. The psychologist took great pains to establish and maintain rapport with Ms. D, including discontinuing any sessions in which she appeared emotionally aroused and using relaxation instructions to reduce her stress.
>
> In a collaborative fashion, the psychologist and Ms. D considered ways in which Ms. D had attached persecutory significance to specific events, such as her feeling that her muscles were "controlled" by outside forces and that the tap water tasted "funny." They discovered that several times Ms. D's muscles felt controlled after she had engaged in exercise. This led to a consideration of other explanations for what were undoubtedly altered sensations in her muscles. In a similar fashion, her therapist gently encouraged her to consider various reasons for unusual tastes to the water, such as her having a dry mouth as a side effect from her medication and using a new brand of toothpaste. Direct confrontation was carefully avoided because it would further reinforce the conviction of her delusions.
>
> Socratic questioning was used to explore the implications and "worst possible scenarios" if her delusions were to be true. For example, her psychologist asked, "What would you expect to happen to you if the water was

> poisoned? Even when you haven't drunk the tap water, it is being used in the kitchen to prepare soups that you've had—did you get sick after eating the soup? Have you noticed any rash on your skin after showering?" Weekly behavioral experiments were initiated with Ms. D during which she was asked to actually drink some of the tap water—and, at a later time, bottled water—and to compare her reactions to each. As time passed, the strength of Ms. D's belief in her delusions subsided, although it never fell below the level of overvalued ideas. Most importantly, however, her social participation and functioning improved.

Social Learning and Token Economies

Organizing the patient's living environment so that caregivers provide frequent, systematic, and positive reinforcement for adaptive behavior has resulted in evidence-based efficacy of social learning techniques in the elderly for activities of daily living, social and leisure time participation, improved memory and cognition, and higher levels of independent living (Patterson 1992).

> Ms. E, a 63-year-old single woman who had lived an isolated and reclusive existence, was hospitalized for mutism and refusal to get out of her bed in her community residence. She slowly responded to positive social reinforcement provided around the clock by nursing staff in response to any sign of social interest on her part. She was given tokens, also within a "shaping" paradigm, that she was able to exchange for cigarettes, a personal tape recorder with headphones, and special privileges (e.g., a single room, time for privacy). Once Ms. E became mobile and began talking, she agreed to take medication, which further improved her symptoms and functioning.

Social Learning for Delusional Speech

Many scientist–practitioners have published studies showing the lawful relationship that exists between the frequency and distressing nature of delusional and hallucinatory speech, on the one hand, and the social attention that it generates, on the other. Token reinforcement and social reinforcement for rational speech have been shown to weaken delusional speech as a response class (Glynn et al. 1994; Liberman et al. 1973). The procedure requires all those having contact with the delusional individual to systematically ignore the delusional speech or change the subject when it emerges in casual conversation. In addition, family members and professional caregivers are given practice in eliciting and responding effusively to any nondelusional utterances. Generalization of improvements to unobtrusive situations has been demonstrated (Patterson and Teigen 1973), especially when gradual fading of the reinforcers was built into the programs and when natural reinforcers were used.

> Mr. F, a 64-year-old scion of a wealthy family, had been continuously hospitalized for 18 years. He spent many hours cutting out articles from newspapers and magazines that he claimed supported his delusions that he had been swindled out of billions of dollars and that plastic lookalikes were impersonating his family members. Neither antipsychotic medications nor electroconvulsive therapy was successful in mitigating the delusions, which he expressed frequently and vehemently. Nursing staff initiated informal conversations with Mr. F four times daily for 10 minutes each time, showing interest and responding verbally and nonverbally to any topics that were not related to Mr. F's delusions. When he did express his delusions, they politely terminated the conversation. In addition, Mr. F earned pleasant chats each evening with snacks with his favorite staff members for the cumulative amount of time that he had spoken rationally during the day. These concurrent schedules of reinforcement resulted in more than a doubling of his rational speech during the day, with generalization noted during the noncontingent evening chats as well.

> Ms. G was a 67-year-old single woman who had been continuously hospitalized for 32 years. When asked about her identity and personal history, she would reply that she was of the European nobility, was 22 years old, and was awaiting her husband's arrival at the hospital to bring her to the family castle to live. Reflecting the refractoriness of her delusions to logical confrontation, she responded to a nurse's pointing out to her in the mirror that she couldn't possibly be 22 years old because she had white hair, was stooped over, and had wrinkled skin by saying, "Yes, dearie, but my hair and body parts have been stolen from me and replaced by those of an old woman."
>
> After a baseline period during which she was given noncontingent token reinforcement, Ms. G was given token and social reinforcement contingent upon responding accurately to questions regarding her birth, background, and family relations. Figure 13–2 shows the increase in her rational responses concurrent with the introduction of contingent reinforcement over a period of 100 days. Three months after discharge, a visitor to Ms. G's community boarding home unobtrusively engaged her in conversation that touched on her background. Ms. G's rational responses were maintained with only natural social reinforcement.

Social Learning for Self-Care Skills

Token economies have been used for more than 40 years to improve the daily living skills of institutional residents (Liberman 2000; Paul and Lentz 1977). Home-based interventions, in which family members or nursing home staff were taught social learning principles, have also been shown to improve the self-care skills of elderly persons, including those with psychosis and dementia (Patterson 1992).

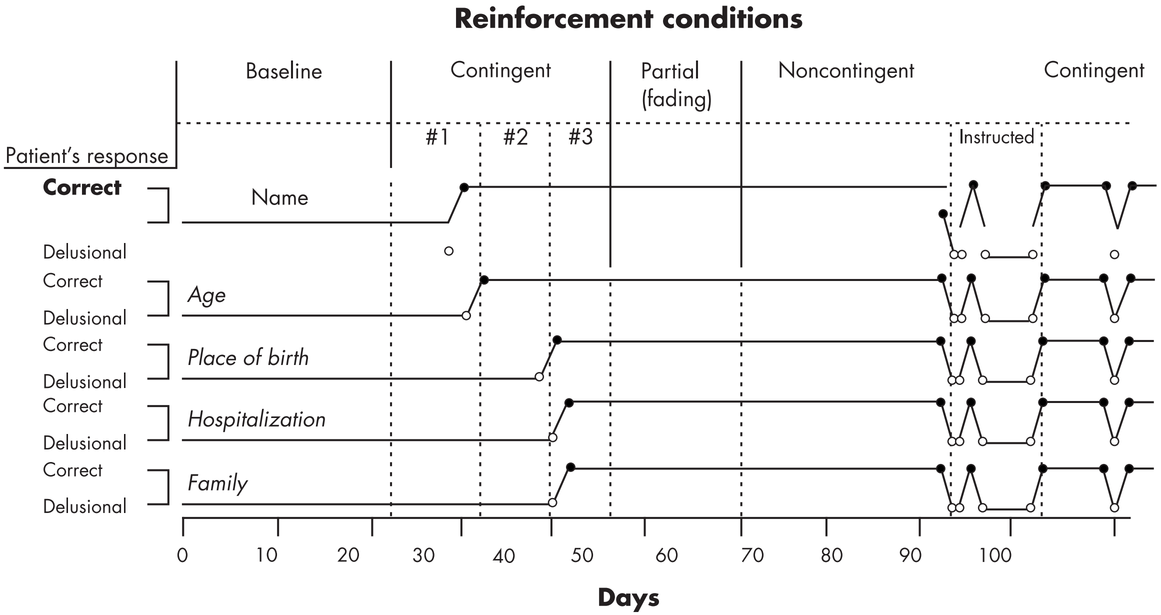

FIGURE 13–2. Effects of token and social reinforcement in reducing delusional speech.

Through use of controlled, within-subject, multiple baseline, and reversal designs, in which the reinforcement contingencies were systematically changed during collection of observational measures of the patient's delusional speech, it was possible to demonstrate the causal influence of social reinforcement in promoting rational speech. The patient's delusional ideas regarding her name, age, place of birth, and other aspects of her identity were displaced by accurate self-perceptions, which were maintained during unobtrusive interactions with her in natural community settings.

Biobehavioral Therapy: Can Psychosocial Treatment Reduce Dosage Requirements for Pharmacotherapy?

Because elderly persons with schizophrenia are especially sensitive to the noxious side effects of antipsychotic medications and because these side effects are often responsible for noncompliance, it becomes essential to develop psychosocial treatments that can protect individuals from psychotic relapse at lower doses of medications. When psychosocial or behavioral treatments are highly structured, are communicated to and comprehended by schizophrenic patients, and place little burden on the patient's capacity for information processing, one can see reciprocal protective benefits between medication and the psychosocial treatment. In one randomized controlled trial, a social learning program for individuals with chronic psychosis was associated with faster learning of self-care and social skills with placebo than with active medication. This protective or salutary effect of psychosocial treatment was not observed when placebo was substituted for active drug in a control ward in which standard psychosocial milieu therapy was provided (Paul and Lentz 1977).

In a study with outpatients having schizophrenia, Liberman and associates found that social skills training conferred protection against relapse equivalent to that conferred by supplemental doses of antipsychotic drug; this result was not observed when a less structured but equally intensive therapy—supportive group therapy—was provided (Liberman et al. 1998a). In a nursing home, psychotropic drug use was significantly reduced in patients (average age = 80 years) when 17 sessions of behaviorally oriented psychotherapy were delivered. The behavior therapy consisted of cognitive rehearsal of desired behaviors, modeling of adaptive behaviors, and positive reinforcement when patients exhibited appropriate behavior (Mansdorf et al. 1999).

Delivering Biobehavioral Interventions in Systems of Care

Efficacy studies of behavioral interventions to improve the symptoms and functional capacity of older schizophrenic adults are usually carried out by academic professionals with specially selected subjects, using resources enhanced by research grants and highly motivated staff. Extending and replicating positive findings from these more refined studies to "effectiveness studies" with unselected populations without enhanced resources and academic supervision is a great challenge to clinicians and administrators alike.

In a sample that included elderly persons with schizophrenia, Paul and colleagues demonstrated in the Illinois State hospital system that social learning procedures could be implemented at a cost no greater than standard care with far superior results (Paul and Lentz 1977). In fact, cost-effectiveness analysis revealed that the social learning program, when extended into community-based homes, was only one-third as expensive as traditional care and deinstitutionalization.

A provincial hospital in Canada adopted a wide variety of rehabilitation procedures for geriatric patients with schizophrenia that had been documented in efficacy studies to improve functioning in hospitalized patients (Bartels et al. 2002b). These included giving patients a greater voice in their activities and goals, opening the kitchen to patients for food preparation, taking patients on community visits in small groups to purchase personal items and enjoy coffee shops, and hiring a rehabilitation coordinator to ensure that planned and scheduled activities took place on a regular basis. Adaptive behavior and activity levels markedly increased, and use of restraints and as-needed medications subsided.

In a pilot study in New England, community health nurses were trained to use social skills training with groups of elderly schizophrenia patients who were living in public housing (Bartels et al. 2002a). The goals of the skills training were identified through ecological surveys of the needs of the elderly individuals, including situations pinpointed by the individuals themselves. Many of the interpersonal situations that were troublesome for the elderly individuals involved difficulties in securing dignified and adequate medical and social services. Thus, in this naturalistic study, services encompassed housing, medical care, social services, and psychosocial rehabilitation. At the end of the first year, individuals who received skills training showed clinically significant and substantially greater improvements in social skills and independent living skills than those receiving standard case management and nursing services alone.

Applying empirically supported and evidence-based practices to services for the elderly mentally ill, the staff of the Florida Mental Health Institute organized comprehensive programs in modules for both residential and daycare settings (Patterson 1992). These relatively short-term, modular programs served individuals who were at risk for hospitalization or who were being prepared for reintegration into community life. The patients' average age was 67 years, and their mean length of prior hospitalization was almost 2 years.

The programs consisted of skills training modules, each of which addressed a different area of community life—leisure time, activities of daily living, money management, disease management, housekeeping, and use of community resources. The manuals developed for the programs were written simply so that they could be readily used by direct care staff with no more than 1–2 years of post–high school education or experience in the human services field. Evaluations of the programs revealed substantial benefits for patients participating in the modules as compared with their counterparts who received more standard services (Patterson 1992). Many of the skills training modules developed by Liberman at UCLA can be easily adapted for use with elderly persons with schizophrenia.

Future Directions

The limited amount of specially designed services and the tiny evidence base of biobehavioral interventions and systems of care for elderly persons with schizophrenia mirror the anemic range of clinical services for this population. Academic and public psychiatry have focused their resources on younger persons with schizophrenia, by and large turning their backs on biobehavioral treatments for elderly persons with the disorder. Even now, the rallying call of those interested in recovery from schizophrenia is for early intervention with adolescents and young adults showing the first signs of the illness.

The rationale for designing and testing psychosocial treatments for elderly individuals with schizophrenia is described in other chapters of this book that document the plight of this subgroup and their burden on families and society (see Chapter 14 in this volume). Elderly individuals with schizophrenia consume a disproportionate amount of health, social services, and mental health resources and overutilize inpatient and residential beds; however, these individuals are eminently treatable and have emerging needs for coordination of their primary care with specialty care (Banerjee 1998).

There is little doubt that psychiatry has a mandate to do more for elderly individuals with schizophrenia. What should the priorities be? In the current zeitgeist of evidence-based best practice, we must be certain that the novel psychosocial treatments developed are dovetailed with the specific, ecological needs of the elderly—that is, the treatments should meet needs defined by the elderly and their caregivers as well as be acceptable and well tolerated by them. The social validation of interventions for elderly persons with schizophrenia may not coincide with the needs and desires of younger persons with schizophrenia. At the same time, it would be a serious error to substitute stereotypes for empirically based needs assessments in identifying the areas in which new treatments and rehabilitation services should be developed. For example, the elderly in our society as a whole are increasingly still working (at least part-time) into their seventh and eighth decades. Why, then, should recreational activities and leisure-time pursuits assume the highest priority for older adults with schizophrenia? Why not a working life as well?

Other needs are also clear. Just as family interventions have become a major arena for helping younger persons with schizophrenia, so too must we pay attention to families attempting to cope with an older member with schizophrenia. Although care of the elderly has become a national theme, little attention has been given to the needs of the family members who care for aging adults with serious mental illnesses. Anxiety and concerns about a loved parent, aunt, or uncle with schizophrenia are multiplied when the younger-generation prospective caregiver lives hundreds or thousands of miles away. The role reversal required of the younger family member in attempting to do something to help the older individual is another challenge, especially when acute emergencies supervene and something must be done immediately.

It is likely to be difficult for practitioners to acquire competencies in 1) motivating younger-generation individuals to learn about schizophrenia and provide support to their elderly family members and 2) teaching younger relatives how to communicate and problem-solve with the older generation. These professional skills have proven difficult to learn and use even when the caregiver is a parent. Psychoeducational guides for practitioners and family members do exist, but they will require adaptation (Mueser and Gingerich 1999; Siegel and Siegel 1993) for use by younger relatives caring for their older parents or siblings. The stressors and rewards of the caregiving role will be determined by the older adult's level of functioning, the ability of caregivers to meet their own needs, and the adequacy and accessibility of the mental health service system (Hatfield 1998).

One area for strengthening family caregiving that will be increasingly linked to primary care of the elderly is psychosocial interventions in the home. For example, many younger-generation family members would be able to provide caregiving for their aging parents with schizophrenia if more respite services were available. The challenges involved in the design and validation of psychosocial interventions for families of aging persons with schizophrenia are covered in greater depth in Chapter 14 (Lefley) in this volume.

Treatment of the dually diagnosed substance-abusing elderly person with schizophrenia is another challenge already on the radar screen. Because the current generations of young to middle-aged adults have higher rates of substance abuse than previous cohorts, the proportion of elderly persons with schizophrenia who will require integrated treatment of dual disorders will undoubtedly increase (Patterson and Jeste 1999). Although few comprehensive and integrated programs exist even for younger persons with schizophrenia and substance abuse, designated modules that teach relapse prevention and disease management may be helpful for older dually diagnosed patients until broad-spectrum programs can be developed for the elderly population (Roberts et al. 1999).

Another area that should receive attention by treatment developers and evaluators is the spiritual realm. Not only are older individuals more likely to become concerned with and give priority to fundamental issues of religion and spiritual renewal (Thomas and Eisenhandler 1999), but the growing area of spiritually based alternative therapies will assume greater importance to elderly mentally ill individuals as the current generation passes into senescence. This area of care has begun to receive serious attention from granting agencies, and more controlled research is being done. Whatever the arena of psychosocial interest, it will be vital that scientist-practitioners submit their pet interventions to systematic study of acceptability, tolerability, efficacy, effectiveness, durability, generalizability, and cost-effectiveness.

Because elderly persons with schizophrenia have greater memory problems and other cognitive deficits than do younger persons with schizophrenia, it will be essential to design and validate psychosocial and biobehavioral interventions that will compensate for or mitigate cognitive impairments to facilitate both pharmacotherapy and psychological treatments. Neurocognitive pharmacotherapy (e.g., atypical antipsychotics, “alerting” drugs such as modafinil, drugs that slow memory loss such as donepezil, and their congeners) and cognitive rehabilitation (Liberman 2002) are likely to assume greater importance in the years ahead as research progresses.

Summary

As the population ages in Western societies, the prevalence of schizophrenia in elders will increase, placing a burden on practitioners and systems of service to design, validate, and deliver effective biobehavioral treatments. Advances in rehabilitation is a worthy goal of geropsychiatry in the twenty-first century and can be guided by the following principles for practice:

1. The principles of biopsychosocial treatment and rehabilitation of schizophrenia, applicable for both elderly and younger persons with schizophrenia, include the integration of biological with psychosocial interventions, the outcome-specific nature of interventions, the preeminence of the patient’s personally relevant goals and quality of life over syndromal definitions of the disorder, and the need to provide multimodal treatments to attain multidimensional improvements in the patient.

2. Elderly individuals with schizophrenia can learn how to control their symptoms and reliably manage their medications; they can also durably learn and generalize social and independent-living skills for community adaptation. Most of the controlled studies with skills training in schizophrenia, however, have been done with adults who have not yet reached the senior age threshold; thus, research and development must continue to be encouraged in this domain.
3. Environmental supports need to be "wrapped around" elderly persons with schizophrenia to ensure that their needs are being met, because it is not reasonable to expect individuals who are physically, mentally, and cognitively disabled to learn or relearn the full range of skills required for complete autonomy. Environmental modifications to support elderly patients include memory aids, indigenous community supporters, and supported housing programs.
4. Elderly individuals with schizophrenia who have treatment-refractory psychotic symptoms appear to benefit from cognitive therapy when the therapy is adapted to their information processing and social needs. However, work in this area has just begun.
5. Social learning and token economy procedures, utilizing contingencies of reinforcement, are very effective for individuals with schizophrenia of all age groups. These programs require the arduous organization of a learning environment maintained for 24 hours a day, 7 days a week. Reinforcement conditions should be implemented with fidelity to consistent application of behavioral principles and adherence to quality assurance procedures.
6. Behavior therapy, when effective in promoting coping skills, appears to confer protection against stress-induced relapse and to displace psychopathology. Thus, the interchangeability of the protective benefits of behavior therapy and medication may reduce the amount of medication required for symptom stabilization and relapse prevention. More systematic and controlled studies must be done to confirm and clarify the nature of psychopharmacology–psychosocial treatment interactions.
7. Several demonstration projects in various practice sites and systems of service seem to indicate that transfer of technology can occur from academic studies to locations where nonacademic practitioners serve a full range of patients.

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CHAPTER 14

Changing Caregiving Needs as Persons With Schizophrenia Grow Older

Harriet P. Lefley, Ph.D.

With progressive deinstitutionalization, many families have assumed the supportive functions of the old state hospitals for persons unable to survive on their own. Research both in the United States and throughout the world indicates that families are now the major caregivers and lifetime support systems of persons with schizophrenia (Warner 2000). Even when patients live in assisted-living facilities or residential housing affiliated with community mental health centers, families continue to be a significant source of financial, emotional, and social support (Beeler et al. 1999). A study of adults with schizophrenia living in noninstitutional settings in the community indicated a high degree of family contact, primarily with parents. Nearly two-thirds had contact with parents an average of twice a week, and almost a quarter had lived in the parental home at some time during the preceding 6 months (Brekke and Mathiesen 1995).

What will happen when family caregivers grow older and are no longer able to fulfill their supportive roles? We begin, first, with an assessment of the scope of co-residential caregiving. Various studies have provided a general estimate of the number of psychiatrically disabled persons who are living with their families. What percentage of family caregiving is performed by parents, that is, by persons who are likely to be outlived by the patient, vis-à-vis caregiving by younger relatives such as spouses or siblings? Can we get an idea of the modal age of parental caregivers and their adult children with schizophrenia? Do we have some understanding of who will replace these caregivers when they are gone?

Are there cultural differences in caregiving patterns, in perception of family burden, and in the availability of substitute caregivers? Do experiences and expectations vary among ethnic groups in the United States and in other countries of the world?

How is caregiving experienced during different stages of the life cycle? Does family burden increase with the age of the patients and the caregiver? Does caregiving of dependent adults vary as a function of the type of disability? For example, are the experiences of aging caregivers comparable in long-term psychiatric and developmental disorders? What are the resources available to caregivers under these conditions? Finally, what are the issues facing aging caregivers, how do they perceive them, and to what extent are they able to plan for the future of their loved ones after they are gone?

In this chapter I discuss these problematic issues in terms of known research findings and questions yet to be answered. The few studies to date offer only partial answers, but the data suggest directions for further investigation and also for clinical practice. My concluding remarks summarize the implications of these findings for both social policy and mental health planning and offer some suggested solutions.

The Scope of Family Caregiving

In any part of the world, the percentages of families caring for their loved ones with schizophrenia are related both to cultural expectations and to the level of development of the country's mental health system. They are also contingent on the availability of alternative housing and other resources for independent living. But even in modern European nations such as Italy, 70%–84% of persons with major mental illness live with their families (Warner 2000). Seeman (1988) noted that in Canada, about two-thirds of people with schizophrenia live with their families. Various studies done in the United States show that ethnic minorities are more likely to be active caregivers in terms of living with their mentally ill relatives. Although national data are lacking, in a number of geographically separate studies the percentages for Hispanics, for example, ranged from 75% to 85% co-residence versus 66% for African Americans and about 40% for families that were predominantly European American. Co-residence estimates for Asian Americans were even higher (Lefley 1996). A stratified random sample of the predominantly white American families in the National Alliance for the Mentally Ill (NAMI) showed 42% living with their relatives with mental illness (Skinner et al. 1992). Among the mentally ill relatives, 88% had never married or were single, and almost 90% had a diagnosis of schizophrenia or bipolar disorder.

Lacking scientific national or international samples, it is difficult to determine, from the limited body of existing research, the actual numbers and characteristics of aging persons with schizophrenia and their principal caregivers. Nevertheless, in the studies cited it was clear that the majority of persons with long-term caregiving needs who lived with their families were unmarried males and that most lived with parents rather than with spouses or other relatives. A number of scientific surveys of NAMI families have revealed that between 73% and 85% of the known caregivers of adults with schizophrenia are parents, primarily mothers (Lefley 1996). Most of these studies show a typical picture of a mother with a mean age of 67 years caring for a son with a mean age of 38 years (Lefley 1987; Lefley and Hatfield 1999; Smith et al. 2000). Moreover, despite episodic absences from the family household, a substantial number of persons with schizophrenia live with parents fairly continuously from the earliest stages of illness.

As persons with schizophrenia living in the community grow older, we are rapidly approaching the historical sequelae of deinstitutionalization in terms of the loss of both institutional and caregiver support. In projecting housing needs for adult patients in New York State who met the criteria for severe and persistent mental illness, the New York Office of Mental Health estimated that between 13,000 and 50,000 lived with one or both parents during the 5 years of the study. Of these, 65% were over 30 years of age, and 12% were over 50 (Grosser and Conley 1995). The caregivers of this category of adult dependents are currently or soon will be members of the geriatric population. Many of these caregivers will have caregiving needs of their own.

Although a substantial literature exists on family or caregiver burden, few data are available on variations in type and level of burden over the life course of the illness. In this chapter I discuss how some dimensions of burden change with the aging of both the person with schizophrenia and the caregiver. I also discuss research on the concerns of aging caregivers, on preparing both caregivers and their mentally ill dependents for inevitable life disruptions and loss, and on practical planning for the future.

Caregiving and Kinship Roles

As noted earlier, in the United States and other Western nations caregivers of persons with schizophrenia tend to be parents—and, with the progression of the illness, aging parents. In comparison with persons with other mental disorders, individuals with schizophrenia are less likely to have a spouse and children. Gottesman (1991) reported that men with schizophrenia are one-third as likely to marry, and women with schizophrenia half as likely to marry, as their non–mentally ill peers in the general population. Moreover, when they do marry, the marriages rarely last. The longitudinal Iowa study, a 30- to 40-year study of schizophrenia outcomes, found that 67% of the sample had never married and that 12% were divorced or separated. Only 21% of the subjects were married or widowed (Tsuang and Faraone 1997). As I will discuss further, cultural norms affect the probability of marriage and the attendant age disparities in those who need and provide care.

In Western countries, most studies suggest a prolonged dependency on parents throughout the life cycle. The Johns Hopkins study of a stratified national sample of 1,401 NAMI families in the early 1990s indicated a modal pattern of an aging parental caregiver, typically the mother, taking care of a mentally ill son in his middle to late 30s (Skinner et al. 1992). This patient cohort is now well into middle age. Yet there is little research on the emergent social problem of who will care for these individuals after the parents die. The scant research that exists suggests that as patients get older, siblings and in some cases offspring become increasingly important for family support. In a study of psychiatric patients 45 years and older living in a large intermediate-care facility in Chicago, 75% reported some contact with and support from families. Participants whose mothers were still living tended to have a greater support network and were more likely to have contact with siblings compared with participants whose mothers were deceased. "This finding suggests that the mother is not only an important support person herself but that she helps to maintain a support network for her adult son or daughter" (Beeler et al. 1999, p. 1223).

Cultural Differences

In the United States, there is not only more home caregiving among ethnic minorities but also apparently greater acceptance of the caregiver role. Numerous studies have found lower perceived burden and less depression among African American family members of persons with psychiatric disabilities than among white American families, as well as a greater tendency for siblings and other younger relatives to be caregivers (Lefley 1996). Nevertheless, family caregiving in mental illness has been associated with objective and subjective family burden in numerous studies throughout the world (Lefley and Johnson 2002). In countries where national mental health systems make no caregiving provisions for severely disabled adults with schizophrenia, the state may attempt through legislation to mandate caregiving as a responsibility of the family. In China, for example, Pearson and Lam (2002) point out that spouses, rather than other relatives, are expected to care for individuals with schizophrenia. Moreover, the one-child policy in China today effectively eliminates siblings as a replacement for either spousal or parental caregivers.

In this connection, family psychoeducation in China attempts to address future needs through culturally specific training. Surveying the empirical psychoeducational literature, Xiong et al. (1994) discarded Western models as being inappropriate for China. They noted that the ultimate social goal in China is to develop a family-based support system for dysfunctional individuals and that the cultural and legal obligations of parents to care for disabled children end when those children marry. Parents' major goals are to obtain stable employment and a spouse for their child, sometimes by offering financial inducements to a person of lower social status and by minimizing the seriousness of the illness. Parents will then encourage the young couple to have their own child to provide for the patient in old age and will give financial and practical aid to the spouse in order to prevent divorce. "Once the patient's acute symptoms are under control, these issues become the major focus of the counseling sessions; the therapist assists the patients and family members in their dealings with work sites, helps them negotiate the hurdles of marriage, educates them about the potential problems of pregnancy, and trains the patient to adapt to the demand of marriage and parenthood" (Xiong et al. 1994, p. 240).

Although this approach is substantively different from psychoeducational interventions in Western countries and might even evoke ethical questions, the outcomes have been salutary. In a randomized controlled trial with three follow-ups, this family intervention had highly significant effects in lower rates of rehospitalization, shorter durations of rehospitalization, longer durations of employment, and reduction of family burden (Xiong et al. 1994). Additionally, this type of intervention is likely to enable persons with schizophrenia to lead a more normal life.

Caregiver Needs Over the Life Cycle

Cohler and Beeler (1996) noted the continuity of ties between persons with schizophrenia and their relatives over the course of a lifetime. There is also a diminution of the strained relationships that may have arisen during the early disruptive years of the illness. However, these authors also reported that recurrent episodes may take their toll on the coping ability of both the patient and the caregiver.

Earlier studies of NAMI families had indeed suggested that caregiver burden increases over time. (Lefley 1987). However, multiple variables may confound a simple age–burden relationship. At a minimum, such variables may include length of illness and the patient's level of functioning, symptomatology, and behavioral problems. Additionally, one must take into account other stressful life events in the family life cycle and the capacity of the caregiver to deal with stress.

I collaborated with Dr. Judith Cook, currently director of the University of Illinois at Chicago Research Center on Psychiatric Rehabilitation, to study the relationship of family burden to aging of caregivers and patients (Cook et al. 1994). The research was conducted with families at the Thresholds psychosocial rehabilitation program in Chicago, which serves persons with severe and persistent mental illness. We postulated a number of conflicting but plausible hypotheses about caregiver age and measures of family burden as assessed with the Thresholds Family Burden Scale, a factor-analyzed instrument that yields discrete measures of different types of burden (Cook et al. 1994). The research tested four possible life scenarios:

1. *Hypothesis 1.* There is a positive linear relationship. Caregiver burden increases with age. This is based on the premise of unchanged or deteriorated functioning of the person with mental illness and the decreased capacity of caregivers to meet the demands of the illness.
2. *Hypothesis 2.* There is a negative linear relationship. Caregiver burden decreases with age. This is based on the premise that burden is highest during the early years of the illness, a period of acute psychotic episodes, unrealistic parental expectations for speedy recovery, and frustrations in dealing with the mental health system. Families are bewildered and confused and still frantically seeking a cure. After 5–10 years of illness, unrealistic expectations diminish and caregivers become adjusted to loss of their loved one's premorbid personality and life aspirations.
3. *Hypothesis 3.* There is a U-shaped curvilinear relationship. As indicated in Hypothesis 2, anxieties and frustrations are highest in the early years of illness. With treatment and rehabilitation, the person's functional level may improve, with a concomitant decrease in behavioral problems. A plateau occurs during the parents' midlife years as they become resigned to a less-than-ideal but manageable life for their offspring. Burden begins to rise, however, as siblings disperse and parents enter the older years. From their late 50s on, caregivers begin to experience their own disabilities and to worry about their offspring's future after they are gone.

4. *Hypothesis 4.* There is an inverted U-shaped curvilinear relationship. Even though the early years may include acute psychotic episodes and their sequelae, family burden is lower while there is still hope, before the years of multiple hospitalizations and dysfunction have set in. Burden rises and is most acute during the parents' middle years, when they have to cope with caregiving and the deficits of the mental health system. At the same time, middle-aged parents may have multiple obligations to their other children and perhaps to their own aging parents. With time, burden diminishes as other life problems are resolved. Siblings graduate, pursue careers of their own, and may contribute financially. Caregivers' elderly parents die, and former obligations are dissolved. In the caregivers' old age, the adult child with mental illness may be a source of needed help and companionship (Greenberg et al. 1993).

These hypotheses were tested by exploring four possible types of statistical relationships between level of caregiving burden on the Thresholds Family Burden Scale and parental age. In addition to parents' age, the research included the effects of length of illness, functional level of the person with mental illness, and psychological strength of the parent. Demographic variables that had been found important in prior studies, such as patient's gender, parent's gender, educational level, and ethnicity, were used as control variables.

The sample consisted of 222 parents (mean age=55 years) of 134 offspring (72% sons and 28% daughters) with severe mental illness, predominantly schizophrenia. The ethnic distribution included 17% minority families. Patients had a mean age of 26 years and an average illness length of 6 years.

Measures of burden were derived from a factor analysis of the Thresholds Family Burden Scale. Items were separated into two pools, according to whether an item assessed emotional involvement (emotional and cognitive strain resulting from ongoing involvement with the ill child) or behavioral conflict related to caregiving responsibilities. Emotional involvement included connection (feelings of ongoing connection to the ill child and his or her needs), cognitive (mental preoccupation and constant worry about the offspring), and responsible (perceptions of ongoing and ultimate responsibility for the well-being of the adult child) factors. Analysis of the behavioral conflict items also identified three factors: behavior (the patient's behavior made the parents feel out of control and unable to manage the illness), disagree (caregivers' critical comments and indications of familial discord), and future (concerns about episodic recurrence of disability and what the future would hold for their offspring).

A test of the U-shaped and inverted U-shaped curvilinear hypotheses indicated that parents' age was not significant in these models. Linear analyses indicated significant correlations for parents' age and two of the outcome measures of burden. Older parents scored significantly higher on the responsible measure, and age fell just short of significance in predicting the cognitive factor. Contrary to Hypothesis 1 (that burden as a whole increases with age), however, younger parents scored significantly higher on behavior, indicating that they were more affected by control and management issues.

Cook et al. (1994) concluded that some aspects of caregiver burden are related to the developmental stage of the illness, regardless of the age of the parents. They recommended refresher courses in conflict management and problem-solving techniques over the course of the illness. However, other components of psychoeducational interventions for families might well be tailored to the age of the caregivers. They suggested that for younger parents, interventions would do well to target substance abuse and behavior management, problems characteristic of the young adult cohort of persons with mental illness. Psychoeducation for older parents not only should include updated information about the illness but also should address caregivers' anxieties and offer resource information and practical planning for the offspring's future.

Aging in Mental Illness and Other Disorders: Comparative Caregiving

Most of the life-cycle literature on caregiving either focuses on the discrete problems of Alzheimer's caregiving or else relates to persons with developmental disabilities. Although there are commonalities in the need to make future plans for offspring who will surely outlive them, parents of adults with developmental disabilities typically have had a different life experience. Since retardation appears in infancy, parents' adjustment to offspring dependency begins early in life. Mental illness, which typically is characterized by deterioration from a previous level of functioning, can involve more profound losses. For both caregivers and patients, there is often a long period of mourning for the premorbid personality. Loss of self-esteem, a problem in all disabilities, is undoubtedly more powerfully felt in formerly functional individuals, many with good intelligence and talents, who must adapt to lower life expectations. Objectively, mental illnesses may involve more household disturbances, impaired relations with neighbors and relatives, and greater use of the mental health system for inpatient, outpatient, and crisis emergency services.

In comparing the two groups of aging caregivers, research suggests that parents of persons with schizophrenia and other psychiatric disabilities experience more severe difficulties than do parents of adults with mental retardation. Family relationships are more conflicted, behaviors of offspring are more disruptive, and support systems are less available to parents of persons with mental illness. In one comparative study, older mothers of adults with mental illness reported higher subjective burden, poorer relationships with offspring, lower levels of psychological well-being, and more behavioral problems than did older mothers of adults with developmental disabilities (Greenberg et al. 1993). Another study indicated that aging mothers of adults with schizophrenia manifested significantly higher levels of distress and lower levels of well-being than did mothers of adults with developmental disabilities (Pruchno et al. 1996). Other research showed that mothers of adults with mental illness were more dependent on social support yet had significantly smaller support networks than did mothers of adults with developmental disabilities (Greenberg et al. 1997). Seltzer et al. (1997b) have suggested that stigma from mental health professionals has added to the burden of caregivers of persons with mental illness. Theories of family etiology and premorbid dysfunction have imposed both external censure and internalized guilt and have often led to poor relationships between families and service providers. These conditions have not been applicable to caregivers of offspring with mental retardation.

The differences in psychological well-being are compounded by caregivers' fears about who will take care of the disabled adult when they are gone. In a study of NAMI families conducted in various states, aging caregivers for the most part looked to their other children to assume their caregiving tasks (Hatfield and Lefley 2000). Yet they had doubts about those siblings' ability or motivation to serve as replacement caregivers. These doubts were revealed to be well founded in a study by Seltzer et al. (1997b) that compared the responses of siblings of adults with mental illness and siblings of adults with mental retardation. Reminiscing about the experience of living with a sibling with mental retardation tended to evoke positive feelings. Moreover, respondents' well-being in adulthood was predicted by their feelings of psychological intimacy with their developmentally disabled sibling. In contrast, the experience of living with a sibling with mental illness evoked negative feelings. Respondents' well-being in adulthood was predicted by feelings of psychological distance from the impaired sibling. These diametrically opposite responses suggest that parents of adults with schizophrenia are quite right to suspect that their other children may not be willing caregivers after they are gone.

Another comparative study by Seltzer et al. (1997a) indicated that in mental retardation, co-resident caregiving ceased when mothers became too old or ill to fulfill this role. In contrast, the end of co-residence in mental illness might occur abruptly when the adult child manifests higher levels of behavior problems and the level of stress becomes too great for the caregiver to manage.

Patterson et al. (1996) used a stress process approach to compare parental and spousal caregiving for older psychotic patients. Primary stressors for caregivers were level of psychiatric symptoms, patient problem behaviors, level of help needed for activities of daily living (ADLs), caregivers' sense of loss, and role captivity (i.e., the wish to be free from the caregiving role). Stress moderators were instrumental and emotional support from others, personal coping style, and self-concept. The investigators found that caregivers of older psychotic spouses reported significantly more role captivity and had to provide more help with ADLs than did caregivers of older psychotic offspring.

Patterson and associates noted that "Under the primary stressor domain, we learned that caregiving to older psychotic patients can create intrapsychic strains…a continuing sense of worry about the patient's future and his or her welfare" (Patterson et al. 1996, p. 781). They reported that 50% of their caregivers were 65 years or older and at a stage of life that involved the loss of social roles and an increase in health-related events and death of contemporaries. Caregivers themselves faced the frailties of age, a shrinking social network, a probable reduction in income, and the loss of many amenities.

Liebowitz and Light (1996) found that caregivers of psychiatric patients reported higher levels of stress and burden than did matched noncaregivers. Caregivers' reported symptoms included irritability, fatigue, elevated levels of anger, and headaches. They also reported feelings of guilt, hopelessness, loss of control, and inability to cope. Rates of clinical depression were significantly higher in caregivers than in control subjects. Thus, psychiatric morbidity is often a sequela of caregiving. Moreover, the stresses of caregiving may add to increased risk for the chronic illnesses and disabilities associated with aging itself. Liebowitz and Light (1996) reported that a series of well-designed studies indicates that the chronic stress of caregiving is associated with alterations in biophysiology. These authors focused on aging caregiving parents of older patients and aging children of mentally ill parents as being particularly at risk. They concluded that "the impact of caregiving stressors on these potentially more vulnerable populations can have [a] profound impact on their health, their ability to care for their relative, and the healthcare system in general" (Liebowitz and Light 1996, p. 790). Thus, caregiving itself is perceived as a sociomedical problem that requires social solutions. Exacerbating this situation are the worries of aging caregivers about what will happen to their loved one when they are gone and about their limited ability to plan for the future.

Studies of Aging Caregivers and Future Plans

Several studies have specifically focused on older caregivers' planning for the future care of their relatives with serious mental illness. Most of these studies were initiated by Agnes Hatfield, professor emerita at the University of Maryland and a former president of NAMI. As a family organization, NAMI provides a natural subject pool for studies of family caregivers, the majority of whom are mothers (Lefley 1987, 1996). For a survey of permanency planning by older caregivers, Dr. Hatfield was co-investigator with Smith et al. (2000) in research that recruited mothers 50 years and older who resided with a mentally ill adult child through announcements in local and national NAMI newsletters. The recruitment yielded 196 respondents from 41 states. Caregiver ages ranged from 50 to 88 years, with a mean age of 67 (±7.7) years. The offspring were primarily male (76%) and ages 20–58 years (mean=38 ±8.1 years). The majority of offspring were reported to be in good to excellent physical health, but only one-third were involved in outside activities such as day programs or supported or competitive employment. Half typically spent their days at home, relying on their mothers for cooking, cleaning, laundry, and other household chores.

The survey specifically examined the extent of residential and financial planning for future care, the desire of other family members to assume future caregiving responsibilities, and the perceived need for and use of the formal service system to aid in planning. Results indicated that nearly half of the mothers had devoted either no effort or very little effort to planning where their offspring would live in the future. Only 11% had made plans they regarded as definite. Those who had done some planning cited awareness of aging and mortality in themselves or a spouse as their chief reason. With respect to financial arrangements, however, 66% reported some planning, primarily through trusts (34%) or money willed to another relative on the offspring's behalf (24%). More than three-quarters of the respondents (76%) said that they would like one of their other children to assume the caregiving role when they were dead, but only 25% of this group felt that this would definitely happen.

More than two-thirds of the respondents perceived a need for formal services related to both residential and financial planning, but the reported use of such services was low. In an earlier study by Hatfield (1994), barriers to residential planning reported by aging parents of adults with mental illness included the unavailability of housing (68%) and the poor quality of existing housing (42%). Most parents reported that worry about their mentally ill offspring was the main barrier to planning for the future. Parents were also greatly concerned about safety, cost, and staff competence in the only resources available to replace their own caregiving.

A major obstacle, however, involved the patients themselves. More than 70% of the aging caregivers said that their mentally ill relative was fearful of leaving home or was too comfortable there to consider living elsewhere. Smith et al. (2000) noted that because of the uneven course of mental illness, many parents are unable to predict what services may be needed in the future and harbor hopes for their child's independence that may not be attainable. Yet another barrier comes from mental health professionals. Smith et al. (2000) reported that elderly parents face a double bind when they are encouraged by professionals to foster independence in their offspring and are seen as controlling if they refuse to "let go." Yet if parents urge separation and the child fails, they face anger and disappointment (and possibly decompensation). Hence they may avoid situations that might result in failure.

In a recent study exploring the most salient issues of caregiving for older persons with schizophrenia, four focus groups of elderly caregivers were convened to identify problems in planning for future care (Hatfield and Lefley 2000). The survey instrument derived from these discussions was specifically targeted toward caregivers 65 years and older. The questions focused on the degree of planning respondents had done and perceived obstacles to informed planning for the future. Fixed-choice items focused on possible barriers in 1) the caregivers' personal lives, 2) the attitudes or behaviors of the person with mental illness, and 3) limitations of the service system. The survey instrument was circulated through the state NAMI newsletters of Florida and Maryland, with a small number coming from interested caregivers in other states. Selection criteria required that respondents be a) 65 years or older and b) the major caregiver of a person with severe and persistent mental illness.

The findings are reported by Hatfield and Lefley (2000). Among the 210 usable responses returned, 90% of the caregivers were between 65 and 79 years of age. Ten percent were 80 years or older. The majority (79%) were mothers. Three-quarters of the relatives with mental illness were reported to have schizophrenia, with the remainder diagnosed with bipolar disorder. The age breakdown was as follows: 33% in their 30s, 56% in their 40s, and 10% 50 years or older. When caregivers were asked to indicate the degree to which plans had been made, 44% reported no planning at all, 38% reported partially completed plans, and 18% reported that planning was completed.

Among the primary obstacles to planning were caregivers' lack of knowledge about how to plan for the future (50%), patients' resistance to making changes (52%), and limited housing resources in the mental health system (48%). Among personal problems reported by the caregivers, 63% described intense anxiety about the future. The characteristics of the mentally ill relative were mentioned frequently as barriers to future planning. Although 43% of the caregivers perceived their relative to be unstable much of the time, almost an equal number (44%) reported that their relative refused to use available resources. Thus, the option of getting their relative into a program with case management and linked residential services seemed unlikely.

What emerged from the findings, in brief, was that even in the face of their own aging and prospective disability or death, family caregivers tended to delay making future plans. Moreover, they were more likely to attribute planning obstacles to themselves or their disabled relative than to the service system. Almost half were concerned about lack of appropriate housing, and about a third worried about poorly coordinated services, but in the main, caregivers' criticism of the mental health system was limited. Less than half had utilized the system's resources for planning, but of these, 67% had found them helpful.

Several conclusions were drawn from these data. First, service providers should be proactive in offering help to aging parents and their mentally ill offspring in planning for the future. Second, local agencies on aging should be enlisted to help deal with the caregiving needs of aging persons with mental illness. These offices have not usually considered this population to be within their domain. In offering help, service providers would do well to consider how to prepare aging persons with schizophrenia for the inevitable loss of their caregivers both through increasing physical disability and ultimate death (Lefley and Hatfield 1999).

Practical Planning for the Future

Planning for the future has both practical and therapeutic aspects and is oriented toward two target groups. The major target group consists of aging caregivers and patients, and their concerned relatives, who need to become aware of the issues and sophisticated about options. But the mental health system itself needs to expand its services. There is a need for professionals to prepare their older patients for separation and loss and for an assumption of new roles for independent living. Toward this end, professionals must also become familiar with the options available to their patients and know how to link patients to available resources.

The survey results of the NAMI studies have been used as a basis for practical planning and family training under the sponsorship of the Maryland Department of Health and Mental Hygiene and the University of Maryland Mental Health Services Training Collaborative. A current publication by Hatfield (no date) on planning for the future care of relatives with major mental illnesses contains sections on overcoming resistance to planning, resources available for needs assessment, selecting an advocate or guardian, and preparing the relative for eventual caregiver loss. Other sections cover the role of siblings in future care, meeting the personal needs of aging caregivers (e.g., health care and living arrangements), and creating trusts and wills. The NAMI survey data thus form the basis of training sessions, workshops, and conferences conducted on behalf of older patients and their caregivers, for both family members and professional audiences.

In an earlier article on these issues, Lefley and Hatfield (1999) described the Planned Lifetime Assistance Network (PLAN) programs that had been developed to help families of adult children with disabilities to plan for the future. Here I will update that older description. PLAN programs cover all disabilities. Essentially, they are privately endowed plans to ensure ongoing case management and financial security for mentally ill loved ones. The NAMI description is as follows:

> In the case of an adult child with a mental illness/brain disorder, a specific future-care plan is developed to delineate the activities and services the family wants to ensure for their loved one. A financial mechanism (most often a supplemental-needs trust, or third-party trust) is then created to pay for these activities and services after the family is no longer able to provide. Subsequently, a service provider and/or trustee is identified to guarantee that the plan is implemented. Thus, a contract is developed that secures that the best possible care from the mental health system and the government entitlement benefits is provided to the family member with mental illness, either in the community or a hospital. (Wolfe 2001, p. 1)

In June 2001, the National PLAN Alliance reported 23 member programs in 18 states for adults with mental illness or other lifelong disabilities. Information on state programs and print materials may be obtained by sending E-mail to npa@nycap.rr.com.

Summary and Conclusions

In this chapter a number of questions have been posed regarding what will happen when the relatives of aging persons with schizophrenia are no longer able to fulfill supportive roles. An empirical assessment of residential caregiving suggests that a large number of persons with long-term care needs live with their families, primarily with aging parents. This picture applies to the United States as well as elsewhere in the world. In most studies, the primary caregiver is the mother. Scientific samples of NAMI members, representing the nation's largest organization dedicated to persons with severe mental illness and their families, found a modal pattern of a maternal caregiver approaching 70 years and a son approaching 40 years of age (Skinner et al. 1992). By contrast, women who need long-term care are more likely to be married (Gottesman 1991) and to live with spousal caregivers or offspring (Patterson et al. 1996).

Other research on older maternal caregivers indicated that 75% looked to another family member, typically a sibling of the patient, to assume care after the mother's death, but only 25% believed that such arrangements would definitely occur (Smith et al. 2000). Even when middle-aged patients (45 years and older) living in the community looked to siblings for support, they were more likely to have a mother who was still living. Smith and colleagues concluded that mothers not only serve as important sources of support but also help maintain supportive networks for their adult children with schizophrenia (Beeler et al. 1999).

Despite cultural differences in co-residence and acceptance of the caregiving role, family burden is universally reported (Lefley and Johnson 2002). Yet research shows that specific elements of burden vary across the life cycle, suggesting that clinical interventions and psychoeducation should be tailored to meet specific needs (Cook et al. 1994). This clearly includes helping aging caregivers plan for the future of their loved ones by offering psychological support and resource information. Studies to date show that whereas aging caregivers report high anxiety about what will happen to their relative when they are gone, they demonstrate little capacity for contingency planning (Hatfield and Lefley 2000; Lefley and Hatfield 1999; Liebowitz and Light 1996; Smith et al. 2000).

Significant differences have been found between caregivers of aging adults with mental retardation and those of aging adults with mental illness. Aging caregivers of persons with schizophrenia show lower psychological well-being. Family relationships are more conflicted, behavioral disturbances of patients are more prevalent, subjective burden and depression are higher, and support systems are less available. Compared with parents of adults with schizophrenia, parents of aging adults with developmental disabilities clearly have less to worry about in terms of siblings taking over when they die (Greenberg et al. 1997; Seltzer et al. 1997a, 1997b).

How Can Mental Health Professionals Help?

A number of specific goals and strategies have been recommended to improve our understanding of the neurobiological and psychosocial factors of schizophrenia in later life as well as the health care and social service needs of this population. Among these, Palmer et al. (1999) called for better social supports and greater help for patients' caregivers.

Of what will this help consist? The previously cited research by Cook et al. (1994) suggests that specific models of family psychoeducation might be developed and targeted toward older caregivers. Older caregivers clearly could benefit from help with both the practical and the psychological aspects of planning for the future of dependent offspring who face the inevitable stressors of separation and loss.

Ways of helping both caregivers and patients deal with the critical psychological issues of anticipatory loss are discussed by Lefley and Hatfield (1999), and mental health professionals are generally trained to deal with these in treatment. However, many practitioners may need additional education to guide families toward the governmental and private resources available to ensure survival and a decent quality of life for older persons with schizophrenia. For anxious families, knowledge of these resources and their points of access will certainly be comforting. For aging caregivers, such resources may offer even more stress relief than the illness management techniques that typically comprise the core of psychoeducational interventions. Particularly helpful in this regard are the resources available from NAMI—that is, the information on PLAN programs in operation in various states. Information on replacement caregiving may also be acquired from area agencies on aging.

Many older persons with schizophrenia live in assisted-living facilities whose services may vary from a wealth of daily activities to no activities at all. Certainly licensing requirements may be amplified to require some level of enrichment of lives that otherwise might be spent in a passive or even vegetative state. Licensing of such facilities might also mandate a higher level of staff training that at present is too infrequently required. Residential staff could benefit from the same psychoeducation provided to familial caregivers about schizophrenia and other severe forms of mental illness as well as the special needs of older patients.

At the societal level, Bartels et al. (1999) have called for interdisciplinary collaborative planning among researchers, clinicians, government and industry representatives, and patient advocacy groups to meet the needs of older persons with severe and persistent mental illness. With inadequate human replacements for aging caregivers, there is a clear need to develop more community resources, both residential and programmatic, for aging persons with schizophrenia. People who have lived with family caregivers generally have not had treatment-refractory illness. But in earlier surveys of this population, Hatfield (1994) found that many people with severe mental illness had rejected or had been rejected by community rehabilitation programs because there was little goodness of fit between their needs and the programs' offerings. This will have to change. There may be increasing need for specialized senior centers where aging persons with mental illness will feel comfortable and welcomed. There will certainly be increasing need for residential services with staff specially trained to serve a geriatric clientele with mental illness. Planning bodies must begin to anticipate and act upon these specialized service needs.

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CHAPTER 15

Mental Health Policy and Financing of Services for Older Adults With Severe Mental Illness

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Approximately 2% of persons 65 years and older in the United States have severe mental illness (SMI), and the number of older adults with these disorders is expected to double in the next 30 years (Jeste et al. 1999). Individuals with SMI are overrepresented in long-term care settings and account for a disproportionate amount of expenditures for older persons seen in mental health outpatient clinics (Burns and Taube 1990; Cuffel et al. 1996). Despite the rapidly growing population of older adults with SMI and associated health care costs, alarmingly little attention has been directed toward services and health policy related to older persons with these disorders.

In this chapter we provide an overview of mental health policy and financing of services for older persons with SMI. First, we briefly present an overview of the need for services for older persons with SMI in the context of a shift from institution-based care to the community. Second, we discuss current fee-for-service mental health services and describe the role of Medicaid and Medicare financing. Third, we provide an overview of managed Medicaid and Medicare and consider whether mental health services should be "carved-in" or "carved-out." Fourth, we describe innovative models for organizing and financing long-term care and their implications for older persons with SMI. Finally, we identify priorities to be addressed by mental health policy to meet the future needs of the growing population of older adults with SMI.

Service Needs of Older Persons With Severe Mental Illness

Although this book focuses on older adults with schizophrenia, this chapter focuses more generally on the larger group of older adults with SMI. For the purpose of discussion, we define older adults with SMI as persons ages 65 years or older with schizophrenia, delusional disorder, bipolar disorder, or recurrent major depression associated with a high degree of functional impairment. Functional impairments, medical comorbidity, and associated cognitive impairment (Bartels et al. 1997a) are frequent characteristics of SMI in older adults.

These impairments require a comprehensive array of services. However, the current mental health service delivery system for older adults is fragmented, not fully utilized, and incapable of providing such long-term services. Mental health services for this population are delivered through a variety of providers; however, services tend to be poorly coordinated, resulting in gaps and overlaps. Overall, many older adults with SMI have limited access to mental health care in both community and institutional long-term care settings. Despite continued need for supportive services, most older adults with SMI who live in the community typically receive only medication support from the mental health system. In addition, individuals without an adequate support system are at greater risk for institutionalization (U.S. Department of Health and Human Services 1999). The inadequacy of the present service delivery system underscores the need to develop appropriate home- and community-based alternatives.

Deinstitutionalization and Service Reform for Older Persons With Severe Mental Illness

The past 40 years have ushered in a new era in the treatment of individuals with SMI. A major event in the transformation of mental health policy was the 1963 Community Mental Health Centers Act, aimed at decreasing the use of institution-based care in preference to services that promoted and supported community-based care. However, its consequences were different for many older persons with SMI than for the younger population. Elderly inpatients were among the last group to participate in the "deinstitutionalization" process associated with the closures and downsizing of the nation's state psychiatric hospitals. The population of state hospital patients older than age 65 years declined by 82% from 1972 to 1987 (American Psychiatric Association 1993) and further decreased by 33% from 1986 to 1990 (Atay et al. 1995). However, unlike younger persons discharged to community-based settings, many older persons were transferred or "transinstitutionalized" to nursing homes. Nursing homes are now the primary institutional setting for older persons with SMI. Among all institutionalized elderly persons with SMI, 89% reside in nursing homes, 8% are in state and county hospitals, and 3% are in Department of Veterans Affairs (VA) or other general hospitals (Burns 1991).

Several findings suggest that the role of institutions will continue to decline as community-based settings increase their capacity. First, despite the substantial population of older persons with SMI in nursing homes, most live in the community (Meeks et al. 1990). Second, federal nursing home reforms were enacted under the Omnibus Budget Reconciliation Act of 1987 (OBRA 1987) in response to the relatively sudden increase in the numbers of nursing home residents with SMI. Regulations were developed that required preadmission screening to identify and prevent potential admissions of persons with serious mental illness who did not otherwise meet nursing home criteria. Finally, as we discuss later, a variety of home- and community-based options have been developed in conjunction with approaches to financing mental health and long-term care services that may promote future alternatives to institution-based services. Home- and community-based settings are expected to grow dramatically as the health care system attempts to accommodate more people with chronic care needs (Institute for Health and Aging 1996).

The structure and financing of long-term care and managed care are changing rapidly. Most of these changes have focused on conventional medical populations that require long-term medical care and supports. Very little attention has been given to mental health services and associated costs for the increasing numbers of older adults with SMI. Although older persons with SMI represent the minority of older persons who seek treatment in community mental health settings, they account for the majority of expenditures. As illustrated in Figure 15–1, an analysis of expenditure data for 2,271 persons ages 60 years and older who were served in New Hampshire's mental health service delivery system showed that whereas

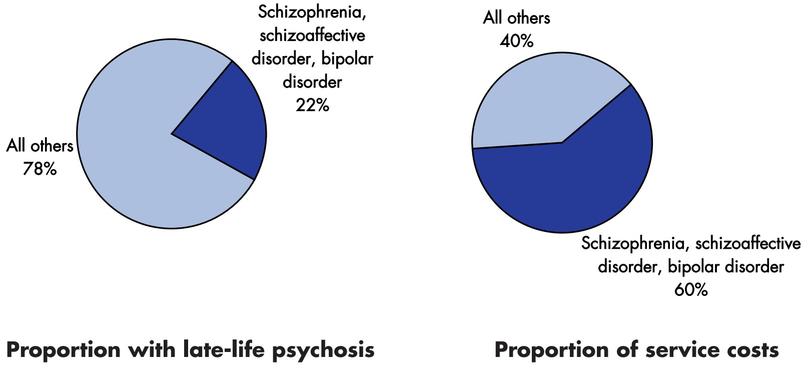

FIGURE 15–1. Public mental health service costs for severe mental illness in adults 60 years and older (schizophrenia, schizoaffective disorder, bipolar disorder) (N=2,271).

Source. Data from Bartels et al. 1995.

only 22% of those served had a diagnosis of schizophrenia, schizoaffective disorder, or bipolar disorders, this group accounted for 60% of all outpatient service expenditures (Bartels et al. 1995). As the population of individuals with SMI within public-sector mental health service programs ages, expenditures for high-cost services will escalate unless alternative models are developed.

Financing of Services for Older Persons With Severe Mental Illness: Fee-for-Service Medicare and Medicaid

Despite the well-documented impact of mental health problems on public health and health care costs, inferior reimbursement for mental health services remains a major impediment to treatment. Mental health and long-term care services for older persons are primarily financed through fee-for-service Medicare and Medicaid. Medicare is a federally funded health insurance program that provides insurance to persons older than 65 and disabled persons younger than 65 years. It consists of two parts: Part A provides reimbursement for inpatient hospital care, 60 days' coverage for skilled nursing home care, and home health and hospice care; Part B covers physician and outpatient hospital services. Medicare is the single largest payment source for beneficiary health care, covering approximately half of the cost of health care. During fiscal year 1999, Medicare spent approximately $212 billion on beneficiaries, of which 48% was for inpatient hospital services and 27% was for physician services (Health Care Financing Administration 2000a). Today, Medicare serves more than 39 million beneficiaries, or 1 in 7 Americans. As shown in Figure 15–2, over the coming 30 years, the number of Americans covered by Medicare will nearly double—to 77 million, representing 22% of the U.S. population (Health Care Financing Administration 2000a).

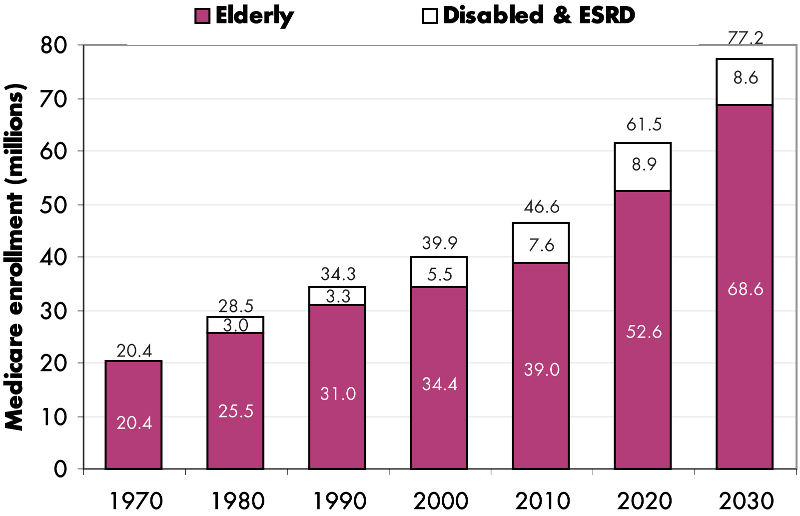

FIGURE 15–2. Number of Medicare beneficiaries: calendar years 1970–2030.

ESRD=end-stage renal disease.

Source. Data from Health Care Financing Administration 2000a.

Several major limitations exist in Medicare coverage of mental health services. Lack of mental health parity under Medicare results in a required 50% copayment for nonmedical psychiatric services, whereas medical treatments require only a 20% copayment. General outpatient prescription drug coverage is lacking, limits are placed on the number of inpatient psychiatric days, and essential services such as adult day care, respite care, residential care, and home health care have limited or no coverage (Administration on Aging 2001). In addition, although reimbursement is provided for home health care, only acute treatment of illness (rather than long-term care) is covered. Most beneficiaries receive home health care services for physical disabilities; mental disorders (including dementia) make up only 2.8% of primary diagnoses (National Association for Home Care 1996).

The availability of home health care for psychiatric disorders has recently been reduced as a result of Medicare reform under the Balanced Budget Act of 1997. Following enactment of these reforms, 14% (*n*=1,355) of U.S. home health care agencies closed in 1998 (National Association for Home Care 1999). Overall, less than 3% of the total Medicare budget is spent on mental health. Less than half of these expenditures (approximately 1.5%) is directed toward mental health services for older adults, and the vast majority is spent on acute hospitalizations.

In contrast, Medicaid provides health insurance coverage for low-income families with children and for people with disabilities, provides long-term care for older adults and for disabled individuals, and provides supplemental coverage for low-income Medicare beneficiaries. Medicaid is the primary insurer for long-term care in nursing homes and is the major source of reimbursement for state-funded services for the disabled, including individuals with SMI. In 1998, only 11% of Medicaid beneficiaries were older than 65 years, yet 31% of total Medicaid expenditures were spent on this population (Health Care Financing Administration 2000b). These increased expenditures were primarily associated with the use of high-cost services, such as long-term care. Medicaid's role as the primary insurer for long-term care has grown significantly. In 1968, Medicaid payments covered one-fourth of nursing home expenses. Thirty years later (1998), Medicaid funded almost half (46%) of nursing home care ($40.6 billion). As shown in Figure 15–3, although elderly, blind, and disabled individuals comprised only one-quarter (26%) of Medicaid recipients, they received the clear majority (71%) of payments (Health Care Financing Administration 2000b).

Medicaid is funded by both federal and state resources. States generally contribute up to 50% of the cost and thus retain discretion in determining eligibility criteria and in designating which mental health services will be reimbursed. For instance, many states provide coverage of prescription drugs; however, most have limitations affecting copayments and the number of refills allowed. States may also impose limitations on mental health care by requiring prior authorization for services and restricting the number of visits to providers. In addition, Medicaid reimburses service providers at rates averaging 20%–30% below standard market rates (Mace and Emerson Lombardo 1992). By limiting the services covered and reimbursing psychiatric care at lower rates than medical care, Medicaid funding creates barriers to providing appropriate mental health treatment for older adults.

In summary, coverage of mental health care for older adults is incomplete because of limitations in Medicare coverage and differences between federal and state governments in the costs of Medicaid. These gaps in

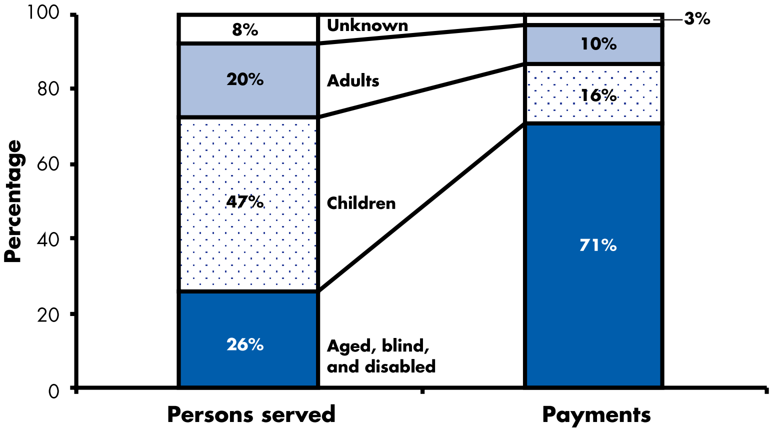

FIGURE 15–3. Distribution of persons served through Medicaid and payments by basis of eligibility: fiscal year 1998.
Source. Data from Health Care Financing Administration 2000b.

coverage lead to increased fragmentation of services and significant out-of-pocket costs. In addition, demographic trends and the rising costs associated with health care will result in dramatic increases in Medicare and Medicaid expenditures over the coming decades. Medicare and Medicaid expenditures consumed 20% of the 2001 $1.9 trillion federal budget and are predicted to increase to 29% of the $2.7 trillion budget by 2011 (Congressional Budget Office 2001). The combination of incomplete coverage and service and escalating costs under a fee-for-service reimbursement structure has resulted in an explosion of managed care initiatives and cost-containment strategies.

Managed Care

Health policy issues have been debated with respect to managed mental health care in general as well as the future challenges of providing mental health services to an aging population. However, successful implementation of managed care models and the delivery of mental health services to older adults with SMI have been relatively unexplored. If managed care is to meet the intensive long-term mental health needs of older persons with SMI, innovative approaches to organizing and financing services will be required.

Escalating Medicare expenditures and efforts to contain cost have resulted in increased use of managed Medicare plans by older persons. The managed care industry promotes integrated services for people with long-term needs; however, the industry's awareness of and response to chronic care needs are still in a formative stage (Institute for Health and Aging 1996). Health maintenance organizations (HMOs) have the potential to provide comprehensive and evidence-based preventive, acute, and chronic care services, but to date, all-inclusive care has been limited.

Nonetheless, several factors suggest that it is unlikely that conventional HMOs will be capable of comprehensively addressing the needs of older persons with SMI. First, specialized geriatric programs and clinical case management for older persons in HMOs are often insufficient and inadequate (Administration on Aging 2001). Second, primary care settings (including primary care HMOs) historically have been characterized by inadequate pharmacological management and minimal use of specialty providers (Bartels et al. 1997b). HMOs are unlikely to use the spectrum of community support, residential, and rehabilitative services that older persons with severe mental disorders require (Administration on Aging 2001). This trend is likely to continue until data on effective interventions and adequate methods are available to adjust for the financial risks of providing comprehensive long-term services to older persons with SMI. Third, recent changes in Medicare financing under the Balanced Budget Act of 1997 have resulted in withdrawal of insurers from the Medicare HMO market in regions of the country (especially rural areas) where reimbursement rates tend to be low. Despite initial growth in Medicare managed care plans in the early 1990s, the past few years have witnessed substantial withdrawal of managed care plans from the market, with an associated reduction of 2.2 million managed care beneficiaries (Berenson 2001). Finally, no consensus exists on optimal organization and financing of mental health services under managed care. These factors contribute to inadequate HMO coverage for individuals with severe mental disorders, suggesting that managed Medicare is ill equipped to meet the long-term care needs of older persons with SMI and is unlikely to be a major source of financing for health care.

Carved-In or Carved-Out Mental Health Care?

A variety of mental health care models have attempted to manage the financial risk of delivering mental health services in managed care. These models can be broadly grouped into two general categories. The "carved in" approach directly integrates mental health services into the package of general health care services. The "carved out" approach provides mental health services through a contract with a separate specialty mental health organization that accepts the financial risk. The financial and clinical features of these models and the traditional fee-for-service model are outlined in Table 15–1.

TABLE 15–1. Summary of features of fee-for-service, managed care carved-in, and managed care carved-out models with respect to mental health services for older persons with severe mental illness

Financing	**Fee-for-service model**	**Carved-in mental health model**	**Carved-out mental health model**
Features	Reimbursement based on services provided or diagnosis Fee-for-service Medicare requires a 50% copay for psychotherapy and a 20% copay for medical management No coverage provided for medications Primarily acute care coverage Fee-for-service Medicaid includes coverage of long-term care, medications, and services for disabled and indigent persons Services covered vary by state	Fixed total rate for medical and mental health care, combined in an overall rate per patient Services usually provided by the managed care organization, including general health and mental health care Coverage for medications often included Long-term care generally not covered unless managed long-term care such as the Program for All-Inclusive Care of the Elderly or a social health maintenance organization	Fixed per-person rate for mental health care Mental health services provided by one or more contracted mental health specialty provider organizations (which is usually different from the general health care provider) Coverage for medications often included Long-term care generally not covered

TABLE 15–1. Summary of features of fee-for-service, managed care carved-in, and managed care carved-out models with respect to mental health services for older persons with severe mental illness *(continued)*

Financing	**Fee-for-service model**	**Carved-in mental health model**	**Carved-out mental health model**
Potential advantages	Greater consumer choice, including option to seek specialty mental health services such as community support services and outreach, rehabilitation, and multidisciplinary geropsychiatric services Reimbursement based on services provided and billed Greater provider autonomy	Less fragmentation of services More potential for integrated medical and mental health care Enhanced capacity to treat comorbid medical and mental health problems Incentive to achieve medical cost savings through effective use of mental health services Cost containment, focus on providing cost-effective general health care	Services provided by a specialty mental health carve-out organization May include specialty mental health services such as community support services and outreach, rehabilitation, and multidisciplinary geropsychiatric services Incentive to achieve psychiatric inpatient savings through effective outpatient mental health treatment Cost containment, focus on providing cost-effective mental health services

Note. Descriptions of fee-for-service, carved-in, and carved-out models are general and idealized and do not account for significant variation among individual plans and providers or for intermediate or blended models.

Source. Adapted from Bartels SJ, Levine KJ, Shea D: "Community-Based Long-Term Care for Older Persons With Severe and Persistent Mental Illness in an Era of Managed Care." *Psychiatric Services* 50:1189–1197, 1999. Copyright 1999, American Psychiatric Association. Used with permission.

Carved-In Mental Health Services

Carved-in mental health services ideally provide more integrated physical and mental health care, decrease stigma associated with mental health care, and produce cost offsets and savings in health care expenditures (Mechanic 1997). The importance of these features is heightened in older adults because of 1) their tendency to have comorbid medical disorders and to use multiple medications that may affect mental status, 2) their characteristic avoidance of specialty mental health settings, 3) and their likelihood of incurring significant health care expenses in association with their psychiatric symptoms (Riley et al. 1997). Carved-in arrangements are designed to enhance collaboration and communication between medical and psychiatric providers by avoiding the arbitrary distinctions between medical and psychiatric origins of symptoms and functional problems. Carved-in services may be especially relevant in this population, given that most older persons who receive mental health care are treated by their primary care physicians.

Several important caveats limit the potential benefits associated with mental health carve-in arrangements for older persons with SMI. In comparison with medical and surgical specialty services, mental health specialty services are typically a low priority for managed health care organizations (Bartels et al. 1997b). Furthermore, the limited range of services provided in carved-in mental health care are likely to be inadequate for older patients with SMI, who require long-term, intensive mental health care (Mechanic 1997). Moreover, general health care providers may be inadequately prepared to provide the range of outreach, rehabilitative, residential, and intensive services needed. Finally, although carved-in arrangements have the potential to provide financial incentives for integrated medical and mental health services, integration is far from guaranteed.

The economics of providing carved-in mental health arrangements may also be problematic. Without mandated parity, different insurers can offer different coverage for mental health care (Shea 2002). Also, providers' or payers' competition for enrollees creates an incentive to avoid those expected to have higher costs from mental health problems, such as older persons with SMI. Finally, it is difficult to develop methods of adjusting payments to compensate for the increased financial risk of providing care to more severely mentally ill enrollees under a capitated payment (Bartels et al. 1999).

Carved-Out Mental Health Services

Carved-out mental health services separate the treatment of mental and physical health problems. Mental health carve-out organizations have the potential to provide superior services to individuals with SMI as a result of specializing in providing comprehensive rehabilitative and community support mental health services. Carve-out organizations provide mental health services for a given population at a set fee. Such organizations offer a diverse set of services; care delivery by mental health providers who have technical knowledge, specialized skills, and experience in treating individuals with severe mental disorders; and a willingness and commitment to serve high-risk populations (Riley et al. 1997). In addition, incentives exist to reinvest savings from decreased inpatient service utilization into innovative outpatient alternatives.

Carve-out arrangements have their own set of clinical and financial limitations. The SMI population is at increased risk for adverse outcomes from fragmented delivery of medical and mental health care services. This risk is pronounced in older persons, who often take multiple medications and have complex medical comorbidities. Lack of communication and collaboration between mental and medical health providers increases the older adult's risk for inaccurate assumptions by providers about medical versus psychiatric causes of symptoms, misdiagnosis, and medication interactions. Such lack of communication also makes it difficult for providers to determine responsibility for providing appropriate community-based services. In addition, increasing pressure to contain costs may reduce the amount of financing available for mental health services. Because of segregated sources of funding, financial incentives exist for medical and mental health providers to shift responsibility for treatment of comorbid conditions. Inadequate care and shifting of the cost burden may result from inaccurate attribution of the cause of a complex medical–psychiatric problem. Misattribution of responsibility and fragmentation of reimbursement sources complicates mental health benefits or cost–savings demonstrations. Finally, without appropriate management of the services and costs associated with medical and mental comorbidity, savings expected to accrue from the carve-out arrangement may fail to materialize.

Innovative Models of Long-Term Care

Home- and community-based alternatives to institutional care have been developed in response to consumer preferences and the need to limit growth in expenditures on nursing home care. These alternatives fostered a 13% decline in the numbers of nursing home residents over the age of 85 between 1985 and 1997 (Health Care Financing Administration 2000a). Conventional home care is largely supported through a combination of fee-for-service and out-of-pocket payments, whereas most assisted-living options are purchased out of pocket.

Innovations in the organization and financing of long-term care include social health maintenance organizations (SHMOs), the Program for All-Inclusive Care of the Elderly (PACE), and state-managed long-term care demonstrations. SHMOs were introduced as a long-term care demonstration project in the mid-1980s. SHMOs are designed to integrate acute and long-term care within a managed care framework and to provide benefits under a single organization based on a prepaid capitation payment pooled from Medicare, Medicaid, member premiums, and copayments. In contrast, PACE accepts individuals eligible for nursing home care and assumes full risk under capitation for all long-term care services (Health Care Financing Administration 2000b). PACE delivers comprehensive medical and social services that are funded by integrating Medicare and Medicaid sources. The goal of PACE is to provide a service package that allows participants to continue to live at home and receive services, rather than being forced to enter an institution. Services are provided on an as-needed basis and are not limited to those that are reimbursed under traditional Medicare and Medicaid fee-for-service systems. The PACE program provides care for chronic conditions without limiting long-term care expenditures, provides routine annual health screening and preventive care, and provides services in a free-standing adult day health center. There are currently 26 approved demonstration sites located in 14 states (Health Care Financing Administration 2000b). Although these model programs have the potential to improve long-term care for older adults with SMI, mental health services are optional or excluded.

Other federal funding and programmatic initiatives that offer alternatives to conventional Medicaid fee-for-service include Medicaid waiver programs (Health Care Financing Administration 2000b). The two primary mechanisms used to test new benefit and service-delivery models are 1) Section 1915(b) "Freedom of Choice" waivers and 2) Section 1115 Research and Demonstration Projects. Section 1915(b) waivers can be used to require enrollment in managed care programs or to create special programs such as Medicaid behavioral health carve-outs. Section 1115 Research and Demonstration Projects provide the opportunity for states to test an array of programs. Small pilot projects can test new methods of providing benefits or of structuring financing, and larger projects can attempt to restructure state Medicaid programs. Finally, the Section 1915(c) Medicaid Home and Community-Based Services Waiver Program allows states to develop alternatives to institutional care. States can design a waiver program that incorporates components of social, supportive, and nonmedical services to provide long-term care in the community and to deliver services to older persons, disabled persons, and persons with SMI who would otherwise be institutionalized. By 1999, 240 Section 1915(c) waiver programs were in place, distributed throughout nearly every (49 of 50) state. Community-based long-term care (including SHMOs, PACE, and waiver programs) increased from 14% to 25% of total long-term care expenditures between 1991 and 1998 (Health Care Financing Administration 2000b).

These waiver programs have allowed for development of a variety of innovative, state-initiated, managed long-term care demonstration programs. These include recent initiatives for persons who are dually eligible for Medicaid and Medicare, persons who are among the highest users of acute and long-term health services, and older persons with SMI. Multistate proposals to combine Medicaid and Medicare resources under a capitated plan are currently being developed. These programs would offer comprehensive community-based and acute and long-term institution-based health services (Riley et al. 1997). Comprehensive medical and mental health long-term care would be provided through public insurance to individuals with high rates of chronic mental and medical disorders. However, mental health care is not a core component or provider of services in most proposals.

Priorities for Mental Health Policy

The welfare of older adults with SMI is uncertain during these times of shifting financial and programmatic settings. The older SMI population often has high functional, medical, and cognitive impairment as well as reduced quality of life and increased use of general health care. Innovative health service models are required to meet the complex needs of this population. The majority of current practices are organized through fee-for-service providers or through Medicaid and Medicare managed care. However, these systems tend to underserve older adults with mental illness, and optimal models for organizing and financing comprehensive services have yet to be developed. The principles discussed in this section suggest several specific directions for future models of mental health long-term care.

Integration of Mental Health and Medical Services

The importance of providing coordinated mental and medical care is heightened in older persons with SMI. Medical comorbidity is present in most older persons with SMI and is associated with worse health status, more severe psychiatric symptoms, increased morbidity, and increased mortality (Vieweg et al. 1995). Psychiatric outpatients are at high risk for undetected medical illness, with one-third of nonpsychiatrists and one-half of psychiatrists failing to detect the medical illnesses of clients referred to outpatient clinics by physicians (Koranyi 1979). Compared with older persons without SMI, older persons with schizophrenia have more severe medical disorders, and their physical comorbidities are often compounded by poor general medical care (Druss et al. 2000). Poor health practices, problem behaviors, and difficulty with treatment adherence further contribute to poor health outcomes and the need for active coordination of medical and psychiatric services (Vieweg et al. 1995). Services are needed that successfully integrate mental health and medical care.

Optimal services for older persons with SMI require close collaboration between primary medical care and mental health services. However, most current models do not provide the array of services necessary for individuals with SMI (Mechanic 1997). Models of integrated care ideally provide collaborative care through collocation of medical and mental health providers and multidisciplinary medical–psychiatric treatment teams or cross-trained medical–psychiatric providers. Collaborative care models that span medical and mental health care provide an important means of ensuring a more comprehensive system of health care. Successful models of integrated care include a specialized primary care medical clinic for patients with SMI and a primary health care provider as an integral part of a specialty mental health outreach team for older adults with SMI (Bartels et al. 1999).

Home- and Community-Based Models of Long-Term Care for Older Persons With Severe Mental Illness

PACE, SHMOs, assisted-living facilities, and community-based long-term care waiver programs constitute promising community-based alternatives to institutional care. However, these approaches generally offer limited access to mental health long-term care services for persons with SMI. To integrate mental health services into these programs, partnerships with specialized geropsychiatric and community support services will be necessary. Although empirical data are lacking, specific elements of these models have been associated with reports of successful community-based services for older persons with SMI. Components of optimal community-based services for older persons with SMI include intensive case management, integrated health care, crisis intervention services, residential support, caregiver training, multidisciplinary teams, and psychosocial rehabilitation (Bartels et al. 1999).

Rehabilitation Services for Older Adults With Severe Mental Illness

To date, there has been a strong custodial and institutional bias with respect to the financing and provision of services for older persons with SMI. Traditionally, state mental health systems emphasized long-term hospital-based care for older persons. Deinstitutionalization over the past 30 years has resulted in the development of community-based support and rehabilitative services for younger persons with SMI. However, older persons have generally been overlooked in state plans and programming of services for SMI. In general, intensive services for older persons predominantly shifted from hospital-based to nursing home care. Community-based treatment has been relatively underdeveloped and largely restricted to maintenance services. Despite the need, there is little support for services that seek to enhance the ability of older persons with SMI to live independently, to maintain social networks, and to engage in activities that improve independent functioning in the community. In contrast, rehabilitation services, including skills training, have been promoted and successfully supported for younger persons with SMI (Kopelowicz and Liberman 1998).

Rehabilitation treatment focused on enhancing independent functioning in the community can comprise a variety of approaches, including specific and targeted skills training as well as involvement in meaningful rehabilitative activities in the community. Numerous reports attest to the effectiveness of skills training in improving social functioning in young adults with SMI (Kopelowicz and Liberman 1998). Rehabilitation services that enhance the ability of individuals to develop the skills to remain in the community have been advocated as a core component of community-based programs for older persons with SMI. Anecdotal reports of psychosocial rehabilitation programs for older adults with SMI suggest that these programs reduce the need for institution-based care. Skills training and cognitive-behavioral therapy may hold promise in enhancing functioning and improving symptoms in older persons with schizophrenia (Granholm et al. 2002).

In addition to skills training, substantial success has been reported with vocational rehabilitation as an approach to enhancing independent functioning in younger persons with SMI. Evidence now documents the economic, clinical, and subjective benefits of employment for younger persons with SMI (Bond et al. 2001). Remaining active in meaningful activities, including paid or volunteer work, is commonly cited by older adults as an important element of successful aging. Despite their success in younger adults with SMI, vocational rehabilitation and support services are not promoted or provided for older persons with SMI. The reasons for the low level of participation of older persons with SMI in rehabilitation services are unclear, but the possibility of age discrimination (or bias) cannot be ruled out—for example, the belief that older individuals cannot learn new skills. These controversies over rehabilitation services seem to reflect the discrimination faced by older persons in general. Older clients with SMI appear to face a double stigma based on both their age and their psychiatric condition.

Innovative Approaches to Financing Services for Older Adults With Severe Mental Illness

Financing mental health services is one of the greatest challenges of providing appropriate care to the growing numbers of aging persons with SMI. Mental illness represents one of the most expensive public health problems confronting the nation—one that affects both government budgets and consumer spending. Current and projected economic costs of mental disorders are staggering and will have a profound impact on direct and indirect costs for health care. In this section we discuss the benefits and drawbacks of the financing models currently available. Medicare represents a critically important source of federal health insurance for older Americans. However, it requires substantial cost sharing for many services, reimburses only 50% of mental health care costs, provides limited coverage for community-based services and inpatient specialty care, and does not cover prescription drugs (Administration on Aging 2001). By contrast, Medicaid is a joint federal and state program that provides the principal funding for long-term care. Within federal guidelines, each state determines the amount and duration of services offered under its Medicaid program. Medicaid coverage is limited because states have the discretion to provide minimal and uneven optional benefits. In addition, both Medicare and Medicaid reimbursement policies are often lower than those of other third-party insurers (Administration on Aging 2001).

Although Medicaid and Medicare provide services to the majority of older adults, their continued financing is indefinite. The Medicare trust fund is expected to be solvent through the year 2025 (Health Care Financing Administration 2000a), and current projections for Medicaid predict substantially increased expenditures in the coming decades. Innovative and efficient use of financial resources is necessary to redeploy funds from current costly institution-based care to supported community alternatives. A pooled resource fund coordinated by financial case managers may meet the demands of fee-for-service funding of medical and mental health long-term care. Alternatively, the most ambitious models of organizing and financing services for this vulnerable population incorporate integrated services under a single system responsible for both acute and long-term care. Funding sources are blended to create systems of acute and long-term care in the PACE and SHMO models, as well as under state initiatives for older persons that are "dually eligible" for Medicare and Medicaid. Additional financial options include funding aging services under federal and state block grant programs, as well as private insurance. All of these financial resources could be combined in efforts to support the least restrictive and least costly long-term care services.

Conclusions

Older persons with SMI represent the most complex, vulnerable, resource-poor, and high-risk mental health consumers. The downsizing and closure of state hospitals that began in the early 1960s ushered in a shift from institution-based care to treatment in the community. This change in mental health services for older persons with SMI presents unique challenges and opportunities. The method of financing services can facilitate or impede changes in the organization and delivery of care. Fee-for-service Medicaid and Medicare vary in regard to the breadth and types of services covered. Although they recently have been associated with rapidly escalating health care costs, such fee-for-service arrangements allow for considerable consumer choice in services and provider autonomy. In contrast, managed Medicaid and Medicare plans are designed to slow growth in expenditures and to support comprehensive preventive and maintenance health services. However, consumer and provider choices and options are more limited under managed care, and controversy exists as to whether mental health services should be carved-in or carved-out. More recently, innovative approaches to organizing and financing long-term care have been proposed with substantial implications for older persons with SMI. Priorities for future development of mental health policy include integration of psychiatric and medical care services; structuring of home- and community-based alternatives to institutional long-term care; development of rehabilitation services; and cultivation of innovative approaches to financing services for older adults with SMI.

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PART V

Future Directions

C•H•A•P•T•E•R 16

Toward the Development of Theory and Research in Aging and Schizophrenia

Carl I. Cohen, M.D.

In this chapter I examine several broad areas that are critical for the development of research on schizophrenia into later life: 1) the current state of theoretical models and the benefits and feasibility of developing a comprehensive model that seriously considers biological, psychological, and social dimensions; 2) the various methodological problems of conducting research, including the relative merit of qualitative versus quantitative methods, the dangers of prematurely circumscribing variables or of using instruments that are inadequate for the object under study, the sociohistorical and value assumptions of research, the potential utility of nonlinear methods, the critical need to carefully consider the implications of so-called significant findings, and the value of establishing partnerships between researcher and participants; and 3) the practicality of adapting extant gerontological models for research with older schizophrenic populations.

Why is There a Need for Theoretical Models?

Over the past two decades, there has been a lack of interest in comprehensive theoretical models of psychiatric illness and outcome (Orford 1992). This waning of interest followed in part from disenchantment with general models such as psychoanalysis and Skinnerian behaviorism. Some of it reflected sociopolitical changes that were driven by curtailment in economic resources as well as an accompanying ideology that was less interested in addressing social forces that affect mental distress (Cohen 1997). A third factor has been embodied in a zeitgeist—influenced by the postmodern perspective—that calls into question grand theories, especially those that minimized the historical and contextual biases inherent in the theories (Holzman and Morss 2000). Consequently, there has been a nihilism with respect to broad, comprehensive theories, and most extant models are vague and insufficiently operationalized (e.g., the neurodevelopmental model of schizophrenia) or are narrowly circumscribed (e.g., the dopamine hypothesis in schizophrenia). For the most part, most therapeutic strategies in psychiatry operate nearly independently of any theoretical model. Thus, antipsychotic agents probably have been more influential in contouring theory (e.g., the role of dopamine or serotonin in schizophrenia) than theory has been in driving the development of these agents. Moreover, there is little hope that antipsychotic agents per se will be sufficient to alleviate all of the dysfunctions that accompany schizophrenia. Similarly, psychosocial interventions such as Assertive Community Training teams, case managers, supportive housing, and social skills training have been used successfully to address various aspects of schizophrenia syndrome. However, none of these approaches has been driven by broad, substantive theoretical models.

There are some compelling reasons for a renaissance in more comprehensive theoretical models in psychiatry, especially in schizophrenia. First, such models provide for some uniformity in the field, with respect to testing aspects of the model as well as the variables to investigate. Currently, features of schizophrenia are tested in isolation, with little recognition of other potential covariates. Moreover, this absence of a theoretical discipline often leads to lack of uniformity both in the definitions of critical variables and in the measures used to assess these variables.

The absence of modern models also leads to clustering of research activities so that genetic researchers have little sense of social research, and when one discipline makes efforts to include the other’s measures, there is a tendency to use rudimentary and unsophisticated instruments. Thus, for example, heritability studies typically do not measure social variables at all, and they assume that any variance not explained by heredity is due to social effects (Cohen 2000). Unfortunately, this assumption that biological and social variables are additive belies the fact that there are surely interactive effects between variables. For example, the failure to examine the interactions of race, IQ, and socioeconomic status is a classic illustration of the dangers of this methodology (Levins and Lewontin 1985). Moreover, genes express themselves differently in different environments (Lewontin 2000). For instance, heredity plays a much stronger role in determining the mean height of the population in the United States, whereas in Bangladesh, environmental factors are more prominent.

From a clinical standpoint, theoretical models can provide a topographical map for points of therapeutic interventions. A comprehensive model allows one to at least consider the impact of biological and psychosocial interventions in a systematic way, as well as to speculate on how interventions at one point may influence outcome at another.

Finally, a comprehensive model may provide a framework for public policy and advocacy. Importantly, it may facilitate alliances among professionals who may have viewed themselves as being in opposing camps. For example, a model that systematically encompasses biological and social spheres would perforce provide a vehicle for alliances among disparate groups. Such alliances have the potential to be forged into powerful advocacy groups and to overcome interdisciplinary feuds and competition.

Despite the advantages of developing a comprehensive model for schizophrenia, there are a variety of impediments to attaining this goal. The most compelling difficulty is whether it is feasible to bring together different levels of organization into a single model. In other words, any comprehensive model of schizophrenia would have to include three spheres of analysis: biological, psychological, and social. These spheres are not reducible to one another (Cohen 1993). For example, social networks cannot be reduced to physiological processes. The distinct nature of these domains is potentially helpful for modeling, because it suggests that there would be less overlapping and that the variables would exert independent effects. However, the fact that each of these domains cannot be reduced to any other does not mean that they are independent of each other. To begin with a concrete illustration: the molecules that form my desk are not distinct from its wood surface. Similarly, in schizophrenia, a delusional statement such as “someone is monitoring me” simultaneously involves physiological processes (electrophysiological and neurochemical), motor processes (use of tongue, larynx, lungs), and thoughts (mental states). That is, the same event occurs at different levels of organization.

Therefore, can theory really integrate different levels of organization? The answer is probably yes, although the psychological realm likely poses the most problems for integration. This is the case because conceptual entities of the psychological level consist of aspects of the biological and social spheres. For example, "anxiety," which is usually categorized within the psychological sphere, contains physiological elements as well as social elements involving its historical and cultural conceptualization and expression. Hence, there are potential difficulties in trying to integrate elements of the biological and psychological levels or the social and the psychological levels. Moreover, we do not adequately understand how biological and psychological mechanisms interact or how the psychological and social mechanisms interact. We have no sense of their temporal interrelationships, and indeed they may sometimes represent aspects of the same event. On the other hand, whereas some components of the social world are biological (e.g., the social world is composed of biological beings), most social phenomena are a step removed from the biological level. Thus, at this point in time, it is more feasible to develop models that integrate biological and social elements. Later in this chapter I discuss methods for beginning to develop such models.

A related issue is whether it is possible to create a viable model that can capture the diverse array of variables from the biological, psychological, and social domains. In creating circumscribed variables, one must abstract them from their larger contexts. This is essential for conducting quantitative analyses. However, what variables we choose to circumscribe and the methods by which we choose to do it must invariably reflect social and historical factors (Pfister and Schros 1997). Although it is typically assumed that there exist distinct, objective entities that correspond to the various categories of the mind, these categories have always depended on the use to which they were put in specific social contexts (Danziger 1997). Thus, cognition, memory, perception, emotion, and anxiety vary from one culture or historical period to another (Gergen 1991, 1994). For example, Kagan and Snidman (1999) noted that the way we conceptualize anxiety today is very different from how it was viewed in ancient Athens, Rome, and Alexandria. Civilizations of antiquity regarded chronic anxiety in a more favorable light because it facilitated adaptation to societies based on conformity and local values.

More problematic is that key elements that should be included in a comprehensive model may represent aspects of social context, cultural phenomena, or subjective meanings and feelings. Can such factors be adequately captured by circumscribed variables, and if not, how do we allow for qualitative factors in our modeling? In a general, roughhewn form, it may be possible to circumscribe some qualitative phenomena within quantitative models. Thus, for example, one can use birth cohorts. Researchers (Weissman et al. 1991) have found that persons born in the 1920s (one historical context) are less likely to develop clinical depression than are those born after World War II (another historical context). Ultimately, through painstaking research, we may be able to pinpoint specific factors within these historical contexts or among these cohorts that account for the differences in depression.

Issues Regarding Methodology

In this section I address issues pertaining to qualitative and quantitative methods. First, as I suggested earlier, qualitative methods may have utility in contexts where quantitative measurement may not be available or even feasible. Such methods are useful for examining variables that cannot be easily circumscribed, such as complex clinical phenomena, interactive variables, and dynamic phenomena. Brier (1988) cited several examples of schizophrenia research in which qualitative, small-scale studies have been useful:

- In examining nonlinearity of the course of the illness. Brier cited work by Strauss et al. (1985) in which they found that schizophrenic illness fluctuates from month to month and involves several broader phases: "moratorium" or stable periods; "change points" characterized by significant shifts in function or symptoms; and "ceilings," which denote the highest level of functioning reached in any time period.
- In assaying personal resources, such as judgment, resiliency, commitment to improved functioning, desire for independence, and capacity to regulate psychotic symptoms.
- In studying evolving aspects of social relations, which includes a "convalescent" phase in which persons are more dependent on others and a "rebuilding" phase in which they become more self-resourceful and autonomous. Strauss (2000) noted that the narrative form "may be the only form available to describe the complexities, meaning, and depth of human experience. It could be argued, in fact, that to synthesize the various domains of psychiatry, narrative may need to be included as a crucial component of our science" (p. 20).

With respect to quantitative studies, as I have alluded to above, reduction of complex phenomena to simpler, unidimensional variables is fraught with potential risks. One risk is that a variable will be quantified prematurely and that aspects of the phenomena under study will be omitted

(Strauss and Hafez 1981). Moreover, there is often a predisposition to dichotomize phenomena, especially when scales are not well developed or are impractical (Gould 1998). Such dichotomizing is further encouraged by statistical analyses that lend themselves to dichotomous variables (e.g., dummy variables, logistic regression). Unfortunately, the real world is not so neatly divided, and even standard categories such as male–female ignore the biological and psychosocial variations in gender.

A second problem is that the instruments used to measure phenomena may not be appropriate for the object under study. Researchers are under pressure to quantify phenomena (Strauss and Hafez 1981). However, instruments may not be adequately validated; for example, instruments developed for use with younger persons or in one sociocultural group may not be valid for older persons or for another sociocultural group.

Instruments also reflect social and historical circumstances as well as scientific progress. Thus, the use of scaled instruments by psychologists and sociologists is a twentieth-century phenomenon and represented their efforts to mimic the empirical features of the physical sciences (Pfister and Schros 1997; Danziger 1990). Similarly, technology has had a profound effect on research over the past half-century. For instance, the availability of neuroimaging techniques has dramatically shaped schizophrenia research, which has led to a focus on structural and functional brain factors in schizophrenia as well as a particular approach to studying these factors. This use of neuroimaging tools in research has reflected the influence of technology in Western society and the technological approach to health and disease (Cohen 2000; Danziger 1990).

Another important issue for quantitative research is the need to develop analyses that move beyond linear, additive models. Research in other fields has demonstrated how an initial small effect can later have large, multiplicative effects because of nonlinear interactions (Prigogine 1996). With respect to phenomena with potential implications for schizophrenia research, stress studies have consistently shown that social supports exhibit a "buffering" or nonlinear effect; that is, they have a geometrically greater impact on psychological well-being as the level of stressful life events increases (Cohen and Wills 1985).

Finally, when conducting statistical analyses, it is important to more carefully consider the implications of significant findings. Too often, when a variable or even a model is found to be significant, there is a sense that some powerful lawlike phenomenon has been identified—akin to a law in the physical sciences—when in fact such variables or models explain only a small portion of the variance, i.e., often less than 5% (Cohen 2000; Danziger 1990). Although significant findings are meaningful and can be clinically revealing, it is also important to recognize that a large proportion of factors that affect outcome remain unknown. Thus, antipsychotic medications account for only 4% of the explained variance in psychopathology in schizophrenia (R. Rosenheck, personal communication, May 2000). What are the other elements that influence psychopathology? Indeed, the inability of any one or two variables to account for any substantial amount of the explained variance for outcome measures in schizophrenia underscores the need to develop more comprehensive models.

In developing research instruments and research priorities, it is increasingly being recognized that traditional research has too often placed researchers apart from and above those being researched. Several authors (Bond 1990; Brown and Tandon 1983; Serrano-Garcia 1990) have criticized this stance and have proposed a nonhierarchical partnership between researchers and participants. Thus, research goals would reflect the participants' view of the problem and their identification or choice of new research questions. In recent years, focus groups have been used to develop research instruments and clinical interventions. Our studies of a community mental health center and a Department of Veterans Affairs homeless program indicated that the research goals of patients and professionals often differ (Cohen 2000; Cohen et al. 1999). In the former study, although patients endorsed priorities for biological research, they also expressed the need for research on family and social aspects of mental illness, two areas that had been deemphasized in the research agendas of the National Institute of Mental Health and the National Alliance for the Mentally Ill. Whereas the homeless veterans called for more studies related to housing, employment, and other material needs, the topics endorsed by professional staff were more broadly distributed, with the greatest emphasis being on substance abuse, psychiatric problems, and the importance of staff–patient contact.

Research also embodies values that are typically not made explicit. Prilleltensky (1997) noted how certain value assumptions, such as health caring (i.e., the care, empathy, and concern for the well-being of others) and self-determination regarding decisions affecting one's life, tend to be in the foreground of clinical consciousness and research, whereas other assumptions, such as social justice (i.e., the fair and equitable allocation of resources and power), remain in the background. The former value assumptions typically emphasize individualism, personal advancement, and wealth accumulation, whereas the latter focus more on equality, mutuality, and the effects of broader social forces. Clinical interventions as well as the dependent and independent variables selected for study incorporate these underlying value assumptions. Hence, in creating models, we must be cognizant of and explicit about the values they reflect.

An Illustrative Example of a Model of Psychopathology for Use With Older Schizophrenic Persons

Although our goal should be to develop a comprehensive model of schizophrenia into later life, such an undertaking would be premature at this time. However, several avenues might be taken in developing intermediate models of various outcome measures in schizophrenia. One such avenue involves adapting existing models of schizophrenia for aging persons. As noted earlier, models used in schizophrenia research have been vague, difficult to operationalize, and too narrowly circumscribed. Another approach is to turn to the gerontological literature, where models have been developed for a variety of potentially relevant variables—for example, psychopathology, service utilization, life satisfaction, and adaptive functioning. Rather than beginning de novo, it is more reasonable to use extant models in the gerontological literature and modify these to incorporate variables pertinent to schizophrenia.

I will use Linda George's model to illustrate how a gerontological model might be adapted for use with older schizophrenic persons. As noted in several other chapters in this book, various changes with age have been reported in levels of positive and negative symptoms and in symptoms of depression. In assessing the factors that influence these symptoms, we have found the social antecedent model of psychopathology—developed by George (1989) for geriatric populations—to be useful (Cohen et al. 1996) because it incorporates a developmental perspective as well as examining a wide array of predictor variables. The model has six components: demographic variables, early events and achievements (e.g., childhood deprivation and traumas, education), later events and achievements (e.g., occupational attainment, income, marital status), social integration (e.g., religious and voluntary organization participation), vulnerability and protective factors (e.g., chronic stressors, social supports), and provoking agents and coping efforts (e.g., life events, coping styles, clinical treatment and services). This model was tested in an earlier study examining depression in older schizophrenic persons (Cohen et al. 1996) and was found to be significant ($\chi^2 = 67.81$, $P < 0.001$).

In research currently in progress, we have combined George's model with Pearlin's conceptual framework (Pearlin et al. 1990) to provide a hierarchical model for testing. Pearlin proposed a causal model in which the effects on psychopathology of background variables, role strains and stressors, and intrapsychic strains are mediated by coping, social support, and clinical treatment variables. That is, the latter group of variables may have buffering (interactive) or moderating influences on the other variables' effects on psychopathology. Our provisional causal model is depicted graphically in Figure 16–1; a list of the variables that can be operationalized by various scales appears in Table 16–1. The model displayed here incorporates variables from nearly all of the topics discussed in this book, and it is also sufficiently flexible to incorporate additional elements as the field progresses. Thus, certain biological variables—for example, genetic and central nervous system structural and neurochemical abnormalities—could be added to the background variables set.

Conclusions

Although there are compelling reasons to develop a comprehensive theoretical model of schizophrenia into later life—such as advancement of uniformity for the field; stimulation of cross-fertilization and alliances between disparate disciplines; identification of targets for clinical interventions, policy making, and advocacy—such models are fraught with methodological problems. These problems include the overlapping of variables from biological, psychological, and social levels of organization; the difficulties of integrating phenomena that are better expressed in nonquantitative forms; and the social and temporal contingencies that affect the delineation of variables to be examined. I have suggested that at present it is possible to overcome these difficulties in a very limited way, but this nevertheless still leaves open the potential to integrate different levels of organization—particularly the biological and social dimensions—and the possibility of circumscribing qualitative phenomenon within quantitative models by, for example, using cohort groups.

Researchers must make greater use of nonempirical methods, without which there is danger of missing much of the complexities, meanings, and depth of the human experience. They must be more circumspect about prematurely developing unidimensional variables, employing instruments that may not adequately capture the nuances of the phenomena being studied, relying extensively on technological measures to the exclusion of other perspectives, and overvaluing significant statistical findings while ignoring the extraordinarily large amount of unexplained variance. Moreover, researchers must be more vigilant about the values that are embedded in research practice and data. There has been a proclivity for Western research to reflect assumptions of individualism and personal advancement rather than mutuality and social equality. Finally, values of participants need to be reflected in research objectives and methods. As a preliminary step toward developing a more comprehensive model for studying aging and schizophrenia, our work indicates that it is profitable to adapt existing gerontological models for use with older schizophrenic populations.

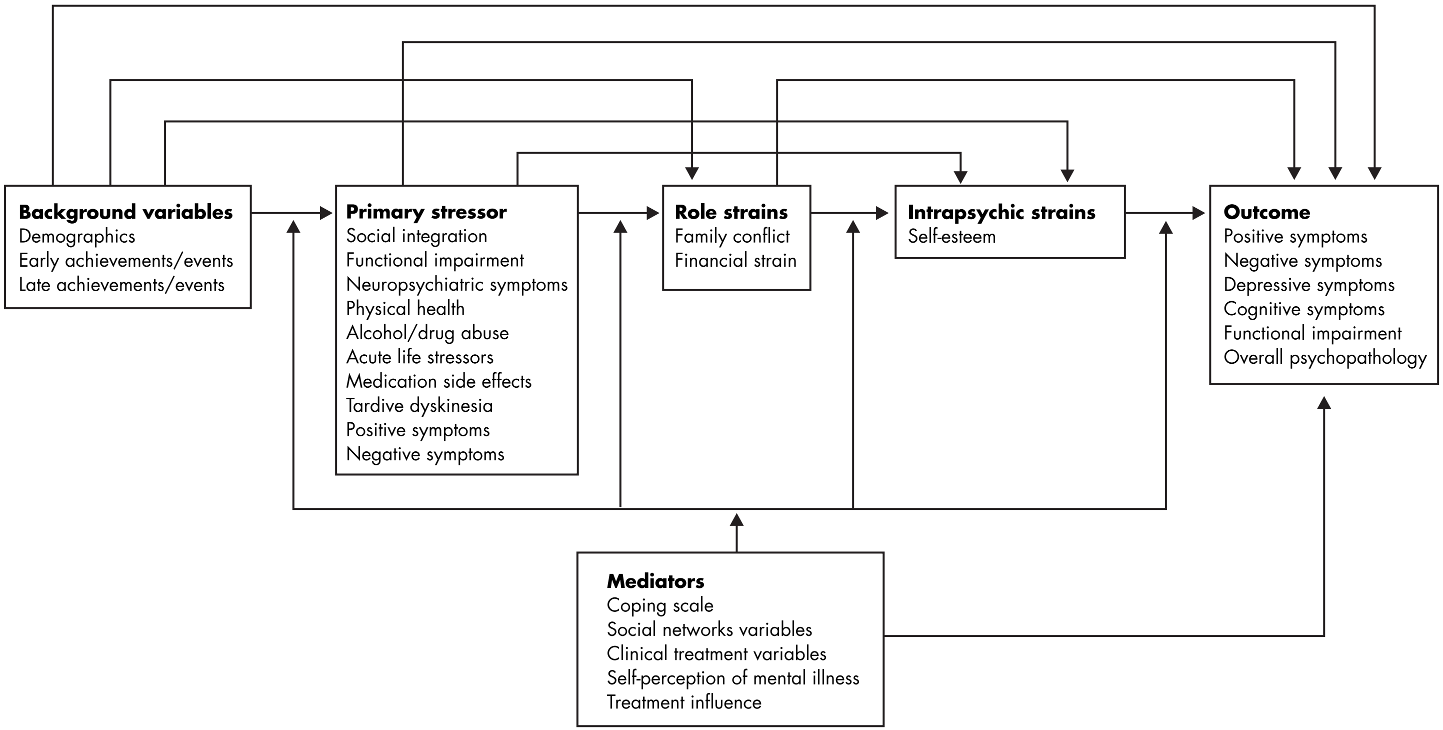

FIGURE 16–1. Illustrative model predicting psychopathology in older schizophrenic persons.

TABLE 16–1. Hierarchical regression model for predicting psychopathology in older schizophrenic persons

Dependent variables: positive symptoms, negative symptoms, depressive symptoms, overall symptoms

Stage 1	**Background variable set**
	Demographics (e.g., age, gender, ethnicity, religion, hereditary factors)
	Early achievements/events: education, early family disruptions (e.g., divorce, immigration), trauma
	Late achievements/events: marital status, occupation level, income, trauma
Stage 2	**Primary stressors set**
	Social integration
	Functional impairment
	Cognitive symptoms
	Physical health
	Alcohol/drug abuse
	Acute life stressors
	Medication side effects
	Tardive dyskinesia
	Positive symptoms
	Negative symptoms
	Depressive symptoms
Stage 3	**Role strain set**
	Family conflict
	Financial strain
Stage 4	**Intrapsychic strain set**
	Self-esteem
Stage 5	**Mediators**
	Coping variables
	Social network variables
	Clinical treatment variables
	Self-perception of mental illness
	Treatment compliance scale

Note. Interactive variables—that is, mediator variables multiplied by other variables—are added after an initial trimming of the model. Dependent variables are also used as predictor variables; however, a variable is omitted from the predictor sets when it is the dependent variable.

Two decades ago, in response to the rather constricted view of "true research" that dominated the mental health field, Strauss and Hafez (1981) underscored the need for clinician-investigators to use a variety of methods extending from case studies, standard exploratory situations with open-ended inquiry, small-sample experimental designs, large-sample natural history, models in which no experimental interventions are made, and experimental procedures with large numbers of subjects and carefully controlled manipulation of variables. The authors concluded that "each of these methods has its own advantages and disadvantages and is appropriate for different types of questions in different phases of development" (p. 1596). This conclusion remains relevant and valid today.

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