

Abandoned Minds:
The Escalating Crisis of Geriatric Mental Illness

by

Michelle Sipics

M.S. Computer Engineering
Drexel University, 2005

B.S. Computer Engineering
Drexel University, 2003

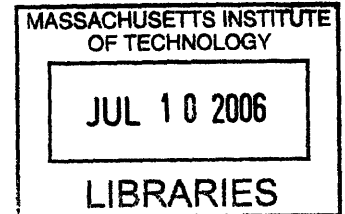
SUBMITTED TO THE PROGRAM IN WRITING AND HUMANISTIC STUDIES IN
PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE IN SCIENCE WRITING
AT THE
MASSACHUSETTS INSTITUTE OF TECHNOLOGY

SEPTEMBER 2006

© 2006 Michelle Sipics. All rights reserved.

The author hereby grants to MIT permission to reproduce
and to distribute publicly paper and electronic
copies of this document in whole or in part.



ARCHIVES

Signature of Author:.....

Graduate Program in Science Writing
May 17, 2006

Certified by:.....

Boyce Rensberger
Director, Knight Science Journalism Fellowships
Thesis Advisor

Accepted by:.....

Robert Kanigel
Professor of Science Writing
Director, Graduate Program in Science Writing

Abandoned Minds:
The Escalating Crisis of Geriatric Mental Health

by

Michelle Sipics

Submitted to the Graduate Program in Science Writing
on May 17, 2006 in Partial Fulfillment of the
Requirements for the Degree of Master of Science in
Science Writing

ABSTRACT

Older adults are susceptible to the same mental afflictions that affect other age groups; depression, anxiety disorders, schizophrenia, and other illnesses affect all adult age groups to varying degrees. Yet despite recent improvements in the research attention given to mental disorders and reductions in the stigma against such illnesses in younger age groups, the elderly remain a vastly underserved segment of the population in both mental health research and care.

They are not underrepresented in numbers, however: the National Institutes of Health place the population of adults 65 and older “on the threshold of a boom,” predicting that the age group will include 72 million individuals by the year 2030 and comprise 20 percent of the U.S. population. The trend is expected to begin in earnest when the first Baby Boomers turn 65 just five years from now, in 2011.

Yet despite these numbers and the population’s high risk of mental illness – the elderly are more prone to mental illness than any other age group – the U.S. health system remains grossly unprepared for the mental health needs of the elderly population. Its major problems include a shortage of caregivers, a notable lack of successful treatment methods, a dearth of research on the aspects of mental illness specific to the elderly, and a lack of funding to facilitate such research. With less than five years left before the first wave of this massive population growth begins, experts unequivocally agree that the nation is already in a crisis.

This thesis documents the medical, social, and political challenges facing patients, researchers, advocates, clinicians and caregivers in the coming decades – and today.

Thesis Supervisor: Boyce Rensberger
Title: Director, Knight Science Journalism Fellowships

Part 1: Introduction

All patient names and family members' names have been altered.

Alice Weinberg beckons to her daughter and poses a question: “Sally, when is Dad going to get here?” None too spry at 84, Alice’s weak voice betrays her age. Still, her frailty is offset by a hopeful smile at the thought of seeing her husband.

But there are two problems. Her daughter’s name is not Sally, but Marla – and her husband died 16 years ago.

For Marla, whose mother first began to exhibit symptoms of dementia five years ago, questions like this one have become commonplace. Alice rarely recognizes relatives, and frequently refers to people who have passed away many years before as though they were still alive. In a recent visit, she spoke of an event from Marla’s childhood as if it had happened only days before.

“I don’t know how to talk to her anymore,” Marla said.

Alice is far from alone in her affliction. According to a report of the U.S. Surgeon General, the elderly are the most prone of all age groups to mental illness. The National Institute of Mental Health estimates that two million adults over the age of 65 suffer from clinical depression, and as many as five million more have depressive symptoms. Other mental illnesses are prevalent as well, including anxiety disorders, schizophrenia, and Alzheimer’s disease, the 8th leading cause of death in America in 2002 (the last year for which official data are available).

The NIMH also reports that older adults are at a disproportionately high risk for suicide; the Department of Labor lists their age group as having the lowest average income; and the Federal Interagency Forum for Aging Related Statistics reported, not surprisingly, that they have the largest reliance on health care, for which costs are increasing rapidly. Further, according to the U.S. Census Bureau, theirs is the fastest growing age group in the country.

This combination—disproportionately high rates of mental illness in the fastest growing segment of the population—makes the problem one of the most acute in the American health care system. Compounding the problem is the fact that many of today’s

elderly grew up in an era that tended to see mental disease as a moral failing, a source of shame to be kept secret from others. Still others write off their symptoms as an inescapable result of old age, not a sign of mental illness. Consequently, relatively few seek help when early intervention could do more good.

“There is a certain stigma attached to the idea of mental illness, especially among older adults,” said Jovier Evans, program chief of the Geriatric Translational Neuroscience Program at NIMH. Evans’s program supports the study of late-life mental disorders by the neuro- and cognitive sciences.

Evans added that few elderly individuals would seek help from a mental health practitioner regardless of stigma: “Most older adults don’t seek medical care from specialty clinics, so they wouldn’t see a psychiatrist or psychologist,” he said. “They see their primary care physician.” Experts cite this fact as one of the reasons mental illnesses are often overlooked in older adults: elderly patients suffering from physical ailments such as fatigue and muscle ache, for example, will generally visit primary care physicians, who are less likely to recognize such complaints as potential symptoms of depression than are psychiatrists or psychologists.

The Alice Weinbergs of this country belong to a large and growing group. According to a 2005 National Institute on Aging report, in 2003, the last year for which figures are available, nearly 36 million people over the age of 65 lived in the U.S., constituting 12 percent of the population.

That number is expected to soar: the NIA report, called *65+ in the United States: 2005*, puts the population of older adults “on the threshold of a boom,” projecting a rise to 72 million by the year 2030 – accounting for 20 percent of the U.S. population. The trend is expected to begin in earnest when the first Baby Boomers turn 65 just five years from now, in 2011.

Older adults are susceptible to the same mental afflictions that affect other age groups; depression, anxiety disorders, schizophrenia, and other illnesses affect all adult age groups to varying degrees. But, mental health experts say, the elderly are particularly prone to major depression, in part because it is frequently brought on by existing physical illnesses such as cancer. And recent studies suggest that depression may not only result

from physical maladies, but contribute to their worsening as well. This intricate cause-and-effect relationship between mental and physical illnesses is an area of research that has grown in recent years and continues to expand, with many potential applications to geriatric mental health.

Another mental health concern specific to the elderly population relates to disorders for which the risk increases with age. Although the average life expectancy of Americans is growing – the Centers for Disease Control and Prevention currently place it at 77.6 years – a longer life does not necessarily mean a healthier one. The CDC distinguishes between the average life expectancy and the average *healthy* life expectancy, which is several years shorter. And as the elderly grow older, their likelihood of developing dementia and other brain disorders grows sharply.

Alzheimer's disease is one of the most common forms of dementia, and affects an estimated 5 percent of the population between the ages of 65 and 74. That percentage increases to nearly *half* of individuals over the age of 85. And while some dementia-causing conditions can be reversed, Alzheimer's disease has no cure. Because of its devastating effects on patients and families, it is one of the most frequently studied illnesses, and typically receives the highest percentage of mental health research funding specific to the needs of the elderly.

In 2000, the NIMH provided \$85 million in funding for aging research, and nearly 30 percent of it went to dementia and Alzheimer's research. But despite the looming explosion of the elderly population and its higher risk for mental illness, the mental health support available to that age group is already insufficient and expectations that it can catch up are low.

While addressing the Policy Committee to the White House Conference on Aging last year, Anita Rosen, chair of the Mental Health and Aging network of the American Society on Aging, cited drastic shortages in the number of trained professionals who specialize in mental health care for the elderly. She reported that as of 2002, only 5 percent of social work practitioners listed aging as their primary area of expertise, and that only 1,115 Masters-level social work students specialized in aging. In contrast, the NIA issued a report nearly 20 years ago emphasizing the need for 60,000 to 70,000 social

workers specialized in aging by 2020. Despite two decades of warning, experts fear that the actual numbers will fall drastically short of the predicted need.

“It’s just not been a very popular, exciting area for folks,” Rosen said, and so little attention has been given to the subject from the medical community or the government over the past 20 years. “If you want to talk about bias and stereotyping, aging has always been a real problem. Then you compound that with another area of bias and stereotyping, and that’s mental health – and what do you have? Two of the most stereotyped, biased kind of areas that are not [attractive to researchers or legislators], and it’s really a problem, to say the least.”

Rosen also cited shortages in the number of psychiatrists providing specialized care for the elderly. At the time of her testimony to the White House conference, less than 7 percent of the 38,691 practicing psychiatrists in the U.S. specialized in aging. According to Rosen, given the existing trends in medical schools and the retirement of current practitioners, there will be 5,682 older adults with psychiatric disorders for every one geriatric psychiatrist in America by the year 2030.

Rosen said that there is little chance that the severe shortage in geriatric mental health professionals can be addressed in time to help Baby Boomers, who will reach the age of 65 beginning just five years from now.

“The reality is that if somebody wanted to take some leadership at a national level and put some sensible and effective resources into this, it’s possible. It really is possible. But the reality is that that’s not going to happen.”

NIMH’s Evans echoed Rosen’s statements. “There’s already a lack of geriatric mental health professionals,” he said, and added that the situation is unlikely to improve in the near future. “Not a lot of professionals think about going into geriatric care.”

This combination of growing problems will affect patients, mental health professionals and caregivers as the elderly population explodes over the coming decade. A shortage of professional caregivers, experts fear, could result in increased reliance on untrained family members like Alice Weinberg’s daughter Marla for care, leaving less time for those individuals to work or attend to their own needs. Practicing physicians in geriatrics will have more patients than they can handle, forcing them to spend less time with each– thus providing less personalized care.

Rosen and other aging and mental health advocates suggest that one long-term solution for the problem, which could also be implemented on a short-term scale to try to mitigate the effects of the coming health care crisis, is to educate all physicians, nurses, and social workers with basic knowledge of aging and mental health. Right now she said, “We’ve got a bunch of professionals who either know nothing about mental health or nothing about aging, or both. What you really need to spend your time on is having all of those professions infuse aging or aging *and* mental content into the curriculum for all students.”

Dr. Gary Moak, a practicing geriatric psychiatrist and president-elect of the Geriatric Mental Health Foundation, emphasizes that it’s just as important to have geriatric mental health professionals working in an educational capacity as it is to have them treating patients, encouraging young students to consider the field as a career choice.

“It never would have occurred to me on my own to go into geriatrics, but I trained in a department where there was a thriving, growing, geriatric division,” he said. “If I’d been in another place where there weren’t the same kind of geriatric faculty available, I probably would have gone in a different direction.”

In 2002, the National Institute of Mental Health established an Aging Research Consortium with the goal of stimulating much-needed research in geriatric mental health. For example, it is known that the late-onset version of some mental illnesses take a different form from diseases better known among younger people. The NIMH has since funded studies of both the cause and treatment of these diseases. Yet the studies are far from being able to help current patients like Alice Weinberg, for whom even small physical problems can cause major repercussions. Marla notices changes in her mother’s lucidity even after short bouts with the flu or physical pain from a fall.

“It seems like whenever she gets physically sick it’s a real setback,” Marla said.

Sharon Heintzelman, a nurse on the dementia floor of Cedarbrook nursing home in Allentown, Pennsylvania where Alice Weinberg lives, adds that seemingly minor changes to a patient’s lifestyle can also have a great impact on a patient’s mental state. Small changes to a daily routine that wouldn’t faze most individuals, like moving a meal to an hour after its normal time, can confuse and irritate Alzheimer’s patients, she said.

Marla recalled having a small birthday party for her mother at the nursing home the previous year, and how the addition to Alice's normally consistent schedule had upset her mental balance. "There were maybe ten or twelve of us, and it really hurt her. It took her days to get over that," she said.

"It's like an overload," Heintzelman agreed, elaborating that an unexpected event or can overwhelm patients and increase their mental instability.

Complicating the problems brought on by dementia and other mental disorders are the soaring costs of public programs that many patients rely on to pay for treatment and care. In 2000, according to the Aging Institute report, *65+ in the United States*, there were approximately five Americans of working age (classified as people ages 20 to 64) paying into the Medicare and Social Security systems that support each individual 65 years or older. By 2030, the NIA predicts that there will be fewer than three working age Americans for each older adult. Since the government programs are built on the pay-as-you-go plan, this means that costs will rise and the number of taxpayers footing the bills will shrink.

With government programs potentially unable to support the number of elderly people depending on them, financial responsibility can increasingly fall to caregivers – usually family members like Marla. This can include the cost of initial diagnosis and treatment as well as the costs of long-term care, which can mount as a patient's condition worsens.

Both Marla and her relatives, part of a closely-knit family that has lived in various small towns near Allentown, for four generations, have experienced both the short- and long-term effects of mental illness since Alice's problems with dementia began at the age of 79.

"It started with some minor surgery for an unrelated problem, and when I went to see her in the hospital she was really out of it," Marla said. She asked the nurse about it, but the nurse was surprised: "Nobody's ever told her that she has Alzheimer's," she questioned. In fact, the nurse's hasty assumption was incorrect – Alice suffers from a non-Alzheimer's form of dementia, a diagnosis that was made shortly after her surgery. "But at the time, all I knew was that something was wrong," Marla said. "It wasn't my mom, at all."

Alice also has a heart condition, and passed out frequently after her surgery. Eventually she was hospitalized again for three weeks, during which time she went into cardiac arrest and had to be resuscitated. Marla believes her mother's heart condition contributed to her development of dementia.

"We can't really be sure, but her doctor said that there's no way to know how long she was without oxygen," Marla said. A sudden and severe lack of oxygen, called hypoxia, can cause dementia by damaging brain cells. "It seems like after that, everything started to snowball."

Alice now resides in a county-owned nursing home, the fourth long-term care facility she has lived in since she developed a serious physical disability in 1986. As Alice's mental condition worsened as well, Marla was forced to move her mother from one facility to another to try to accommodate her needs. She had a particularly bad experience with the second nursing home, a privately owned facility where "Alice's personal property would go missing – things would mysteriously disappear and no one knew where they went," as a friend of the family put it.

Finally, Alice settled in at her current care facility in Allentown, where Marla visits her once a week. The mother-daughter relationship has been reversed. The daughter – herself a mother of three and grandmother of six – handles all of Alice's financial needs, accompanies her to doctor's appointments, and works with the nursing home staff to ensure that she is as comfortable as possible. Marla, whose father died of cancer 16 years ago, said that knowing her mother is being well cared for is some comfort – but seeing her condition worsen never gets any easier.

Marla's situation is becoming a familiar one for an increasing number of middle-aged Americans whose parents are part of the growing elderly population. If, as experts expect, the number of elderly patients continues to grow without a comparable increase in the number of professional caregivers and facilities to support them, the children of those patients will be left to carry the burden of caring for them with very little help. For Marla, taking on the responsibilities her mother is no longer capable of handling is her second experience caring for a seriously ill parent, though it is her first involving mental illness.

"I saw my dad deteriorate physically and now I see my mom deteriorate mentally. I don't know which is harder," Marla said. "As of right now, I'd have to say it's my mom."

Because Alice does not in fact have Alzheimer's, Marla is at least spared from the fear that haunts many children whose parents suffer from it: an increased risk for themselves developing the illness. Although the difference is considered small, the siblings or children of Alzheimer's patients are at a slightly higher risk, which experts generally believe to be genetic in origin. The same is true of many mental disorders, some of which are more likely to run in families.

As far as Marla can tell, her mother is usually unaware that she does not perceive the world accurately. This may be a blessing in disguise, as the realization that her brain is betraying her would no doubt be a terrifying ordeal. The elderly already worry about heart disease, cancer and other physical maladies, but an illness of the brain – the source of thought, reasoning and personality – can be much more frightening than one that attacks other parts of the body.

Individuals who do recognize and seek help for their symptoms often encounter difficulties determining where to go or who to call. Some even call their local Congressman's office, where staff members are trained to act as liaisons between constituents and the various divisions of government, but not to dispense mental health advice. These caseworkers struggle to point people in the right direction – particularly in situations that involve questions about Medicare, the primary provider of health insurance coverage for the elderly population.

"The situation is so complicated – we don't want to give them misleading or incorrect or bad advice," said one congressional staffer who asked not to be named. "We want to make sure people get the best option possible, but since we aren't trained [in mental health care], we are not the place to go." Typically, the best a caseworker can do is to refer individuals to state-run offices of aging.

But even if a person finds the right place to go and receives a diagnosis and treatment, the problems don't end there. The financial cost of mental health treatment is a heavy burden on patients, particularly those with low income. If a hospital stay is required, the standard Medicare plan requires a patient to pay a deductible of \$912, which covers a 60-day hospitalization; paying that bill would require an entire month's worth of Social Security benefits for a disabled worker.

Outpatient coverage is provided under a different segment of Medicare, called "Part

B.” Most people pay a fee for Part B, which still provides only partial coverage for mental health services. And although many elderly patients have additional insurance from other providers, Marla Weinberg said that in her experience, health insurance coverage is “not even remotely adequate” to care for a mentally ill elderly patient – and she is far from being the only person to say so. That sentiment is echoed by caregivers, patients, doctors, policymakers and the researchers who realize the importance of providing care to the patients who cannot immediately benefit from their work.

“There are treatments that are out there that work in this population, but they’re not getting it,” said Jeffrey Harman, an assistant professor in the University of Florida’s college of public health and health professions. Harman, whose research into the social and economic factors involved in late-life depression is funded by the NIMH, says that far more effort is needed to better integrate mental health care into the larger mental health system.

“A lot of health plans are set up where mental health is a carve-out; it’s not included,” he said. “It almost encourages people to *not* get the care they want. To really improve treatment rates, that’s what we should focus on.”

Ruth O’Hara, an assistant professor of adult psychiatry at Stanford University, echoes Harman’s concerns about the importance of integration, both within the health care system and in research.

“The importance of mental health is relatively well-acknowledged in the United States compared to some other countries, but within the U.S. health care system, it is very underrepresented,” she said. “And within the field in general, geriatric mental health is underrepresented as well.”

This is the first of a four-part series on geriatric mental health. Each of the next segments will focus on one type of mental disorder-- depression, Alzheimer’s disease, and schizophrenia.

Part 2: Geriatric Depression

Mildred Reynolds is a very active woman. The 76-year-old sits on the executive committee of the National Coalition on Mental Health and Aging; she represents the National Depression and Bipolar Support Alliance; she is a former mental health professional, having worked as a therapist, and continues to try to help individuals with a mental illness, whether it is by lending a friendly ear or by helping to set up a depression and suicide support group at the retirement home where she lives.

And if anyone knows how important it is to have a support system, it's Reynolds: she suffers from clinical depression herself.

“Because I have experienced it, I can understand better what it's about and help to educate people,” said Reynolds, who struggled with the decision to admit to her battle with depression. “I kept it a secret for many, many years. It was kind of a risk – I didn't know what would happen, what would be people's response.”

When Reynolds says “many, many years,” she's not exaggerating. The former therapist, who concentrates her efforts specifically on campaigning for the mental health of the elderly, had her first experience with depression quite some time ago – in 1966, when she was 30 years old. But she kept her illness a secret for more than 20 years, for reasons that she says are similar to those many older adults face today.

But why is a woman who had her first bout of depression before middle age focusing on the mental health needs of the elderly?

“I feel that my experience when I was younger is similar to what older adults experience when they first develop depression,” Reynolds said, recalling what the attitude about mental illness was in the 1960s. “We, our generation, didn't have the courses in psychology and all of the literature that is available on the Internet; the stigma against mental illness was very great. You'd figure, ‘my goodness, what has she got to be depressed about?’ And I asked myself the same question. For most older adults, things are still like that today.”

An estimated 18 to 25 percent of elderly individuals have some form of mental

illness, including depression, schizophrenia, anxiety disorders, and other maladies. Of those, the National Institute of Mental Health estimates that two million have clinical depression, and another five million have depressive symptoms for which they should see a mental health professional. Those numbers are expected to rise as the size of the elderly population nearly doubles over the coming decades. Yet the number of older adults who seek receive treatment for depression is staggeringly low in comparison – experts estimate that only 10 percent of elderly individuals with depression receive treatment.

Much of the current research in geriatric psychiatry involves efforts to study factors that can dissuade or prevent older adults from seeking treatment for depression, and learn how to neutralize them.

Jeffrey Harman, an assistant professor of health services administration at the University of Florida, is conducting an NIMH-funded study to explore social and economic factors in late-life depression and its treatment. Harman says that one of the most important areas of research within the field that needs more attention is elderly people's use of health care.

“We need to do more research to understand how the elderly access mental health care, and what we know so far is that it's primarily through primary care physicians,” he said. “They don't go to psychiatrists – they present problems that are symptomatic of depression, but [those problems] will be general aches and pains or appetite disturbances or such things, and the depression is overlooked.” Experts say that it is unlikely the inclination to rely entirely on primary care physicians will change until elderly adults are better informed about the symptoms of depression. Many experts also feel that primary care physicians should also be better educated about the symptoms of depression in the elderly, which could make them pause before automatically treating physical symptoms without considering whether depression is their ultimate source.

Harman's project, which began in 2001, will conclude in June of this year. To this point, he has focused primarily on trying to ascertain the factors that determine whether or not an elderly individual will seek treatment for depression. Economics, he says, seems to play a huge role.

“I examined measures of religiosity and social support as well as perceived financial

burden, and it was only the perceived financial burden that really predicted whether or not somebody received treatment,” he said. Prior to the study, Harman had hypothesized that high levels of religiosity and social support would decrease the likelihood that a person would seek help for depression. His prediction was based on the idea that many individuals would choose to rely on support systems already present in their lives rather than seek external, professional care. Instead, Harman said, those factors had almost no effect compared to economics. “If somebody said that they couldn’t make ends meet, they did not seek treatment.”

Harman’s full results will not be published until the study ends, but his initial findings fit in well with existing research according to Ruth O’Hara, an assistant professor of adult psychiatry at the Stanford University School of Medicine. O’Hara is also on the editorial board of the *Journal of Geriatric Psychiatry*, the primary peer-reviewed publication in the field.

That economics are a primary factor, she said, “fits in with both my knowledge of previous research and my experience in the field. Individuals with a low socioeconomic status are much less likely to seek treatment.”

Education is another factor, O’Hara said.

“People who are [younger] adults now have been more exposed to information [about mental health], and might be more likely to seek help for problems when they get older,” she said. “But the people who are elderly now were not exposed to the same information when they were younger and are more likely to write off depressive symptoms as common effects of aging.”

Dr. Gary Moak, a practicing geriatric psychiatrist and president-elect of the Geriatric Mental Health Foundation, said the problem is compounded by the era of self-reliance that many older adults grew up in, where asking for help was a sign of weakness. “Many people who are now geriatric patients grew up in an era where a sense of self-reliance was really the credo of the day,” he said. “You take care of your problems yourself, you pull yourself up by your bootstraps.” Many depressed older adults continue to live by that credo, he said, refusing to ask for help when it’s needed.

Even when the elderly want to ask for help, memories of what mental health treatment was like when they were younger sometimes keep them from reaching out.

“In those days the ‘help’ that you got [for a mental problem] involved being whisked away to an asylum for a long period of time, or it was a Freudian lay-on-the-couch kind of analysis,” Moak said. And, he continued, elderly individuals today are often afraid of losing their sense of independence. “There’s a fear that if you recognize a problem and go to get treatment for it, you’ve sort of got one foot in the nursing home. People are terrified of nursing home placement, and sometimes conclude that the best way to deal with the problem is to ignore it.”

O’Hara said efforts are made to inform the public, including the elderly, about treatment options for mental illness; the information is there for those looking for it. But the message still fails to reach some people: “Maybe they aren’t reading the science section of the local newspaper, or they’re not reading the AARP pamphlets delivered to their doors,” she said, referring to the advocacy group for the elderly.

Yet even when the message gets across and economics are not a factor, many seniors are still reluctant to seek treatment for their symptoms. Reynolds recalls what it was like for her in the 1960s, a situation that she says is similar to what older adults face among their peers now.

“I remember when I got the first major episode I would tell myself, count your blessings Mildred, you’ve got a good education, good husband, good job, all of those things – and of course it didn’t help,” she said. She didn’t want to admit that anything was wrong, being afraid of what others might think, but finally went to see a psychoanalyst in secret.

Reynolds says the initial psychotherapy she was given helped briefly, but her depression returned. “After the first episode I’d thought it would never happen again. What I didn’t know then was that it is a recurring disease. Nobody talked about clinical depression – I don’t think that phrase was even in the literature.”

That, Reynolds says, is one advantage that older adults suffering from depression today have that she didn’t 40 years ago: more knowledgeable mental health professionals.

Clinical depression is now recognized as a recurring illness, and combinations of medication and therapy can be extremely effective in treating the disease. Unfortunately, she points out, “All the treatment in the world isn’t going to help unless you identify the people who have it. I remember a [woman in my retirement community] was in the hospital being treated for bipolar depression, and I asked the husband if had there been any [symptoms] before. He said, ‘well, there were several things, but we just thought she was eccentric.’”

The importance of seeking treatment for geriatric depression becomes even more apparent in light of elderly individuals’ higher risk of suicide – in 2002, older adults comprised 12.3 percent of the U.S. population but accounted for 17.5 percent of the nation’s suicides, the highest rate for any age group, and the Centers for Disease Control and Prevention estimate that one older adult commits suicide every 90 minutes in the U.S. The elderly have a far higher likelihood of succeeding in suicide attempts, as well: it is estimated that for every 200 suicide attempts among younger individuals, only one actually dies. Among older adults the death rate is 50 times higher – one in every four suicide attempts is fatal.

Joseph Gallo, an associate professor of psychiatry at the University of Pennsylvania, is currently studying death rates in the elderly population. Gallo hopes to estimate the risk of mortality among patients with major depression when those patients participate in treatment in a primary care setting. So far, he said, his research suggests that such treatments can have more than just short-term effects: they may actually result in lower death rates.

But Gallo noted that the real difficulty is in getting older adults to receive treatment in the first place. Researchers at the University of Pennsylvania also participated in the multi-site, so-called PRISM-E study, which examined the results of integrating behavioral health care into primary care programs. Elderly patients in the study were treated in one of two settings after an initial appointment with a primary care physician. One group remained under primary care, but with integrated treatment from on-site mental health specialists. The patients in the second group were referred to geriatric psychiatrists after their first primary care appointment. If the patient was referred to an

outside specialist, “everything was taken care of for them – the appointments were set up and expedited, transportation was arranged, everything,” Gallo said. “But only 20 percent of the people who were referred went for even one appointment with the geriatric psychiatrist, while 80 percent participated in the primary care treatment.”

Gallo, who is also a practicing primary care physician, said that integrating mental health care into the primary care setting could have a big impact on public health. The mentally ill elderly are “a huge part of the demographic, so if there’s not coordination between [primary care and mental health specialists], you’re never going to get everybody treated. You can’t have everybody see a geriatric psychiatrist – there’s not enough of them to go around. So if you’re going to think about it from a public health standpoint, you’ve got to figure out how to disperse the interventions in a way that can help everyone.”

While researchers like Gallo and Harman examine treatment-related issues, still others study the roots of the illness itself. Although it is believed that depression stems in part from both environmental and biological factors, the biological factors in particular are not well understood. Experts suspect that the neurotransmitters serotonin and norepinephrine, two chemicals that transmit messages within the brain, are involved in the onset of depression. The currently accepted theory is that decreased levels of these two chemicals can lead to the anxiety, irritability, fatigue, mood and sleep problems associated with depression.

There is mounting evidence that late life depression may also be associated with age-related changes to blood flow in the brain. Moreover, it is also likely that the increased stresses introduced by aging, including bereavement and an increased number of physical ailments, add to the overall risk of developing the illness.

Because the causes of the illness are not clearly understood, research efforts have increasingly focused on improving knowledge about factors responsible for the onset of depression, in hopes that methods of prevention can be developed. In the meantime, there are many forms of treatment currently available for geriatric depression; the most common in mild cases is psychotherapy, just as in younger patients. But doctors treating older individuals must deal with the added complexities of aging when diagnosing and

determining a treatment plan for their patients. One reason is the increased risk for depression that can result from serious physical ailments.

“There is a strong link between cardiovascular disease and depression, for example,” O’Hara said, citing one of the many physical ailments more common among older adults. A doctor must take care to consider the role that an existing physical condition might be playing on a patient’s mental state.

When an individual suffers from more serious and lasting symptoms, antidepressant medication is sometimes used in conjunction with psychotherapy. But that creates difficulties of its own.

The first problem is drug interaction. Older adults are frequently prescribed medications to treat heart problems, high blood pressure, even cancer – but when antidepressants are added to the mix, the combination can sometimes cause side effects that *increase* depression. The risk of such side effects can often be minimized if a doctor is careful to examine potential interactions between the drugs a patient is taking, and can monitor the patient closely to address any side effects that emerge. However, the risk of drug interaction increases among older patients simply by nature of the number of doctors and medications they routinely deal with. It’s not uncommon for a senior citizen to have two or more regular doctors, and forget to tell one about a drug another has prescribed. Some patients are embarrassed to tell a primary physician that they are also seeing a psychiatrist; in such cases, a physician might prescribe medication to treat a heart problem not knowing that the patient is also taking antidepressants to treat a mental disorder.

To date, there are no antidepressant medications designed specifically to treat geriatric depression. A relatively new class of drugs, however, called selective serotonin re-uptake inhibitors (SSRIs) are often prescribed to elderly patients because they cause fewer side effects than older kinds of antidepressants – an important distinction considering the possible ramifications of drops in blood pressure or loss of balance, common side effects of antidepressants, in older individuals. Such problems can cause falls that lead to broken bones, which are simultaneously more common in the elderly than in the younger adult population and require more time to heal. SSRIs have a lower

risk of these side effects than other antidepressants.

For many people, however, a combination of therapy and antidepressant medication can be very successful in treating the illness. Reynolds, who finally found a psychiatrist who recognized her symptoms as those of clinical depression in 1984, spent *nine years* trying to find a medication that adequately and consistently kept her depression at bay – but since she did in 1993, she hasn't had a single depressive episode.

“‘The dose that got you better keeps you better,’ was my psychiatrist’s slogan,” said Reynolds. “The chances of recurrence increases with each episode, so I’m still on medication to hopefully prevent another episode.”

But even if a particular drug proves effective for a patient, another problem can persist: the financial burden of paying for prescription medications. Doctors and patients have criticized the Medicare Prescription Drug Plans first offered on January 1st of this year for leaving patients with large, sometimes impossible, costs to shoulder. Medicare users are told to choose among a bewildering variety of plans, which will cover the costs of different medications. Many of the plans cover only the most frequently prescribed drugs, which can leave patients whose illnesses don't respond to those medications, or who take several that are not all covered under the same plan, with high out-of-pocket costs.

In addition to the staggering individual costs that these guidelines impose on the segment of the population with the lowest average income, they come with added insult: unintelligibility. The official explanation for the plan's costs and benefits has left so many elderly patients confused about their options that the burden of determining the best way for a patient to receive his required medications has fallen to pharmacists and caregivers – the latter being without any training in such matters.

Twenty-eight-year-old Niko Abramski is one of the plan's critics. Abramski spent two weeks going over the new rules trying to help a close friend, 68-year-old Nancy Forgach, decide which of the options available through the program would be best to pay for the seven prescription drugs she is currently taking for both physical and mental illnesses.

“The most confusing aspect of the program is the program itself,” Abramski said. “The insurance companies are dictating what a patient is entitled to as far as his or her medications are concerned. They have all created these ‘formularies,’ which, in my opinion, are their Bibles. You either go by their gospel of coverage or you can choose another plan with another company.”

Abramski said she started her review of the plans with the most expensive option, which, combined with the cost of Forgach’s Medicare premium, would cover all of her medications for \$200 a month. But with that plan, said Abramski, “After considering her living arrangements, her co-pays for all of her physicians, and the co-pays for the medications, she would be over-extended by about \$300 a month.”

Abramski, who herself takes eight medications to treat physical and mental disorders, kept looking. “We moved on to the next plan, and the next, and the next, until the added premium and medication coverage would [allow her] to break even and have the bare minimum to live off of,” she said. “She is still going to need my assistance and the assistance of her son, who is currently sending her \$400 a month just for her medications.”

Moreover, the only plan that Forgach could reasonably afford does not cover all of her prescriptions; she may have to stop taking one of her cholesterol medications and hope that an increased dosage of another will be sufficient to replace the first. But if Forgach’s physician changes her drug regimen, there is no guarantee that the new prescriptions will be covered by the plan she has chosen, which she is required to stay with for a period of one year.

Financial hardship is not limited to those suffering from depression. Research on the condition is also impoverished. Of the \$85 million provided by the NIMH to fund research in geriatric mental health in 2000, approximately 20 percent went toward efforts to study depression and suicide – a relatively small total of about \$17 million. This amounts to less than three dollars of research funding for each older adult with clinical depression or depressive symptoms, one of the smallest allocations of Federal research dollars for any disease.

This is not surprising when compared to conditions such as heart disease, which kills more Americans each year than any other illness. But among the research expenditures of

the NIH in 2003 was \$55 million for Cooley's anemia, a serious but extremely rare illness that affects fewer than 1,000 individuals in the U.S. The disease is often referred to as Mediterranean anemia because it occurs almost entirely in people of Mediterranean origin – yet this condition received more than three times the research funding awarded to the study of depressive illnesses that affect 2,000 times as many Americans over the age of 65. Looked at another way, the Federal government's priorities give \$3 of funding for each elderly patient suffering from depression, and \$55,000 in funding for each patient with Cooley's anemia.

Anita Rosen, chair of the Mental Health and Aging network of the American Society on Aging said she was unfortunately not surprised by the relative paucity of funding.

“It is clear that mental health and aging research is a critical policy area in dire need on the national level,” Rosen said.

Experts acknowledge that money is not the answer to all of the challenges facing the field of geriatric mental health in the coming decades; Rosen and others continue to press for the addition of aging and mental health content into medical curriculums, and Moak emphasized that no one can be treated for depression or any mental illness until they first seek treatment. Before that can happen, older adults must accept the fact that mental illness is not a normal part of aging, and that it's important to ask for help. Still, Moak said, the importance of funding for mental health research definitely cannot be ignored.

“In order to provide better health care of all kinds to older people, you really need more research so we can come up with better, innovative solutions to the problems older people face,” he said. “I'm not a researcher, but for someone like me who's a private practitioner out in the field, I can tell you that research is the lifeblood of effective practice.”

Right now, Moak said, that lifeblood is draining away.

“Funding under the current administration has been cut back terribly,” he said, echoing the concern of Rosen and other experts in the field. He does not limit the need for additional funding only to research, however. He said there is also a need to support mental health training and to offer reasonable reimbursement to practicing mental health care professionals. “You can do the research and you can produce new breakthroughs,

but if nobody can get paid to [use them], then nobody can provide the care,” he said. “There’s no question it’s a crisis, and the way things are going it looks like it may get much worse rather than better.”

This is the second of a four-part series on geriatric mental health. The next segment of the series will focus on research and treatment of Alzheimer’s disease in the elderly.

Part 3: Alzheimer's disease and dementia

James Mortimer has been involved in research on Alzheimer's disease for almost 30 years. In the mid 1970's, he received a grant to set up a geriatric research and clinical center within in the Veteran's Affairs system, intending to study Parkinson's and Alzheimer's disease, two of the most devastating neurological diseases to afflict the elderly. He began doing research on both diseases, and soon realized that the cause of one was completely unknown.

"I've been interested in the causes of Alzheimer's disease since then," he said.

It has been nearly 100 years since German psychiatrist Alois Alzheimer first documented the disease in 1907, after studying the brain of a woman who suffered from memory loss, disorientation and hallucinations before her death. Despite the best efforts of countless scientists, researchers and practicing physicians over a century, very little is known about the causes of Alzheimer's, and even less is known about its prevention. But with the number of Americans over the age of 65 expected to rise faster than ever within the next two decades, researchers – and individuals reaching the age where their chance of getting the disease mounts – there is hope that recent advances are the beginning of a trend in Alzheimer's research.

During the 29 years since he first noted the lack of general knowledge about the disease's roots, Mortimer has been involved in numerous studies analyzing the causes and risk factors for Alzheimer's disease, which affects an estimated 4.5 million Americans - a number that researchers say will grow as the number of older adults in the U.S. increases rapidly in coming years. Like many scientists, the professor of epidemiology and biostatistics at the University of South Florida says the intellectual challenge of his work inspires him to continue – but he acknowledges a secondary motivation for his efforts.

"I guess you could say I have a personal interest," the 61-year-old researcher admitted. "I have a family history of Alzheimer's disease as well."

The cost of providing care for Alzheimer's patients is already enormous in the U.S., with Medicare costs alone for the disease amounting to more than \$90 billion in 2005. As the number of Alzheimer's patients in the country grows, and with Medicare costs

predicted to increase 75 percent by 2010, the cost of caring for patients through Medicare alone could soar as high as \$160 billion just four years from now.

The financial toll also affects caregivers, who absorb as much as 75 percent of costs when caring for a patient in their home. And that burden extends beyond the purely financial: caregivers themselves become more prone to medical problems.

“There are risks associated with poor self-care – not getting enough sleep, not slowing down when you need to rest, not being able to find respite or support,” said Richard Schulz, director of gerontology at the University of Pittsburgh. “There is a host of evidence that immune function is compromised by care giving, and there is some evidence for increased mortality among highly stressed caregivers.”

The earliest symptoms of Alzheimer’s disease are mild memory problems, which are sometimes overlooked as normal results of aging. These difficulties, however, worsen over time, eventually leading to more severe cognitive problems including paranoia or hallucinations. In the late stages of the disease, patients cannot perform daily life tasks alone, and in the worst stage, lose the ability to respond to their surroundings.

A look inside almost any nursing home reveals the damage. In the dementia floor at Cedarbrook nursing home in Allentown, Pennsylvania, for example, patients lie motionless on their beds, staring blankly at anyone who happens by; still others are in wheelchairs, sitting silently in hallways with no apparent reason to be there and, often, not even any realization of where they are. The elevator call button is recessed into a tiny hole in the wall. Pressing it requires the use of a pencil stored higher on the wall, out of the reach of patients in wheelchairs. A passing nurse explains that without the precaution, disoriented patients would simply leave the floor and wander away.

Most patients’ symptoms continue to worsen until death; there is no known cure for the disease, and most research on treatment involves attempts to slow its progression rather than halt or reverse its effects.

Typically, patients with Alzheimer’s live about eight to ten years after their diagnosis. The National Center for Health Statistics reports that in 2004, the last year for which official data are available, Alzheimer’s was the seventh leading cause of death in

America. The disease took the lives of nearly 66,000 individuals that year, pushing it up from eighth position the year before.

Contrary to the general belief that Alzheimer's only affects older individuals, it is not entirely a disease of the elderly. Although typical onset begins after the age of 60, younger people are sometimes stricken. Still, advancing age is the greatest risk factor for Alzheimer's disease; while 65-year-olds have approximately a 3 percent chance of getting the disease, those over 85 face a risk of nearly 50 percent. Some experts suspect that if people lived long enough, nearly everyone would develop the disease.

Other risk factors for the illness are not well understood, and much current research is devoted to exploring the roles that genetics and environmental factors play.

One recent study led by Margaret Gatz at the University of Southern California suggests that the heritability of Alzheimer's disease is substantial – more so than had been proven before. The study, published in the February 2006 issue of the *Archives of General Psychiatry*, was the largest on Alzheimer's to date using data from identical twins, which are scientifically considered to be the best source of data to determine the strength of genetic factors in a disease.

Gatz and her colleagues found that the heritability of Alzheimer's is between 67 percent and 88 percent - much higher than previously thought. In other words, between 67 percent and 88 percent of the likelihood of developing Alzheimer's is determined by the genes an individual inherits from his or her parents.

James Mortimer was one of Gatz's collaborators in the study.

“The general public belief is that this is not a genetic disease – that some small proportion is genetically inherited, and that the rest is caused by some strange environmental factor,” he said. “In fact, even some geneticists will say it's not really a genetic disease. This study is important because, given the fact that in the past people have said it's not a very genetic disease, we're able to say, ‘yes it is’ with about 95 percent confidence.”

The finding has important implications for researchers' hopes to someday prevent Alzheimer's. While scientists have already found one gene known to increase the risk for developing the illness, current studies are looking for others. Mortimer hopes that this

recent study will bolster efforts to uncover more of the genes responsible for Alzheimer's risk, with the goal of one day finding a gene-based prevention.

“If you know the disease is a lot more heritable, then of course you want to know how it's inherited, so you're interested in locating the genes for the disease,” he said. “The question always comes up, well, if it's 100 percent genetic or 90 percent genetic, does that mean we can't do anything about it? And the answer is, of course not. This just spurs on preventions related to genetics – in prevention of a disease, you definitely want to know exactly how it's caused.”

The known gene associated with Alzheimer's risk, called ApoE, comes in several forms; one is known to increase the risk of getting the disease. Most research in this area, Mortimer said, is aimed at changing its expression pattern. Gene expression can be thought of as the activation of a gene; when this occurs, the information carried by the gene – a sort of recipe – is turned into a certain protein. Studies have found that when the ApoE gene is excessively active, producing high levels of its coded protein, Alzheimer's risk can increase to four times that of individuals with normal levels of ApoE activity.

Although they say that a gene-based prevention is far off, researchers believe that changing the expression of the form of ApoE associated with Alzheimer's could result in a reduction of risk for the disease. In the meantime, although a blood test can determine whether a person carries the form of ApoE associated with a higher risk of Alzheimer's, such a test can provide no positive answer as to whether or not the individual will develop the disease.

Despite establishing the high genetic component of Alzheimer's risk, Gatz and colleagues still emphasized the importance of studying other potential causes of the disease. They say that non-genetic risk factors such as environment are still a viable target for attempts to reduce the risk of the illness, or delay its onset.

Despite continuing uncertainty about causes, treatment options are available for Alzheimer's patients. The U.S. Food and Drug Administration, for example, has approved five prescription drugs to treat the illness, the first of which received approval 13 years ago. The newest, approved in 2003, is the only drug available to treat moderate to severe Alzheimer's-type dementia; the other four are used to treat milder stages of the

illness. All five can sometimes delay the progression of the disease, though they are usually only effective in doing so for six months to a year.

As with many other psychiatric medications, it is not fully understood how these drugs work in the brain to relieve the symptoms of Alzheimer's disease. Namenda, the drug used to treat more severe dementia, is suspected to regulate the production of a chemical in the brain that can lead to the death of brain cells. By contrast, the remaining four medications are thought to stop the breakdown of chemicals that may be involved with memory and cognitive processing.

With no available treatments that can prevent the worsening of the disease for very long, researchers are focusing on understanding its basic mechanisms of onset and progression. One, for example, is nurse practitioner Su Cartmell, who works at the University of Pennsylvania's Memory Disorders Clinic, a part of the university's Alzheimer's Disease Center, which is highly research-oriented in addition to providing clinical care. Cartmell believes that the future of Alzheimer's research lies within in two specific areas.

The first is what she refers to as the disease's hallmark: the formation of plaque deposits in the brain. This occurs in all patients suffering from Alzheimer's, and while no one knows whether the plaque causes the disease and its symptoms or is a result of them, some experts suggest that in either case preventing its formation may lead to the prevention of Alzheimer's.

"The known pathology of Alzheimer's disease is the formation of plaques and tangles," Cartmell said, although she acknowledges the uncertainty surrounding these neurological abnormalities. "I think the future will be related to impeding that process."

Plaques are clusters of an abnormal protein, Apo E, that gather around neurons. Tangles are made up of strands of a different protein that twist together inside neurons, disrupting the normal structure of the cells and eventually killing them. Both have been known to develop in some elderly individuals even without Alzheimer's symptoms, but they unfailingly appear in the brains of Alzheimer's patients, and to a much greater extent. Experts like Cartmell believe that this inconsistency between the brains of healthy individuals and those of Alzheimer's patients supports the theory that preventing plaques and tangles could prevent the disease.

Cartmell also believes that brain imaging has huge potential as a tool for Alzheimer's research. Certain types of imaging could allow clinicians to see the hippocampus, a part of the brain involved in memory. The hippocampus is usually one of the first areas of the brain to sustain damage as a result of Alzheimer's. Such imaging could reveal disease-related changes in the area, making it possible to track the stages of the illness and measure the physiological changes related to its progression.

In the absence of such technology and until further advances can be made in the treatment of the disease, medication remains a clinician's best hope for slowing its progression. Unfortunately, as with all prescription medications, these drugs do not come without a risk of side effects. Although no drug interaction risks have been found in three of the five medications in laboratory studies, all five can cause physical side effects, ranging from headache and nausea to potential liver damage.

Still, in nearly all cases the benefits of the medications outweigh the drawbacks of the side effects, according to Cartmell.

"We are usually able to work around the side effects," she said. But even when there are no side effects, the drugs provide only a temporary reduction in symptoms or slowing of progression. In the best case, "most of the drugs would only hold the person [at their current level of the disease] for two to three years, sometimes a little bit longer," Cartmell said. For many patients, such drugs prevent the disease from advancing for only a few months. And even if they slow the progression of Alzheimer's, none of these medications can reverse the effects of the disease.

Non-prescription treatments are also used; some research indicates, for example, that taking Vitamin E can provide a small benefit to Alzheimer's patients, possibly by helping to defend brain cells against damage from so-called free radicals, which can damage molecules inside cells. In addition, making small lifestyle changes for the patient sometimes reduces sources of confusion and frustration in their daily activities. Simplifying a person's daily routines for example may aid a patient's failing memory and can sometimes reduce anxiety. In long-term care facilities for Alzheimer's patients, schedules are designed to make individuals feel more in control of their lives, and reduce the confusion introduced by participation in too many strenuous activities or variations in routine.

“We try to keep everything in the same routine,” said Sharon Heintzleman, a nurse on the dementia floor of the Cedarbrook nursing home, explaining that meals and activity times are held at the same time each day. The routine, she said, attempts to bring consistency to patients’ lives, which may be lost as their memories become unreliable. “In the beginning, in the first stages [of Alzheimer’s], patients may remember who you are, then the next day they may not remember who you are. So you try to keep everything as consistent as you can for as long as you can.”

With so few treatment options available for patients and the most affected age group growing rapidly, experts say the importance of research on Alzheimer’s disease couldn’t be more apparent. James Mortimer is one of them. Even though the results of his latest research demonstrated that his own risk for the disease is even higher than he’d previously thought – both his father and his father’s mother had Alzheimer’s – Mortimer said there is a clear benefit to the new knowledge.

“It [could] be useful for people to know their risk,” he said. People who are aware that they are at a higher risk for Alzheimer’s “are the folks who are most likely to benefit from preventions.”

Unfortunately, the preventions that some speculate may reduce Alzheimer’s risk, including vitamins C and E, mental and physical exercise, and strong antioxidants, still can’t guarantee immunity. Mortimer’s research provides a starting point for new preventive research – but not much more.

In the meantime, the population most at risk for Alzheimer’s disease continues to grow. Mortimer will turn 65 just four years from now, and one year after that, the first of the Baby Boomers will become senior citizens, a step accompanied with an estimated 3 percent risk for Alzheimer’s. Twenty years later, when they turn 85, the size of the U.S. elderly population will have doubled. By then, the Baby Boomers’ risk of Alzheimer’s will have doubled, too – four times, to almost 50 percent.

This article is the third of four on geriatric mental health. The final segment of the series will focus on research and treatment of schizophrenia in the elderly.

Part 4: Schizophrenia / conclusion

Daniela Dumitrescu immigrated to the United States from Romania at the age of six. Her mother Elisabeta, who accompanied Daniela and her older brother on the trip, was 40 when they arrived in the U.S.

Daniela doesn't remember anything unusual about her mother's behavior for the first few years after they were reunited with Daniela's father, who was already in the country. Her mother was lonely and sad, Daniela said – “we came to the States and she didn't have any family, didn't know the language, didn't know how to drive, didn't have a job” – but aside from this depression, Daniela remembers nothing out of the ordinary until the year she entered the 8th grade. That year, her mother was sent to the hospital.

“My brother and dad said she was just sick and getting tests done,” Daniela remembered. But she would find out years later that her mother's hospital stay took place under much different circumstances: Elisabeta Dumitrescu had tried to kill herself.

Elisabeta, now 57, is one of an estimated 2.4 million Americans suffering from schizophrenia, a severe brain disorder that has no cure. The cause of the disease is unknown, although there are many theories; however, its effects are unfortunately apparent. In addition to paranoid delusions and suicidal tendencies, both of which have plagued Elisabeta, schizophrenia can also result in hallucinations, disorganized thinking, inappropriate behavior, and loss of emotional response. These symptoms can lead to severely impaired communication skills, and, eventually, an inability to function on one's own. In particular, schizophrenics often let their personal hygiene and physical health slide; have extreme difficulties keeping their jobs; and lose the ability to form or maintain personal relationships. For many schizophrenics, as in Elisabeta's case, these symptoms can lead to attempted suicide. Recent studies indicate that more than 5 percent of schizophrenics commit suicide, while the risk for the general population is less than 1 percent.

Schizophrenia is primarily considered to be a disease of the young, with typical onset in the 20s or early 30s. Unfortunately, most patients continue to experience psychotic episodes throughout their lives, and the negative symptoms of the disease – including the inability to interact with others – tend to worsen with age. By the time many

schizophrenics reach elderly status, they have become so functionally impaired as to require full-time institutional care.

It is estimated that up to 180,000 Americans over the age of 65 already suffer from schizophrenia, and with the number of adults over 65 expected to more than double in the coming decades, experts fear that the late-life effects of schizophrenia in a growing number of elderly Americans could overwhelm a healthcare system that is already struggling to meet the needs of the mentally ill.

As is the case with many forms of mental illness, the effects of schizophrenia on the elderly have been given very little research attention, despite the fact that most mental disorders can affect members of different age groups in very different ways. This is particularly true for late-onset schizophrenia, generally defined as schizophrenia that first manifests after the age of 45, which has been the subject of even less research within the study of the disease as a whole. The differences in the pathologies of early- and late-onset schizophrenia are not well understood, but studies have shown that the late-onset form results in more severe and recurring episodes of paranoid delusions.

Although the late-onset form of the disease affects a far smaller percentage of individuals than the early-onset form – estimates vary, but are usually placed between 20 and 25 percent of total schizophrenia cases – experts say that the growing size of the elderly population is a strong motivation to devote more research to this form of the illness.

Earlier this year, researchers at Khon Kaen University in Thailand examined the results of 38 studies comparing the use of antipsychotic medication to other treatments for recently diagnosed elderly patients with schizophrenia or similar disorders.

They found that of the 38 studies, only one focused specifically on late-onset schizophrenia. The researchers used the results of their review to emphasize the lack of trial-based data to generate standard treatment approaches for late-onset patients, and encourage more clinical research in the field. A similar review by researchers in the U.K. found that little to no data is available to aid clinicians in deciding which drug will best treat a particular patient's schizophrenic symptoms.

Such evidence is obviously troubling, especially when taking into account the high suicide rate among schizophrenics. And in elderly schizophrenics, suicide risk may be

even higher as a result of compounding age-related issues; the age group most at risk for suicide in the U.S. is adults over 65. Experts say that those numbers could be lowered if patients could be encouraged to seek help.

“There are plenty of resources in many communities that could really help an older adult that might be struggling, if it became known that they were struggling,” said Jerry Reed, executive director of the Suicide Prevention Action Network. Reed thinks that many, perhaps most, elderly suicides could be prevented if the victims had sought help or treatment.

Even when schizophrenics don’t specifically seek treatment for their symptoms, however, they often need support from others. Because many of the symptoms can make it difficult for a patient to function normally – many schizophrenics have problems keeping jobs, for example – reliance on others for some form of care is common. This dependence tends to grow as the disease progresses, adding to an aging individual’s growing reliance on others.

Compounding the problems of schizophrenics are the usual age-related disabilities. A 70-year-old schizophrenic patient may have been living with the disease for 50 years, perhaps longer, but the added difficulties of aging can make his situation even more complicated. If he develops a physical disability that requires him to move to a nursing home, the staff will have to provide him not only with physical support, but with mental health support as well.

Such situations can result in a medicate first, think later approach that often leads to over-sedation of the elderly, says author Robert Whitaker. Whitaker wrote the award-winning 2002 book *Mad in America*, which focuses heavily on the history of treatments for schizophrenia. “This shows up in nursing homes [in particular]: as people who are older, if there’s not much [perceived] value in the quality of life those people might have, there’s such a move to just quiet them – rather than deal with the stress they might have,” he said. “You see in the nursing homes such an incredible use of anti psychotics to sedate people. It’s basically been a problem since the 1970s.”

Despite the fact that the disease has been acknowledged for over a hundred years and that situations such as the one above are not uncommon, the growth of research devoted specifically to studying schizophrenia in the elderly is a recent development. To date, for

example, most decisions about treatment options for elderly schizophrenics have not been made based on data specifically related to elderly patients. Instead, particularly in cases involving antipsychotic medications, such decisions have been based on the effectiveness of such drugs on younger schizophrenia patients, and on doctors' personal experiences with using the treatments for his or her previous patients.

This practice can be counterproductive and even dangerous when treating any mental illness in an elderly patient, most notably because of the differences in tolerance levels between older and younger patients. As people age, the way their bodies absorb and react to medication changes; recent studies have found that many elderly schizophrenics with the late-onset form of the illness *can* be treated with the same drugs used to treat younger patients, but only at a fraction of the dosage given to younger patients.

Yet even when medications are prescribed at proper dosages for schizophrenics, patients may balk at taking them. Elisabeta Dumitrescu takes antipsychotic medication that is frequently prescribed for schizophrenia to treat her symptoms, of which the most frequent is a persistent paranoia that someone is trying to harm her children. But like many schizophrenics, she has refused to take her medication on many occasions, and the responsibility has fallen on her husband and her family to ensure that she is seeing her doctors and keeping up with her treatment. In the case of elderly schizophrenics, experts say that the difficulties of keeping patient within their treatment regimens are compounded by the fact that many older individuals simply forget to take their pills.

"Most older adults are already on several medications," said Ruth O'Hara, an assistant professor of adult psychiatry at Stanford University. "They may forget which ones they've already taken, or [take too much] of one medication."

One facet of the disease that is of particular concern in the elderly is cigarette smoking. An estimated 88 percent of schizophrenia patients are heavy smokers; it is thought that in such individuals, smoking relieves some symptoms of the disease that are not typically treated by most medications. In fact, the symptoms in question are comparable to those experienced by smokers going through nicotine withdrawal.

But smoking among elderly individuals poses serious and immediate threats, even more so than in the general population. A recent European study found that smoking may increase the rate of mental decline in older adults. That increase, however, drops when a

person quits, even at an old age. Other studies have demonstrated a clear connection between the cessation of smoking and the complications associated with heart disease, as well as with a decreased risk of lung cancer – even in late-life smokers. But if a 70-year-old schizophrenic smokes to alleviate symptoms that can't be treated by his medication, should he be told to stop?

But this or any treatment-related question can be addressed, experts must face a problem that reaches beyond just schizophrenia to all aspects of geriatric mental health: getting patients to admit that they need help.

“Older adults at this point in time don't really talk about their mental health needs,” said Reed. “They come from [an age group] where that's just not done.”

Although elderly patients' fear of seeking treatment is common among all mental illnesses, the nature of schizophrenia introduces a unique problem: many patients don't realize that they're mentally ill. While a depressed person can often recognize that he or she is depressed, a schizophrenic who is delusional does not realize that what he or she is experiencing isn't real. Because patients are often unaware that their views of reality are skewed, the responsibility may fall on family members or caregivers to recognize the need for treatment.

Daniela might have had more reason to initially be concerned about her mother's depression and strange behavior if she had known more about her family's history. She later discovered that her great-grandfather had killed himself, as had her grandmother; and when she spoke with relatives in Europe about her mother's problems, she found that they were not surprised.

The Dumitrescus' experience is unfortunately not surprising in light of schizophrenia's tendency to run in families. Individuals who have a parent or sibling with the disease have a 10 percent risk of developing it themselves – ten times that of the general population. Even nieces, cousins and grandchildren of schizophrenics are at an increased risk. But the genetic factor, although established, is not well understood: to this point, researchers have identified genes that may be responsible for an elevated schizophrenia risk, but have not yet determined exactly which ones are responsible for the development of the illness.

But it is widely believed that genetics are not the only factor; even when one identical twin develops the disease, for instance, the other does not develop it in all cases.

Elisabeta Dumitrescu's schizophrenia may have developed partially in response to a psychosocial issue: her emigration from Eastern Europe to the U.S.

There is a documented higher level of schizophrenia incidence in immigrants who move from poor countries to wealthier ones. In fact, the level of risk in such individuals is higher than the risk among the populace of their home countries.

There are several proposed explanations offered for this finding, ranging from the stress of culture shock (certainly experienced by Elisabeta) to a higher tendency for immigration among individuals who are already at an increased risk for the disease (which may have been the case with the Dumitrescus as well). The risk for the disease does not seem to increase when a person moves from one country to another that is similar in wealth and health care.

Immigration is not the only social factor listed as possibly raising schizophrenia risk; many major sources of stress, including relationship problems, may be involved in prompting the onset of the disease. Physical factors that scientists suspect may affect a person's risk for schizophrenia include trauma during birth and viral infection in the womb. Such infections, which are more common during winter months, may explain the results of some studies that have found an association between schizophrenia and winter birth in North America and Europe.

None of these factors, however, are considered causes of schizophrenia; as with all of the mental illnesses in this series, scientists have still not uncovered the source of the disease. The same is true for the various forms of depression as well as for Alzheimer's disease, and while researchers continue to work to uncover the causes of these and other mental illnesses, the fastest-growing segment of the population remains at risk for all of them – possibly at a higher risk than ever, some experts say, due to the experimental drug use that was common among Baby Boomers in their youth.

Even if the cause of any one of these illnesses was discovered tomorrow, it is unlikely that a prevention or cure for the disease could be developed quickly enough to help the 36 million Americans already over the age of 65, or even those who will reach that age over

the next decade. In the meantime, patients, family members, doctors, caregivers, advocates and politicians are left with a volatile mixture of unresolved problems.

“It’s medical and social and political,” said Whitaker. “It’s such a mixture of forces that have to be dealt with. And given the fact that the country’s going broke, and you have this burgeoning population, where are we going to find the money to provide humane care?”

The problems of mental illness among the elderly run the gamut from a shortage of money for care to an unwillingness to seek care at all. In between is a shortage of caregivers, a notable lack of successful treatment methods, a dearth of research on the aspects of mental illness specific to the elderly, a lack of funding to facilitate such research, and an exploding population that is forced to suffer the effects of each and every one of these problems. With less than five years left before the first wave of this massive population growth begins, experts unequivocally agree that we are already in a crisis. The only uncertainty is whether the situation has any hope of improving – or whether it will continue to get worse.

This is the final segment of a four-part series on geriatric mental health.

ACKNOWLEDGMENTS

This thesis could not have been completed without the help of a great many people. Many of them were nowhere near Cambridge during my time at MIT, but helped keep me focused and on track (more or less) from as far as 300 miles away.

My sincere thanks first and foremost to my thesis advisor, Boyce Rensberger, who not only took on an advisee while on book leave but peppered each of my revisions with humorous comments and encouraging words, even when major edits were required. I was extraordinarily lucky to be able to work with Boyce, whose experience with both the newspaper medium and with reporting on mental health care issues was invaluable in the development of this thesis. His unmatched sense of sarcasm was a nice bonus, too.

I would also like to acknowledge the efforts of the entire faculty and staff of the Science Writing program, particularly Marcia Bartusiak, who patiently worked with me for more than a month while my thesis topic emerged from an initial sea of potential, but not very good, ideas; and Shannon Larkin, whose ability to sense and alleviate stress and despair in graduate students is unparalleled by any individual I've met in my academic career.

My classmates deserve a standing ovation and my infinite gratitude for providing insightful comments and suggestions, and for tolerating the massive mood swings that corresponded with periods of enthusiasm for and frustration with my thesis.

I would like to thank Lazar Trachtenberg at Drexel University for reviving my then-flagging interest in science; if I had not had the privilege of being both his student and his teaching assistant, I might never have made it to MIT. My sincere thanks also to Harish Sethu, Spiros Mancoridis, Albert DiBartolomeo, and Eric Gallo for convincing me to actually apply and go to MIT after nearly chickening out about fifty times.

Many thanks to my parents and to my sister, Mel – despite our differences of opinion on just about everything, they have unfailingly supported my academic efforts, for which I could not be more grateful.

No words can adequately express the thanks I owe to Andy Mroczkowski, who probably never wants to hear the word “thesis” again after listening to me complain about it on the phone practically every evening from 300 miles away. He supported me in more ways than I can mention over the course of this undertaking, not the least important of which was to tell me to shut up when I repeatedly expressed doubts about my writing ability.

Finally, I must thank the many individuals who have devoted their lives to addressing the problems raised in this work. Despite the bleak picture I have painted in this thesis, there are numerous doctors, researchers, caregivers, advocates, and patients who recognize the challenges facing the elderly in the coming decades and have taken it upon themselves to help in any way they can. It is my hope that the efforts of these individuals will someday render this entire work obsolete.

ABOUT THE AUTHOR

Michelle Sipics grew up in Catasauqua, Pennsylvania and moved to Philadelphia in 1999 to attend Drexel University, becoming the sixth of eight extended family members who eventually majored in engineering. (The family has now covered six of the discipline's major divisions, including electrical, chemical, mechanical, civil, biomedical, and computer engineering – which Michelle vehemently asserts *is* a real engineering discipline, despite others' arguments to the contrary.) In 2005, she graduated from Drexel with a Master of Science in computer engineering.

Sipics enjoys writing about many aspects of science, including communications technology, applied mathematics, and matters of public health. Her career goal is to disprove the widely adopted notion that engineers, as a matter of principle, cannot write.

REFERENCES

In developing this thesis I conducted interviews with patients and their family members, clinicians, caregivers, researchers and advocates. The results of many of these interviews can be found throughout the thesis in whole or in part, though some names have been withheld at patients' requests.

Listed below are organizations from which I gathered and verified statistical information, as well as additional recommended material for the interested reader. Any publications used to provide statistical information were quoted directly in the thesis text and do not appear below.

Agencies and organizations

Alzheimer's Disease Education & Referral Center of the National Institute on Aging

American Association for Geriatric Psychiatry

National Alliance on Mental Illness

National Institute on Aging

National Institutes of Health

National Institute of Mental Health

U.S. Census Bureau

U.S. Department of Health and Human Services

U.S. Department of Labor

U.S. Social Security Administration

Additional recommended reading

Jamison, Kay Redfield. *An Unquiet Mind: A Memoir of Moods and Madness*. New York: Random House, 1997.

Whitaker, Robert. *Mad in America: Bad Science, Bad Medicine, and the Enduring Mistreatment of the Mentally Ill*. Cambridge: Perseus Publishing, 2001.