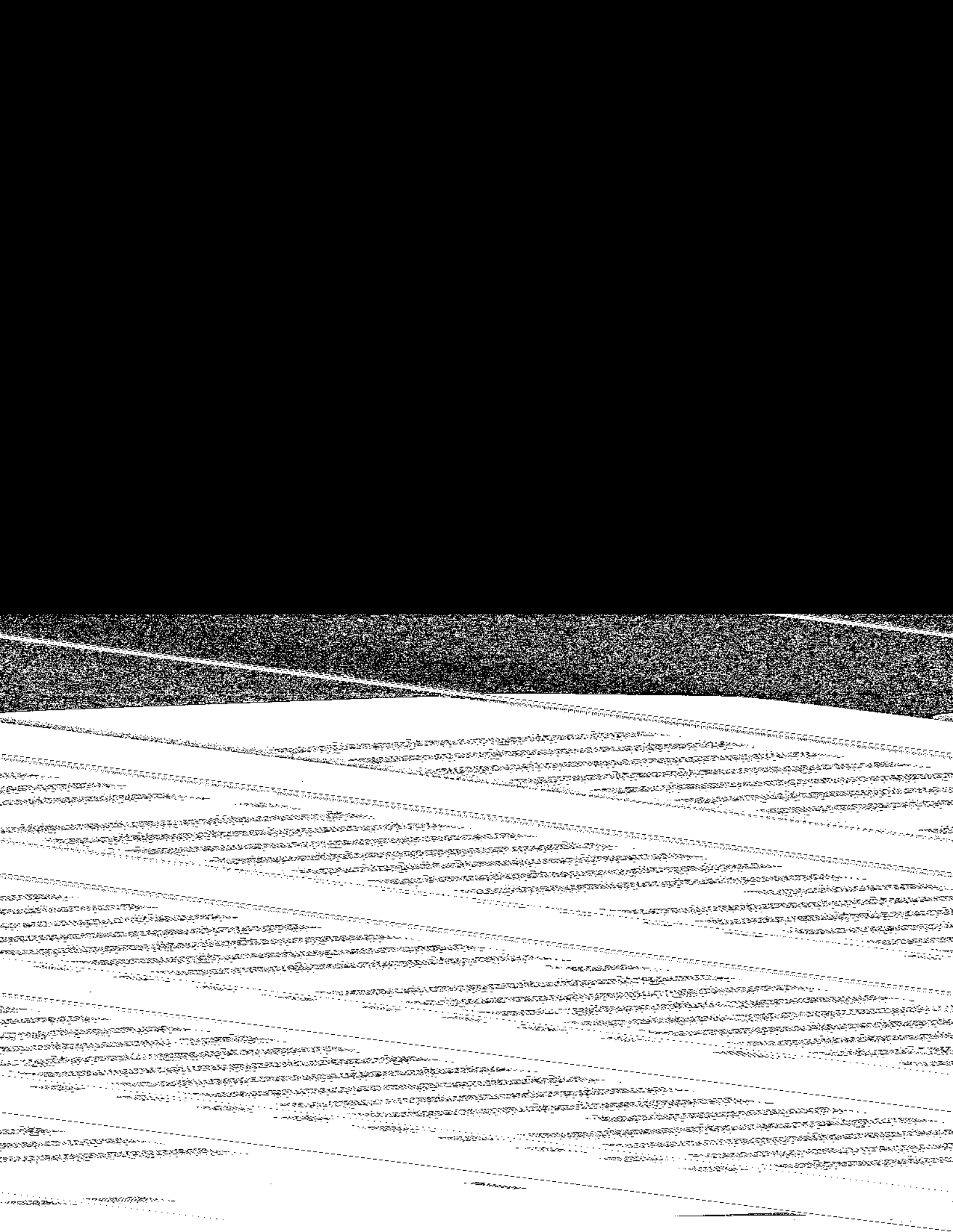

monies to end with mass weeping, involving hundreds or even thousands of people shedding tears, wailing, and hitting themselves on the head and chest. Despite globalization and creeping Westernization, in Islamic societies and most other traditional Eastern societies, there is still a tendency to see a constructive and even necessary role for moods akin to sadness, melancholy, depression, and other experiences that in the Western context would typically be shunned, stigmatized and treated as illness.

Even studies conducted by Western-trained researchers, using instruments geared to identify depression in the Western model and focusing on participants (typically university students) who are part of the modern Westernized sections of non–Western societies, have uncovered cross-cultural differences in the domain of depression. A consistent finding has been that depressed individuals in Western societies report feelings of guilt and self-blame, as well as mood states such as loneliness and anxiety, whereas guilt does not seem to be part of the experiences akin to depression in non–Western societies, where the focus is less on internal mood states and more on somatic symptoms, such as bodily pain and fatigue. Even when researchers translate the term *depression* into other languages, in which often there is no direct translation, and squeeze the experiences of non–Western people into the Western mold, it is clear that depressed individuals in the West tend to focus on internal mood states and their independent experiences, whereas individuals in non–Western cultures typically look outside and refer to rain, seasons, fate, and numerous phenomena outside the self to explain their experiences.

Concluding Comment

From the perspective of Western medical models, depression is an illness with specific dispositional causes, and the treatment of depression in practice focuses on changing aspects of the individual. Practical and particularly economic limitations mean that drug therapy is at the heart of treatment, and sometimes actually the only treatment, and so Prozac and other drugs are in danger of taking on the role that soma plays in Aldous Huxley's *Brave New World*. There is a real possibility that anyone unable to conform to the norm of a positive self-presentational style will increasingly come under pressure to use drugs to "make themselves better," just as people in *Brave New World* were expected to use soma to avoid negative moods. Not surprisingly, in this normative system those who slip back into feeling "bad" also experience guilt; after all, they are doing something wrong because they are not presenting themselves as happy-

This focus on the individual completely misses an essential point: Depression can be sustained through carriers that are interwoven in family and personal relationships, a style of small-group life that often transcends generations and impacts the lives of different age groups. The case of Mary is not atypical. Drug therapy could help Mary improve if she were left alone, but no person is an island, and the web of personal and family relationships in which Mary was enmeshed pulled her back into depression again. This is not to suggest that therapy should focus exclusively on family and personal relationships, but that it should seriously attend to them.

There is also a need to reconsider the treatment of varieties of emotions in the larger society. In the United States in particular, far too high a priority is now given to positive self-presentation, leaving too little room for a whole variety of emotions that do not fit in with the "I'm great!" image. Sadness, gloominess, and various negative emotions are part of the natural range of human experiences. They allow human beings to feel deeply and differently, to become more creative and original, and just because they are not "fun" does not mean they should be a cause for taking "happy pills." The growing literature on depression and creativity suggests that there is great value in negative moods. Humanity would be a lot poorer culturally if we all opted for sustained fun and happiness: One wonders what Van Gogh would have painted if he had been on Prozac.

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14 Alzheimer's Disease and the "Margin of Performance Expectations"

Dr. M, a woman living in a major U.S. urban center, has two advanced degrees and had been a professor for decades. She had enjoyed the role of teacher and the opportunity to use her finely tuned communications skills with students. It was particularly painful for her when she began to experience word-finding and memory problems. By the age of 75, standard psychological tests revealed her to have decreased ability in a number of cognitive areas, consistent with dementia. Dr. M had built a successful academic career and achieved high social status through her memory, verbal abilities, and intellect generally, but she was now cruelly being deprived of just these assets.

Aging brings with it biological changes that influence performance capacity: how well we do on traditional tests of abilities, which typically assess us in isolation in examlike situations. Our capacities for hearing, seeing, sensing touch, and so on are diminished once we reach adulthood and the years march on. Accompanying this are changes in performance style, so that the meaning of behavior is transformed as we get older. Even when we behave in the same manner as we did when we were younger, *others now have different expectations of us and interpret our behavior differently.* When a 35-year-old professor forgets where she put her keys, this event is likely to be taken as just another indication that she is an absent-minded professor. Students, friends, and family will jokingly recount such incidents as evidence that she really *does* fit the stereotype. However, a 65 year-old professor who forgets where she put her keys is more likely to be seen as suffering from dementia. "Her mind is going," people will say.

In this chapter we explore the *margin of performance expectations*, the difference between the actual performance capacity of individuals and the expectations that others have about their performance. Using the example of seniors with a particular degenerative disorder, I shall argue that there is a strong tendency for the expectations of others to influence the behavior of individuals

All things being equal, *the larger the margin of performance expectations, the poorer will be the performance of individuals compared to their actual performance capacities.* For example, if Joe is a 75-year-old who has the capacity to score 90 out of a 100 on a particular language test, he will score closer to 90 if the expectation is that he will score 89 than if the expectation is that he will score 19.

The margin of performance expectations is sustained by carriers, such as the physical carrier represented by an "old body." Biological aging has clearly visible signs, such as wrinkled skin, white hair, and the like, and the physically aged body is a carrier of specific stereotypes —"Old people have poor memories," "Old people are not technologically sophisticated," and so on. Just the physical appearance of an old person can trigger in the mind of observers stereotypes about seniors, leading to a huge margin between what that senior can actually do and what the holder of the stereotype expects him or her to be able to do. Expectations can put pressure on a senior to underperform, to do what is expected rather than what he or she is actually capable of doing.

While the biological process of aging is gradual, the social process of changed expectations for correct behavior can be sudden and rapid. In the case of Dr. M, the shift in social expectations was even more dramatic because (1) she was now seen as old and (2) she was diagnosed as having Alzheimer's disease. *Alzheimer's disease*—named after Alois Alzheimer, the German physician who first identified it in 1907 –is a degenerative disorder that destroys the brain, robbing victims of memory, sense of identity, and decision-making abilities, leaving them dependent on others. Dr. M was now labeled in such a way that her remaining abilities suddenly went unrecognized.

Although Alzheimer's is a progressive disease, often taking years and sometimes even decades to have severe effects, the shift in social relations for those suffering from Alzheimer's disease can be sudden and swift, a matter of days or even hours or minutes. Once labeled as having Alzheimer's disease, an individual quickly becomes enmeshed in dramatically changed social relationships, with the individual expected to play the role of a dependent, ill person. There is pressure to conform to the changed social expectations, and by conforming and taking on the role of a dependent, ill person, the Alzheimer's sufferer participates in the collaborative construction and objectification of the new social context. The expectations of others with respect to the performance of the person with Alzheimer's disease become fulfilled.

Consequently, although Alzheimer's is a disease affecting biological processes within individuals, to understand the actual deterioration of the Alzheimer's sufferer it is often necessary to consider the larger social context and societal characteristics. To better appreciate the urgency of attending to this situation, it is useful to consider the demographic changes taking place and the prevalence of Alzheimer's disease.

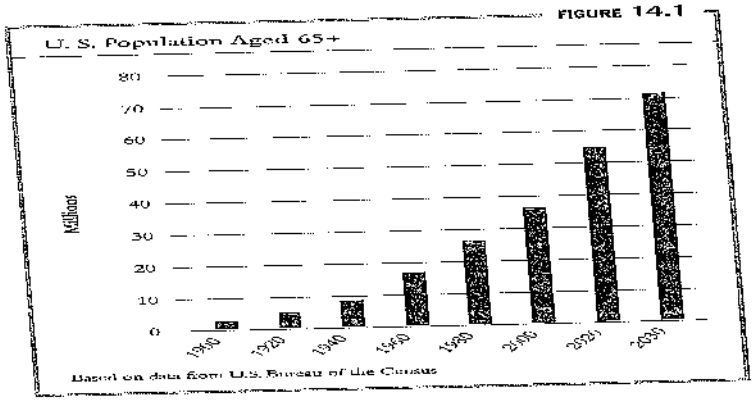
Demographic Trends and the Performance Capacity of Persons with Alzheimer's Disease

Why is it important to attend to the problems of Alzheimer's sufferers? What do we know about the biological causes of the disease? By addressing these two questions, I shall prepare the way for an exploration of the social and cultural aspects of Alzheimer's disease.

The Aging Population and Alzheimer's Disease

Alzheimer's disease represents a major challenge to modern societies because of the aging population and the prevalence of this disease among the aged. Since the beginning of the twentieth century, life expectancy has increased markedly, particularly in the United States (see Fig 14.1) and other Western societies, leading to a sharp rise in the number of elderly people and therefore

FIGURE 14.1



Based on data from U.S. Bureau of the Census

the incidence of dementia associated with aging. Alzheimer's disease accounts for about half of all dementia cases in the United States.

But Alzheimer's is not just a challenge for industrial societies. In 1975, about half the world population over 60 years of age lived in lower income countries. By 2000, more than 60 percent of people over age 60 lived in lower income countries, and by 2025 this figure will have reached almost 75 percent (see Table 14.1). How this aged population will be affected by Alzheimer's disease is suggested by trends in the United States, where the affliction rate is 2 percent of people aged 65, 4 percent by age 70, 8 percent by age 75, 16 percent by age 80, 32 percent by age 85, and almost 50 percent of people over 85. However, there are indications that the rate of increase drops off for the very old. In sum, the number of Alzheimer's sufferers increases exponentially every five years after the age of 60 and plateaus sometime after the age of 90. In the United States the number of Alzheimer's sufferers is already over half a million.

At the personal level, Alzheimer's disease is the cause of considerable suffering for both victims and their families and friends. The disease progressively worsens over a course of anywhere from 2 to more than 20 years. It starts to manifest itself when victims have difficulty keeping focused on a task and have lapses of memory. Eventually, the afflicted person cannot concentrate even on important things and forgets essential bits of information, such as the names and telephone numbers of close family members. As the disease robs victims of basic cognitive abilities, including the ability to recall simple events, persons, and places, normal functioning as an independent person becomes increasingly difficult—and eventually impossible. Social relationships break down. The victim eventually becomes completely dependent on others.

This deterioration is extremely painful for both victims and their loved ones. The victim may at first deny that any change has taken place, explaining away memory lapses as simple "forgetfulness." However, as memory deteriorates and decision making gets poorer, the victim reaches a point where even close family members, such as a spouse or children, are not recognized. Even

TABLE 14.1

Population aged 65 and over (in millions)

	1980s	2000	2020
Higher income countries	128	166	230
Lower income countries	132	237	530

Based on data from the United Nations

when reminded that "this is your wife, who has lived with you for 40 years," a victim may ask "Who is this?" when his wife returns to the room after an absence of just a few minutes.

At the economic level, Alzheimer's disease is contributing substantially to the increased costs of health care. In the United States alone, the disease is estimated to cost over $100 billion annually. The health care crisis confronting the United States and other Western societies is associated with the ballooning cost of caring for Alzheimer's sufferers. Clearly, on both humanitarian and economic grounds there is a need to try to meet the challenge of Alzheimer's disease.

Performance Capacity and Alzheimer's Disease

Physical change is part of normal aging. Our bodies change a great deal when we develop as youngsters, and change is just as dramatic during old age. But not all parts of our body change at the same rate. Age-related changes in the central nervous system—the spinal cord and the brain—are selective. Although we experience substantial neuronal loss in some parts of the brain, other regions remain relatively unimpaired.

As people age, neurofibrillary tangles, made up of twisted protein fibers, develop within the cells of those parts of the brain associated with memory and other vital cognitive functions. In addition, increased numbers of senile plaques appear in parts of the brain. This is a normal change experienced by most or all older people, but it occurs to a much greater degree among persons with Alzheimer's disease. At the same time, these individuals experience particularly marked abnormalities of certain neurotransmitters. Neurofibrillary tangles, senile plaques, and neurotransmitter abnormalities all contribute to impairment of communication between neurons, and this in turn may cause loss of memory and other cognitive functioning. Over the next few decades, medical research is expected to arrive at a better understanding of what causes these problems and also to develop more effective medical responses. But we have a long way to go on this front.

Given that some level of neurofibrillary tangles and other such changes are a normal feature of aging, why is it that some people age without suffering from Alzheimer's disease but others fall victim to it? Studies have established that one group of Alzheimer's sufferers are from families with a higher than normal prevalence of the disease, which suggests a genetic basis (although it does not exclude the possibility that environmental factors, such as family climate, play an important role). Even if some cases of Alzheimer's disease prove to be caused by infectious agents, as proposed by some researchers, this raises the likelihood that some individuals are genetically more predisposed to this disease. Comparisons of positron emission tomography (PET) scans of the brain

and genetic tests of members of families prone to the disease suggest it may be possible to predict *the likelihood of* Alzheimer's years, perhaps decades, before the symptoms appear.

However, another substantial group of Alzheimer's sufferers do not have a family history of the disease. This suggests an important role for environmental factors, as well as for complex interactions between genetic and environmental factors. Among the more obvious environmental risk factors is that of head injury; for example, through involvement in certain types of employment and sports. But a more subtle environmental factor is suggested by the relationship between education and Alzheimer's disease: There is the strong probability that individuals who remain mentally active in old age will be more likely to postpone or even evade Alzheimer's disease.

Carriers, Performance Style, and Alzheimer's Disease

In the search for solutions, it is important to go beyond issues of performance capacity and to attend with care to issues of performance style, the meaning of behavior, and the carriers that sustain meanings. This approach requires closer attention to culture and the details of everyday social interactions.

Searching for Solutions

Ours is the age of science and technology. We tend to see all human health problems from a medical perspective and to place our faith in technical solutions. Not surprisingly, the main focus in the search for solutions to Alzheimer's disease has been biological research. Some progress is being made in discovering biological changes associated with Alzheimer's disease, in identifying and predicting susceptibility to the disease, and even in finding possible remedies. For example, cell repair may provide practical solutions to at least some cases of Alzheimer's disease in the next few decades. But like other biological solutions to Alzheimer's disease, there are a lot of uncertainties in this approach. We cannot be sure as to when research projects will yield practical solutions or which research avenues will ultimately prove successful.

The urgent need for more immediate solutions is underlined by the suffering of the increasing number of people afflicted by Alzheimer's disease in both Western and non-Western societies, as well as by purely practical economic challenges. In the United States alone, if the onset of Alzheimer's could be

delayed in individuals by five years, there would be an estimated annual savings of more than $50 billion in health care costs. Western nations are finding it difficult to bear the heavy health care costs of Alzheimer's disease, but the costs are an even greater challenge for third world societies already struggling to make any real economic progress. Clearly, we cannot wait for the far-off solutions promised by biological research; immediate solutions are needed.

A very promising path to solutions *is* at hand. This path has been opened up by researchers looking at the social relationships of Alzheimer's sufferers. By contrasting change at the biological level and change at the level of social relations, an important insight has been gained. Although Alzheimer's disease typically involves biological change that spans many years and even decades, change in social relations for Alzheimer's sufferers is often very rapid and dramatic. Change in social relations can occur instantly, as soon as psychological tests are completed and a person is labeled an "Alzheimer's sufferer." In one moment, perceptions change and the still-intact abilities of Alzheimer's sufferers are overlooked.

The dramatic and powerful impact of this kind of labeling has been demonstrated in numerous different settings, including the classroom. Research shows that when children are given a positive label, such as "gifted," their academic performance can improve markedly, in large part because of the changed expectations of not only themselves but also of teachers and other key people in the social environment. This happens even when the tests on which such labels are based have no objective merit and the children labeled "gifted" are selected purely on a chance basis.

At least since the 1950s, sociologists have demonstrated the powerful impact of labeling and stigmatization on individuals and groups. Study after study has demonstrated that those who are labeled come under tremendous pressure to adapt their self-conceptions, such that they come to think of themselves in the way that they are labeled. Of course, this does not mean that all minorities have low self-esteem and feel stigmatized. The ghettoization and marginalization of minority groups can serve as mechanism for self-protection under certain conditions. The redefinition of "Black as Beautiful" was no doubt influenced by such processes. But in situations in which a single individual, such as an Alzheimer's sufferer, comes under pressure from powerful medical, professional, and familial forces, it is more likely that labeling will have a negative and major effect on the target.

Stereotypes as Carriers

Imagine that a huge publicity campaign is launched by government security forces with the purpose of catching a group of terrorists suspected of planning a

bomb attack. Photographs and descriptions of the suspected terrorists are published in all newspapers and broadcast on television, and all your friends notice a striking resemblance between a picture of one of the terrorists and you. For a while you laugh about the "joke," but after being stopped and searched several times by police, the situation stops being funny. Each time you go out in public, to shop or to go to a movie or restaurant or for some other reason, you are anxious that people might see you as a terrorist. This threat in the air begins to make your life uncomfortable. After a week, the real terrorists are captured and the threat evaporates for you. However, for many seniors the threat of being stereotyped as an "Alzheimer's type" is real and very difficult to shake off.

Being social constructions themselves, stereotypes are well adapted to survive through numerous carriers. For example, plays, songs, and jokes and "humorous" stories with ethnic characters serve as powerful carriers for stereotypes about ethnic minorities in Western societies. Even at the turn of the twenty-first century, one can find demeaning sculptures of African Americans in the gardens of some houses in the southern parts of the United States. All kinds of artistic works serve as carriers for stereotypes, many of which are about groups of people deemed to be mentally ill.

Fortunately, there are many effective strategies for dealing with such "threats." Individuals diagnosed as suffering from Alzheimer's disease do not just passively conform to the stereotype of what an Alzheimer's sufferer is supposed to be like. Other people may assume them to have no memory or cognitive or social abilities left, but they often try to find opportunities to use and demonstrate their abilities that are still intact. Such opportunities may not arise in many contexts, but when they are available they are often snatched. The following cases illustrates this point.

Mrs. D had been diagnosed with Alzheimer's disease when she was 65 years old. By the time she was 70, standard tests assessed her as moderately to severely afflicted. She experienced frequent word-finding problems, she failed to remember some basic things (such as her age, the day of the week, and the year), and she could not coordinate her movements to accomplish some everyday tasks (such as getting food to her mouth). According to her husband, she might have suffered from delusions. For example, when her husband drove her to a day-care center, she would urge him to hurry so that she would not be late "for work."

The label "Alzheimer's sufferer" could easily have led others, even her husband, to view Mrs. D's behavior as "delusional." However, a more careful and detailed investigation into her situation revealed that her concern for not being late "for work" made good sense. Mrs. D's "job" was to serve as a morale raiser, to be the "life of the party," at the day-care center she attended. She had been brought up in a show business family, and she still knew numerous songs and jokes. She would sing and tell jokes and get people singing and laughing along.

with her. Although her husband reported that she did nothing around their home, Mrs. D did a lot around the day-care center. She helped set tables for meals, moved furniture around for different activities, helped people in wheelchairs get around, alerted staff to people needing attention, directed people to bathrooms. She would strike up conversations with people who seemed isolated, and the staff at the center began to rely on her to help them lift the spirits of individuals doing poorly. She even cheered up staff members.

Although Mrs. D was not officially employed at the day-care center, the work she had taken on was important, both for her personally and for the rest of the people at the center. She served a highly useful function. She also made herself useful in other ways, such as by volunteering as a participant in research projects at the National Institutes of Health. Clearly, this kind of "job" gave a great deal of satisfaction, because she was willing to expose herself to psychological test batteries on which she knew she performed poorly. It was more important for her to do the job of being useful than it was to "look good" on tests in front of psychologists and others.

Mrs. D seemed to have developed two separate existences. At home, she was passive and did not seem able to participate in activities. She showed little initiative and was more dependent. In the day-care center, however, she had a "job" and performed her "duties" conscientiously. She showed initiative and seemed to get satisfaction from participation. One explanation for this is that after she was diagnosed with Alzheimer's disease, her intact abilities were overlooked in the home environment. She could not do a lot of routine things and she could not remember many routine bits of information, and this seemed to conform to the idea that she was completely dependent. It was overlooked, by her husband and others, that there was still a great deal she could do. Her intact abilities had an opportunity to blossom in the day-care center. One of the interesting things this points to is the positive role some types of day institutions can perform in caring for Alzheimer's sufferers.

A great deal of criticism has been leveled at total institutions as a solution for the aged, and for the most part rightly so. Total institutions have typically restricted old people and robbed them of opportunities to remain active. However, some part-time day-care centers have been much more successful — economically because of their lower costs and in terms of health because they often allow participants to remain more active.

The Margin-of-Performance Expectations and Scaffolding

Despite the shortcomings of Western societies in coping with the challenge of old age and Alzheimer's disease, the actual coping strategies of individual Alzheimer's sufferers provides some hope. As Steven Sabat and others have

recently documented through detailed case studies, Alzheimer's sufferers adopt a variety of different coping styles, many of which are aimed at influencing change rather than just remaining passive in the face of it. The cases of Dr. M, briefly discussed earlier in this chapter, and Mrs. D represent contrasting coping styles. Dr. M tried to cope by withdrawing from the activities of the day-care center, by simply avoiding all social interactions that threatened her status and showed what she *could not do*. She made a point of having minimal exposure to psychological testing situations. As she put it, she did not want her life to be one of "always going to see people to see what's wrong with me." She withdrew from an Alzheimer's support group because she did not want to embarrass herself in a group setting, where she found her level of speech very limited compared to what it had been previously. From one perspective, Dr. M's strategy seems passive, because she withdrew from activities. But from an alternative viewpoint, her strategy was active and intended to maintain greater control of change, to not allow herself to be pushed along by forces she could not influence.

Mrs. D also adopted a combination of coping styles. In the home setting, she coped with change by retreating, by doing very little, and by allowing her husband to direct activities. But her behavior changed dramatically in the day-care center, where she was continually diving into social situations in order to initiate change, exert influence, help others, and thus gain status in this new social context. Mrs. D was interested in changing her own label from "patient" to "helper," from receiver of help to giver of help to others. Unlike Dr. M, she went out of her way to be a participant in psychological research. It mattered so much to her to be seen as a "helper," "volunteer," and "active" that she was willing to take tests that she knew revealed her inabilities on even simple tasks. Also, it was exactly because she could have said "no" to the opportunity to participate in research that it was more attractive to her to demonstrate her active and participatory nature by saying "yes." Such cases underline the strong role of social context and societal expectations in the development of even those aspects of experience, such as suffering from Alzheimer's disease, that may at first appear to be based purely on performance capacity and biological processes.

But the individual with Alzheimer's disease needs effective professional support to cope with the enormous challenges confronting him or her. One way in which such support can be provided is by training professionals and family caregivers to use a method akin to scaffolding, a Vygotskian strategy we discussed earlier in Chapter 11. In the following, Steven Sabat (S.R.S) demonstrates this method while interacting with "B," an Alzheimer's sufferer:

S.R.S: The other day you mentioned that you had some problem with (name of the program director). Does that strike any familiar notes?
B.: Every so often I, I get uh, frustrated with him.

S.R.S: This is (name) –with the moustache?
B.: Yeah, yeah. I like him very much. Um, he, he goes to a, let's see how could I do it? I'm very not nasty with him at all whatsoever, and but uh, every so often, uh, uh, the uh, Barnum and Bailey– it's the Barnum and Bailey that I don't like.
S.R.S: You mean it's like a circus around here?
B.: Oh yeah. It's a big, tremendously big circus . . .
S.R.S: All of the chaos becomes very difficult for you to deal with?
B.: Yeah . . . –Sabat, 1994, p. 337

In this interaction, Sabat makes the connection between what the Alzheimer's sufferer says and a circus, and directly asks: "You mean it's like a circus around here?" Next, Sabat asks if it is the chaos that is difficult to deal with, and the Alzheimer's sufferer confirms this. What we have here, then, is a collaborative process, whereby a scaffolding is constructed to help the person with Alzheimer's disease express his intended meaning. Because the margin of performance expectations is minimal, and because of scaffolding support, the Alzheimer's sufferer is able to communicate better than his individual performance capacity alone would allow.

Concluding Comment

Over the next few decades there will be enormous moral and economic pressures to find effective solutions to the problems of the rapidly increasing population of Alzheimer's sufferers. Effective and affordable medical treatment in the form of drug therapy does not seem to be at hand in the immediate future and may not be available for many years to come. But the detailed, innovative, and truly insightful research of a small handful of scholars, as discussed above, suggests that the situation can be alleviated in major ways. Such research can help to better educate both professionals and family caregivers.

Negative stereotypes about old people generally, and Alzheimer's sufferers specifically, mean that the margin of performance expectations is often very wide: Caregivers and even professionals, as well as the general lay public, tend to expect a person labeled as an Alzheimer's sufferer to communicate poorly or not at all and to be cognitively impaired in serious ways. But this expectation can often be wrong, particularly in the early stages of the disease.

Although the biological changes associated with Alzheimer's disease can take many years to have a serious impact, the labeling of a person as an Alzheimer's sufferer can have an immediate and terrible impact. Standardized tests on

an isolated individual, assessed out of social context, can in a matter of minutes negatively label a person and lead to dramatically changed expectations for behavior. As long as standardized tests focus exclusively on performance capacity and ignore performance style and the carriers that sustain meaning systems, they will continue to be part of the problem rather than the solution to the plight of individuals with Alzheimer's disease.

On the other hand, appropriate training for caregivers and professionals can allow a person who is identified as being in an early stage of Alzheimer's disease to function adequately and at least semi-independently for many years. Part of such training should be the use of scaffolding—providing support to Alzheimer's sufferers so that they can communicate more fully in order to express their intentions more clearly.

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