Divided Gazes

Alzheimer's Disease, the Person within, and Death in Life

ANNETTE LEIBING

Starting in Brazil

SCENE 1: It was my first day of observation at a small psychogeriatric outpatient clinic, part of the Institute of Psychiatry at the Federal University of Rio de Janeiro (UFRJ).¹ This was one of my field sites for my study of the psychiatry of aging.² In came the first patient, a small, friendly woman of sixty-four. She sat down in front of the attending psychiatrist, Dr. Fisz, and told him in a coherent manner that lately she had been feeling constantly depressed.³ She explained that her family had once been large, but now the kids had left home and her husband did not like to go out. "I withdrew from life." The psychiatrist asked her questions about her general health and requested that she come back for a battery of medical and neuropsychological tests, an electroencephalogram ("just in case"), and some blood tests. He prescribed an antidepressant and recommended that she attended a church group. He told me, after she had left, that he was considering the possibility of Alzheimer's disease, something that astonished me, since the woman's narrative had made sense to me and her self-diagnosis of depression fit exactly into my lay diagnostic schema.

SCENE 2: Some weeks later, a Canadian visitor came to the clinic. She was a social psychologist responsible for a World Health Organization (WHO) project in Brazil. She accompanied me one morning to observe some psychogeriatric treatments. A resident in psychiatry was applying the CAMDEX (Cambridge Examination for Mental Disorders of the Elderly) neuropsychological test (Roth et al. 1986) to an older woman who was sitting at a small table with her daughter. The young resident was charming and the patients liked her, but she was a bit bored by the repetitive task of administering the test to almost everybody

who came to the clinic. After giving us permission to observe the session, the resident continued with her task, but interrupted the test to explain to the Canadian visitor the elderly woman's condition. Embarrassing details of the patient's life and "misbehavior" were revealed as if the person about whom she was speaking was not even present. The Canadian visitor was visibly shocked and tried to stop the explanation, but was reassured by the resident that it was all right.

SCENE 3: Very soon it became evident to me that many Brazilian family caregivers located the origins of Alzheimer's disease in the affected person's life, a hard life with which the person was not able to deal (Leibing 1997, 2002a).⁴ I mentioned this at the weekly *sessão clínica* at the Institute of Psychiatry, where that week a case of dementia was being discussed by doctors, other health professionals, and students. One of the psychiatrists stood up and told me that he doubted my account, since he saw numerous patients and no one had ever brought this up with him.⁵

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What do these scenes have in common, besides revealing how differently certain symptoms related to dementia can be understood by various social actors? And with this question comes another: how do different epistemic cultures (Knorr-Cetina 2000) matter to the person diagnosed with dementia, if at all? In this chapter I argue that the scenes described above reveal two major ways of dealing with dementia, generally perceived as opposed to each other. One is based on an epistemic culture within biomedicine, often described as neutral, natural, and universal (see Gordon 1988). The other is based on "psy sciences," perceived by many as subjectifying and directed toward interiority (see Rose 1998). Although I draw on my fieldwork in Brazil, my argument is that these vignettes point to a *general* structure in Alzheimer's care and research that is independent from the Brazilian context and that is in need of being problematized.

It is easy to detect the two opposed epistemologies—the two gazes—in the vignettes above. The first scene is about a potential forgetting, something the psychiatrist was reading through the lens of the signs of a depressive mood. The patient, as the observing anthropologist, perceived the symptoms as embedded in the life of the elderly woman; the psychiatrist interpreted her sadness as the first sign of an underlying brain disease.⁶ This scene is from a time (1995) when public awareness about Alzheimer's, "the disease of the century," was spreading in urban Brazil—as had occurred ten years earlier in North America (Leibing 1998, 1999).⁷

In this psychogeriatric unit, Alzheimer's was suspected, or at least investigated, in nearly every patient, although it was a unit for mental health in

general. This felt persecutorial to me at the beginning of my fieldwork, but I also respected Dr. Fisz's knowledge, as he was one of the country's leading geriatric psychiatrists. Reasons for this rather exclusive focus on Alzheimer's include a general recognition of the rapidly growing number of elderly persons in Brazil (Veras 1994) and the discovery of this population as consumers and voters; the growing number of articles in scientific journals pointing to a promising new field; an extensive discussion of matters related to aging within the general media (Leibing 2005); and the desire of some to gather a sample for future publications or pharmaceutical trials in this emerging field of expertise. My initial feeling was that many elderly people were transformed through this sometimes hypothetical diagnosis into something "less alive," a new kind of being. In the mid-1990s, in the both popular and professional literature, Alzheimer's was regarded almost exclusively as a "loss of self" (Cohen and Eisdorfer 1986).

In the second scenario above, the resident considered the old woman to be too far removed from reality to be part of "us." The Canadian visitor, who at that time was herself dealing with a close friend's suffering from Alzheimer's disease at home, saw in front of her a disabled person who somehow, despite having difficulties, still shared a common reality with the people around her.

IT WOULD BE EASY to see these vignettes as proof of reductionist (mostly) biomedical perceptions and interventions, as opposed to humanistic biopsychosocial approaches in the social sciences and many health professions. This dichotomy, though, is too simplistic when aligned with the moral categories of good and bad rather than being viewed as belonging to the history of thought. The dichotomy has roots in the old division between *Naturwissenschaften* and *Geisteswissenschaften* (see, for example, Taylor 1999; Rouse 1991; Latour 2004). I do not want to focus on the roots and origins of these two strands of science, in addition to their common history, as others have done this already (see note 12). Rather, I argue that this opposition is, in reality, much more complex and intertwined. I do so by taking a closer look at the "personhood movement" and its recent history of rescuing "the person within"—and how the tenets of this movement have been incorporated into biomedical care.

The personhood movement needs to be seen in a wider context. It is often defined as holistic care that acknowledges the fading self of the Alzheimer's patient. It is explicitly opposed to biomedical epistemologies. Indeed, following Foucault (1966), I argue that the personhood movement problematizes the prevailing biomedical discourse on Alzheimer's disease. The movement apparently introduced uncertainty and a loss of familiarity to this prevailing biomedical discourse on Alzheimer's, something that Foucault considered essential for a problematization, because it requires a certain detachment from that phenom-

enon as something taken for granted (see Foucault 2003). Consequently, the task should not be to repair the conflict between two epistemologies, as in biomedicine and the personhood movement, but “to understand and to put forth a diagnosis of ‘what makes these responses simultaneously possible’” (Rabinow 2003, 18ff.).

Personhood Wars

Personhood, in general, refers to the person within—the reflexive, immaterial, communicable essence of a person that is located deep within the body, but that is sometimes veiled by symptoms.⁸ Symptoms to be treated by medical doctors, such as depression or forgetfulness, are localized in the brain. Making these pathologies visible has been important throughout the history of Alzheimer’s disease. Nonetheless, both the staining of nerve cells by Alois Alzheimer at the beginning of the twentieth century and positron-emission tomography (PET) scans and other forms of brain-imaging technologies nowadays show overlapping results for “normal aging” and pathologized brains.⁹ It was common in the mid-twentieth century to evoke personhood (meaning personality) as the factor that made the difference. For example, Harvard psychiatrist David Rothschild wrote in 1941 that “the person’s capacity to compensate for the damage [of senile lesions] seems to be the factor which determines whether or not a psychosis [that is, senile dementia] will occur. Here one must reckon with unfavorable traits of personality, innate or acquired, which may be associated with a weak capacity . . . , but psychological stress and strain may also play a role by lowering the patient’s resistance” (Rothschild and Sharp 1941, 53; see also Leibing 1999, 2000; Ballenger 2000). Since the beginning of the 1990s, compensation has been derived from the “brain reserve capacity”—the notion that a higher degree of education or IQ (sometimes also the size of the brain) results in a later appearance of symptoms. Although “this relationship may be an indirect one” (Coffey 1994), brain reserve capacity is now invoked to explain apparent mismatches between observed degrees of neuropathology (for example, the so-called plaques and tangles of Alzheimer’s disease) and measurements of cognitive performance. Most biomedical reasoning regarding Alzheimer’s is related to *cognition*.

From the point of view of the psy sciences, which encompass the previously mentioned personhood movement, the difference in question is not only the assumed materiality of the brain or of genes in biomedicine versus the immateriality of the person or self, comparable to what once was the soul, but also that the latter approach is linked to a personal narrative, to communication, and to the ethics of good caring. The biomedical care of persons suffering from senility is therefore often seen as iatrogenic, in its denial of personhood and is thus causing premature social death.

SCENE 4: In 1997 the Institute of Psychiatry in Rio de Janeiro received an unusually high level of funding from the Ministry of Education to build a center for the elderly (CDA) within the Federal University of Rio de Janeiro. Although the center was intended to treat all mental health problems in those over fifty-nine years old, the then director of the Institute of Psychiatry determined that the name of the center should contain the word *Alzheimer's*, to call attention to the disease and possibly result in more funding.¹⁰ Alzheimer's, in 1997, was the disease of the moment.

The center's multidisciplinary team, however, faced a great challenge: while the medical doctors had direct access to research and publications from abroad, the other health professionals (psychologists, occupational therapists, physiotherapist, and so on) did not. Except for one psychologist who was starting an academic career (her master's thesis was on personhood), the others were mostly trained in clinical work based on "the spoken word." This kind of approach was not always useful in sustaining the desired therapeutic relationships with people suffering from senility, a condition that in an advanced state makes coherent communication extremely difficult. On some days, the individuals who were in treatment wanted to go home; asked repetitively for their partners; did not react to suggestions; cried; offended other people; or did not care for painting, carpet weaving, or other activities, while others behaved just the opposite. Initially, a trial-and-error approach predominated at the day center, while the professionals faced a "mysterious disease," as Alzheimer's is often characterized.

After a while, though, a kind of routine was established. Many patients enjoyed coming to the center, family members joined the institution and offered assistance, dance parties were organized once a month. The music therapist discovered that even in an advanced stage, some elderly persons suffering from a dementia could remember whole texts from songs from their youth; one psychologist helped the patients to plant flowers in pots and observed some who did not forget to water the plants in the following days. Even psychotherapy was initiated for some patients—the CDA had discovered the person within.

This kind of practice, addressed to the person within, contributed to a deep division within the center; a battle between "hard science" and "soft science" became the cause of passionate fights and power struggles. Doctors were accused of treating patients badly, of not caring. There were, of course, the "other doctors" (*os médicos diferentes*), those who spent more time with each patient, subjectified the suffering, and often had problems with time management because they spent too long with each family (fifteen minutes was scheduled for each medical encounter, compared with forty-five to sixty for a meeting with a psychologist). However, also on the "psy side," some professionals did not work the expected way; they were uninterested, without the necessary empathy, or ended up quitting because working with Alzheimer's patients was excessively

frustrating. The center soon had its “personhood war”—the staff were divided almost completely in half, with the exception of certain professionals who bridged both sides.

WHILE DOCTORS WERE treating symptoms that were peripheral to the phenomenon of “Alzheimer’s”—its central sign, cognition, has no effective treatment (Blech 2004)—they were nevertheless legitimated in that they were treating a medical condition. The other helping professions were facing “the mysterious disease Alzheimer’s” without institutionally anchored texts to legitimate their practices. This changed when the first texts on personhood were discussed in staff meetings. (Among them was Diana McGowin’s book [1993] on her own experience with Alzheimer’s.) These kinds of texts declare that nonmedical interventions are central to the care of Alzheimer’s because of their “holistic approach,” something that biomedical interventions were unable to provide.

Tanya Luhrmann (2001) describes psychiatric training in the United States as a “somehow brutal experience.” She concludes, however, “It is, of course, more complicated than that. But much about hospital experience invites a young psychiatrist to feel detached and distant from her patients, while outpatient psychotherapy invites a more tangled, intimate involvement” (84). Luhrmann convincingly describes how medical training enables detachment for some, but not all, doctors, by separating “the person from the body.” The Brazilian scenes described above seem to show the consequences of these two orientations within medicine: the way one understands a disease influences the way one asks questions, influencing—but not determining—how one is *able* to perceive a person and his or her disease and how one is able to provide treatment (see Hacking 1986). An important element of the conflict between “the two gazes” is what Pierre Bourdieu calls “doxa” (Bourdieu and Eagleton 1992)—taken-for-granted dominant knowledge and the tensions created by reacting to it. What follows is a discussion of the contestation of biomedical knowledge, as seen by the personhood movement, in dementia care that is based on an attachment to the patient and on the attempt to communicate with the person within.

This is generally formulated by creating dichotomous absolute categories. For instance, the personhood movement explicitly contrasts itself with biomedicine, the latter perceived as inhuman and objectifying. In this sense, Bond et al. (2002) point to the “medicalization” and “labeling” of insight in Alzheimer’s patients as found in forty-nine psychiatry or psychology texts, a practice that results in a “more [acute] depersonalization [and] loss of independence” (313), while an Irish initiative for dementia care describes this new vision as the following:

Throughout the continuum of care, it is critical to keep the individual person at the forefront. *A worldwide movement is growing to maintain the*

“personhood” of dementia patients, so easily lost in the language of neurological diagnosis, management of symptoms, financial costs and care arrangements. As the late Tom Kitwood, who had been leader of the Bradford (U.K.) Dementia Group, explained: “A radically different approach has been gathering momentum, bringing with it a quiet transformation of attitude and care practice . . . in many countries throughout the world. . . . One of the most striking facts about this convergence is that almost identical conclusions have been reached by virtually independent routes. . . . The *beginnings of a paradigm* can now be discerned: while its principles and practices aim to be thoroughly compatible with the well-attested findings of biomedical science, the central difference is that *its principal focus is the person, not the brain*” (European Institute of Women’s Health, n.d.; emphases added).

The person within has been discovered relatively recently in dementia care, but there already exists a long discussion on personhood in the social sciences. The classical text by Marcel Mauss (1950) on the social history of the person shows that within many Western societies, a person, a psychological being, became his or her consciousness. More specifically, anthropologists have challenged the notion of a unified self and revealed the ethnocentrism within many of its notions (for an overview, see Sökefeld 1999).¹¹ Professionals who work with psychodynamic theories create, as did Sigmund Freud, an archeology of the inner self, and ethicists discuss when personhood begins and ends. The bioethicist Theodore Fleischer, in a recent article on what he calls “the personhood wars,” distinguishes between *personalism*, in which a “human being achieves a claim to life and medical resources only if he possesses certain capacities, *primarily cognitive abilities and self-consciousness*” (1999, 309; emphases added), and *physicalism* or *vitalism*—comparable to Charles Taylor’s *human potential*—whereby “every human being, even one who lacks capacities, is entitled to have a life” (1999, 309). Fleischer’s sympathies clearly lie with the latter approach, arguing that a human being is more than cognition and self-consciousness, an argument that many recent Alzheimer’s activists would agree with.

Charles Taylor (1999) juxtaposes two types of scientists: “the correlators,” who are linked to the natural sciences, and “the interpreters,” who follow a hermeneutic approach. This is another example of opposing bad (objectifying and *erklärend* [explaining]) with good (*verstehend* [understanding]) science. The roots of much modern biomedical theory were formed in the seventeenth century and are generally opposed to the Romantic origins of the “interpretative” approach, especially linked to Herder and Humboldt.¹² Clifford Geertz (1994) criticizes Taylor’s analysis as too simple-minded. Geertz points to the constant changes in the framing of these sciences and to the several forms of “crossing over” from one type to the other, using the example of current science studies.

He claims that Taylor's description of the natural sciences is too schematic and suggests, instead, reframing natural and human science by taking into account the existence of "a loose assemblage of differently focused, rather self-involved, and variously overlapping research communities in *both* the human and the natural sciences . . . and the abandonment therewith of the Taylor-Dilthey conception of two continental enterprises" (89; emphasis in the original).

Nonetheless, Taylor also states that within this "dialogue of the deaf" there is a place for both (an argument I very much agree with), although Taylor notes that the "limitless imperialism of the correlators" (1999, 129) is the source of many tensions between the two. Taylor's point is confirmed by the recent appearance of criticism in the media about unethical practices within the pharmaceutical industry (for example, Angell 2000). This kind of criticism has to be separated from a general notion of biomedicine as ontologically bad, because the latter type of thinking limits an informed, critical view. By looking at the historical roots of the "two gazes," it is possible to describe the personhood movement as a "natural companion" of the biomedical approach—or at least, to describe the two as epistemologies with a long history of coexistence. What I want to argue is that the divided gaze and its almost automatic division into good and bad science, psychology and cognition, or soft and hard science has a long history and is deeply rooted in "Western" thinking (see, for example, Ginzburg 1980). I now turn to the personhood side of dementia research in order to illustrate that at least part of the discussion of personhood is, first, essentially a dynamic formation of a morally loaded category and, second, part of an ongoing historical process of defining life and death in many societies, of what one could call a "biosocial death."

Personhood, Life, and Death

What could it mean in general to say that possible ways to be a person
can from time to time come into being or disappear?

—Ian Hacking, "Making Up People"

Personhood is everywhere. The first three submissions we received for potential inclusion in this volume described the person within. Gerontology congresses discuss personhood extensively. Even within more biomedically oriented meetings, personhood is a topic, in addition to all the "hard" facts. There are different approaches: for instance, phenomenological perspectives; accounts given by individuals suffering from senility; and measurable "insight"—the difference between what the affected person says, as opposed to the words of the caregiver or of neuropsychological tests, as providing the baseline of truth (for an overview, see Clare 2002).¹³

Personhood is generally invoked in reference to forms of human life and to

certain human beings (and sometimes to animals)—for example, fetuses, comatose people, and some disabled people—who cannot speak for themselves. In most cases, discussing personhood (although sometimes understood as personality; that is, what makes a human being specific and distinguishable from others) gives life to people who might otherwise easily become transformed into a mere “capacity to be killed” or “bare life” (Agamben 1998, 114). In this sense, the unveiling of personhood is an attempt to extend life in life, but it also reframes life itself in novel ways: “[B]iological ethics ascribes each human life equal worth. But our practices and techniques show us that, on the contrary, the biological lives of individual human beings are recurrently subject to judgements of worth. . . . [S]uch a judgement [is] about the relative and comparative ‘quality of life’ of differently composed human beings and of different ways of being human” (Rose 2001, 21–22).

The extension of the human life span generally refers to practices directed against a death that might be called biological, although death’s very biology has been redefined recently and is still an issue of debate. The change in the definition of death, from failure of the heart and lungs to failure of the brain (“brain death”), that occurred in some countries at the end of the 1960s (Lock 2002) hides another historical shift that no doubt is less radical, but still has important consequences for affected people and their families. I am talking here about the changing notions of personhood in Alzheimer’s disease and other forms of dementia in relation to a death in life, or what social scientists, for some time, have been calling a “social death.” My argument here is that when talking about personhood, one can understand it as a kind of life extension, or one could frame it as the cultural negotiations around a biosocial death.

A person can simply be excluded from society by others ignoring him or her (for example, through incarceration or stigma). There is also a second, more specific form—a biosocial death—in some medical conditions or with some medical technologies, in which a person’s capability of participating in society diminishes to the point that the person is considered a nonperson or as not having full personhood. I here use the term *biosocial* because the two are inseparable; a social death occurs because of a person’s biology, and biology cannot be described apart from the social body. Additionally, related to what Paul Rabinow (1996) calls “biosociality,” it is very likely that new groups and new identities are formed around certain forms of a biosocial death (see, for example, Jaber Gubrium’s [1986] description of the formation of Alzheimer’s lay groups in the United States).

People who are able to stay alive only with the help of machines provide examples of biosocial death, but reduced cognitive functioning (as in, for example, dementia) in an individual can lead to the perception that that individual is a nonperson.¹⁴ Contrast the criterion for dementia as given in the *International Classification of Diseases*, tenth edition (ICD-10)—the “deterior-

ization in both memory and thinking which is sufficient to impair personal activities of daily living” (Cummings and Khachaturian 1996)—with the traditional definition of *person* as a “self-conscious or rational being” (*Webster’s Encyclopedia*, 2d ed.), emphasizing the importance of reflexivity and rationality.

It is fashionable to quote Giorgio Agamben, whose work on “bare life” has influenced a number of scholars, but I want to focus here on only one aspect of his work. Agamben (1998) calls attention to a space without rights located between life and death. It is a frightening no man’s land, representing “black holes in world society” (Assheuer 2002). These “black holes” are both geographical spaces (such as death camps and some long-term-care facilities for the elderly [Augé 1992; Scheper-Hughes 2002]) and existential spaces where only the body counts, not the person. One who inhabits such a space is a “living dead” person, leading a “life devoid of value,” as Agamben puts it, in terms that might also describe a person with dementia under certain, changing circumstances, as we will see.

Charles Taylor (1994) has made a similar point. There is a “universal human potential,” and this potential, “rather than anything a person may have made of it, is what ensures that each person deserves respect” (41)—even those who are disabled or comatose and incapable of realizing this potential by themselves. This “potential” bears a certain relation to Agamben’s idea of the body stripped of its personhood: bare life. The difference is that although bare life can be killed “without [it] being murder,” Taylor’s idea of universal human potential is exactly what protects life from being killed. Applying these insights to the terms of the personhood movement, some biomedical practices involving Alzheimer’s patients assume bare life, while “holistic approaches” assume universal human potential.

But there is more to the new ethics of dementia care. These ethics have led to new sensibilities that are of inestimable value for formerly “mad” people or the “living dead” and that at the same time have created new values that often are taken for granted. I now turn to the imagined and flexible boundaries between life and biosocial death, within a discussion of personhood. A focus on these boundaries gives rise to an analytical image, of a space between life and death that results in norms and values for both the living and the dead. Four short discussions of interrelated moral landscapes of personhood help to make my point about these shifting boundaries of life in life.

Dead Windows/The Great Astonishment

We never really knew when to say good-bye.

—the son of a deceased Alzheimer’s victim, in Bob Artley,
Ginny: A Love Remembered

The first nonmedical texts written about those suffering from Alzheimer’s disease often stemmed from caregivers mourning the loss of a loved one in life.

Their descriptions are embedded in accounts that deal with the frustrating experience of caring for a partner, parent, or friend who resembles only physically that loved one, a person whose essence has been destroyed by the “gray plague.” Most of the early literature on Alzheimer’s is centered on the suffering of family caregivers; there are very few works on the despair experienced by the affected person when dealing with the dramatic changes in him—or herself. According to the earliest handbooks on the disease, caregivers need to supervise the person suffering from dementia day and night because of the danger this person may pose to him—or herself and others (sources of such danger being gas, fire, the risk of getting lost, and so on). The diagnosis engulfed the whole person.

The hopelessness and emptiness expressed in the language that was used to situate a demented person outside a shared world are illustrated by book titles such as *Alzheimer’s Disease: Coping with a Living Death* (Woods 1989). In another book on early public Alzheimer’s culture, Jaber Gubrium reproduces, for example, a poem called “No Longer You,” written by a caregiver about her husband. This poem had been published several times in the newsletter of the Alzheimer’s Disease and Related Disorders Association (ADRDA) in the early 1980s. The author writes that “the body is yours, a shell,” and compares the eyes of her sick husband with the “windows of a vacant house.” The poem finishes with the statement that “that person” was no longer her husband and that she was only his caregiver (Lois Ellert, quoted in Gubrium 1986, 131–132).

In writings such as these from the 1980s, the notion of the nonperson comes through clearly for three main reasons. First, the image of a nonperson (“a shell”) dominated the early popular and scientific literature on Alzheimer’s disease because at that time little could be done for the sufferer. A second reason for this extremism is that new diseases are often described in apocalyptic terms. It might be difficult to imagine that Alzheimer’s, the disease of the century, as it has often been called, was an unknown phenomenon only twenty years ago. As Barry Reisberg noted in one of the first books of the “new era” of Alzheimer’s, “It is difficult to discuss *a condition for which no name exists*. Indeed, it is very easy for people to completely ignore or deny *a condition which they do not even have a word for*” (1981, 3; emphases added). Jaber Gubrium (1986) described the dawning public awareness of Alzheimer’s and specifically how interest developed at the grassroots and political levels. Patrick Fox (1989) traced the political, economic, and professional influences that shaped the new category *Alzheimer’s disease*, as a new battle was joined against an ailment that threatened all who were aging.

A third reason for the prevalence of the nonperson in the early Alzheimer’s literature is that, in general, people visited a doctor much later in the disease than they do today, simply because public awareness was not as widespread as it is now. These advanced cases became the model for nearly all people with dementia. Reisberg, in 1981, described one case: “The tragedy was that this brilliant

and wonderful man was being gradually and inexorably destroyed" (94). Reisberg delivered an empathetic and sensitive account of his case, but it was "the man"—not a part of the man's faculties—that was being destroyed. This totalization was typical of the 1980s, and it continues today in many medical and nonmedical texts (for example, Spohr 1995, 0).

In a related development, after the publication in 1980 of the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III), psychiatry changed dramatically. It was rebiologized: the unconscious was replaced by the brain as the primary site of mental health—a shift from "symbol to sign" (Gaines 1992)—and later, in the early 1990s, the new genetics appeared (Young 1995; Leibing 2002b).

As I have shown elsewhere (Leibing 1998, 1999, 2000), interest in studying Alzheimer's disease reemerged in the mid-1960s with the Newcastle study (Roth et al. 1966). The authors tried to find a significant correlation between the number of plaques in the brain and the degree of cognitive impairment.¹⁵ Symptoms were linked to the degenerating brain both through the brain's new visibility, made possible by new technologies, and through the potential for quantification that came with these new technologies. A similar, more recent study also perpetuated the image of elderly people as children. Shakespeare's notion of a "second childhood" was clearly evident:

A new MR imaging technique used to study white matter in the brain has found something intriguing—the brains of Alzheimer's patients show some of the same signs as the immature brains of children.

Diffusion tensor MR imaging examinations were performed on 60 normal persons, ranging in age from infancy to late adulthood, says Jeffrey Lassig, MD, of the University of Michigan, and lead author of the study. . . .

"When we compared 13 Alzheimer's patients' brains to 13 others of the same age with no signs of dementia, the Alzheimer's patients' brains showed significantly higher water molecule diffusion. In other words, the Alzheimer's patients' white matter behaved more like the white matter of a child's brain than that of a normal adult," says Dr. Lassig. However, the increased diffusion in Alzheimer's patients is most likely related to damage or dysfunction of axons (white matter tracts), while the higher water diffusion in the white matter of children is a normal phenomenon in immature brains, he says.¹⁶

These brain images were (and still are) exceedingly powerful; with their growing influence, the general notion of the nonperson dominated discussions of dementia, even in cases in which the disease was only in the beginning stages. And even when there was clearly self-awareness in patients diagnosed with Alzheimer's, they were often automatically considered irresponsible and

irrational, which likely influenced the way in which they experienced themselves and the world around them. The effects of this view of Alzheimer's is described in McGowin's (1993) book, one of the first accounts of living with the disease; her doctor mentions that her insight "is uncharacteristic for [Alzheimer's]" (152), and some doubt her diagnosis completely.¹⁷ In an especially touching and often-quoted section of the book, her outcry is specifically against this attribution of nonpersonhood: "If I am no longer a woman, why do I still feel I'm one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the soft texture of satin and silk against my skin? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone!" (114)

Accounts such as McGowin's illustrate Charles Taylor's claim that nonrecognition or misrecognition "can inflict harm or can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being" (1994, 25). Although the early biomedical and caregiver images of Alzheimer's disease mostly overlapped, first-person accounts were published and read in the 1980s, a sign that an awareness of personhood was developing. These accounts were followed in that decade by quickly growing groups of Alzheimer's caregivers and interpretive health professionals dedicated to the new challenge of "Alzheimer's" (see Gubrium 1986).

The New Voices of Alzheimer's

Dorothy [Wordsworth] seems to have recognized the onset of her own mental confusion some time in the year 1835. . . . Three lines of verse in her last journal suggest her self-awareness: My tremulous prayers feeble hands/Refuse to labour with the mind/And that too oft is misty dark & blind.

—Robert Gittings, and Jo Manton, *Dorothy Wordsworth*

In contrast with Dorothy Wordsworth, who worried in her diary about the changes in her "misty" mind, a growing number of affected persons today make their experiences and worries more public, at least in North America and Europe.¹⁸ The impact on the general public is probably minimal, but affected families have increasing access to these kinds of accounts that shed light on "lived" aspects of the disease. These writings enable others to connect to the reality of the person with Alzheimer's, in other words, to recognize a shared reality with, or 'personhood' in, the family member after the diagnosis of the disease. Thus, the diagnosis does not immediately signify a biosocial death (see Snyder 2000).

Recently, Thomas DeBaggio (2002), who had previously been a journalist,

published an account of his journey into Alzheimer's disease. His book reveals a markedly different perspective from that of McGowin's account, which was written by her in the 1980s (her book was published in 1993, but the story she tells takes place when her symptoms started, more than ten years earlier). In the image shown on the cover of DeBaggio's book, only half his face is depicted, implying that he is only in part a full human being.¹⁹ He writes: "For me now, any question of identity becomes profound and difficult. Without memory you lose the idea of who you are . . . I am flooded with early memories preserved in protected places of my brain where Alzheimer's does not reign supreme. These memories become the last remnants of my search for who I am. Am I anything without them?" (19).

DeBaggio describes himself as sometimes confused, sometimes angry, and sometimes full of fear of the moment when the "eager beast in my brain gobbling time in both directions" will take over completely. However, there is never a notion of being treated as a nonperson; on the contrary, he describes his family and friends as supportive and understanding. He exposes the great suffering of family members witnessing the sick person fade away and brings to light the fear that can arise: his son worries about carrying the genes that increase his possibility of getting the disease himself. For DeBaggio, the real moment of becoming a nonperson—although coinciding with the loss of cognitive functioning, the feared black hole—is primarily linked to his becoming a burden. As a result of earlier diagnosis as well as patients' enjoying the attribution of personhood, today's Alzheimer's patients are more independent, which in many Western societies is highly valued. Nevertheless, the preoccupation with becoming a burden is present: "At some point, I will no longer experience the pain of watching my mind deteriorate to a point of incomprehension. Then the loved ones around me will have the unwelcome task to look after me and shelter me from harm. My burden is slight compared to that of the truly living (DeBaggio 2002, 102).

The beauty of these texts lies in the strength and courage of their authors in dealing with a reality that signals great trepidation for many. They describe a new world, and their effort can help many in similar situations. Anne Basting (2003) correctly states that these accounts nevertheless write *about*, and not *from within*, dementia, since a coherent text is thought to be the only way to address the readers. Coherent memory, independence, and identity are so strongly interwoven that the authors themselves limit personhood to the periods of "normalcy," when they are part of the "truly living," as DeBaggio puts it. Basting, like some advocates of the personhood movement (cf. Kitwood 1997), suggests a reformulation of the concept of memory as a more inclusive notion, conceived of as social and interactive (see also Halbwachs 1992; Kirmayer 1996; Leibing 2001).

Experts for the Person Within

When personhood emerged as a topic within dementia care in the 1980s and (more intensively) the 1990s, it challenged the previous, pessimistic assumptions held about the personhood of the person diagnosed with Alzheimer's. Texts were published by professionals and caregivers who had more intense contact with Alzheimer's patients than did many doctors and, therefore, were better able to perceive the interactive person within. Further, they were, like most psychologists, trained to recognize interiority. Michael Ignatieff, writing about his mother, who had suffered from Alzheimer's, describes exactly this kind of discovery:

It [my mother's disease] changed my view of what a person is, *to realize that she remained a person* when no attribute of personhood remained. Go figure, as they say. . . . It seems to me slightly scandalous that . . . it has not been made a properly philosophical subject, because these people are taking us to places we would rather not think about and what they have to say—to that degree that they can say anything at all—should teach us something about what a person is, what human identity is. It taught me, for example, to be less sentimental about memory as a carrier of human continuity. My mother had no memory whatever, but she was the same person. There were continuities. (1999, 19–20; emphasis added)

And a Brazilian psychologist, working with patients suffering from dementia in a public psychogeriatric institution, declared, “My interest in this topic, the impact of [Alzheimer's] on the family and the patient, started when I was treating patients with [the disease]. They told me clearly how bad they were feeling when they perceived that now they were different persons than they were before and how much that had changed their daily life” (personal communication).

Assuming that “the correlators” and “the interpreters” form a historically intertwined, almost interdependent unit, it is not surprising that it was in the 1980s that the personhood movement emerged as a reaction against the “atheoretical and explanatory” approach in psychiatry after DSM-III. The rebiologization of psychiatry, certainly responsible for a greater detachment of psychiatrists from their patients (Luhmann 2001), provoked a reaction that represents probably one of the most important driving forces behind the emerging moral economy of the personhood movement.

The personhood movement is also intimately linked to new sensibilities in end-of-life issues. In the 1980s, the phrase *terminal care* was replaced by *palliative care*. Palliative care, referring to the relief of pain and other symptoms, further accentuated what had started in the 1960s, a general individualization and control over death and its rituals (Walter 1994). Dying people, through the help of

counselors, were encouraged to talk about their feelings and to actively shape the final period of their lives. Cicely Saunders, the foremost figure in the adoption of palliative care, reveals in her biography (Du Boulay 1984, quoted in Walter 1994) that for her, as a Christian, a good death did not mean that one had to come to terms with God; rather, a good death was one in which the patient “was himself.” Religion was now often replaced by spirituality, entailing a claim on self-realization and the search for “your God within” (ibid.). All these elements have directed a gaze into people’s interior world and contributed to the emergence of personhood as a value designating good care. This does not mean that interiority did not exist before—indeed, Peter Gay (1995) has written an extensive moral history of introspection. What I want to argue is that in the 1980s a long-existing trend was reformulated in a more inclusive way, one that encompasses the whole of life’s course; not only the fetus but also the comatose and those near death have become persons to be rescued from a biosocial death.

As a result, the boundary between life and biosocial death has been further remodeled by scholars and health professionals who specialize in rescuing the cognitively impaired. Taylor (1999, 102) observed that we need “a rather different theory of meaning, more in line with those developed in the Romantic period,” and two important authors within the personhood movement initiated a discussion on this point within the health professions (for an overview, see Brack 2002; Hulko 2002). Naomi Feil (1982, 1993) developed validation therapy, which interprets some of the signs or symptoms of dementia as feelings that express conflicts stemming from earlier periods in life.²⁰ And Kitwood, contesting the common notion that dementia is a “death that leaves the body behind,” in his book *Dementia Reconsidered: The Person Comes First* (1997), summarizes his approach toward what he calls “person-centered care”: “Contact with dementia or other forms of severe cognitive disability can—and indeed should—take us out of our customary patterns of over-busyness, hypercognitivism and extreme talkativity, into a being in which emotion and feeling are given a much larger place” (5).

Quoting Martin Buber’s comment “All real living is meeting,” Kitwood and his followers insist on two prerequisites for proper care: (1) an emphasis on the capacities of the feeling person and not only on his or her losses, and (2) a redefinition of memory as interactive and not individualized. It is probable that these ideal prescriptions have never been attained within an institutional setting. Nonetheless, they have inspired a number of admirable projects that have made a difference (see Brack 2002, Basting, this volume).²¹ To follow Kitwood’s instructions through completely would bring about a major revolution, not only because it would mean a large investment in time and staff during a period of ever tightening health budgets, but also because redefining “memory as interactive” would only be possible after a major shift from what is deeply rooted in

our thinking and practice: that memory is the carrier of individual identity and personhood. I argue in the conclusion of this chapter that a certain shift is already happening, at times when the boundaries between self and other is blurred.

Medicating the Person Within

Another recent impulse for defining the boundaries between person and non-person stems from the pharmaceutical industry, which is discovering the person within. A relatively new focus on “behavioral and psychological signs and symptoms in dementia” (BPSSD or BPSD) (Finkel 1996; Kurz 1998) is, in reality, nothing new. Alois Alzheimer’s first patient, Auguste D., suffered initially from an obsessive jealousy regarding her husband and developed a number of other symptoms in the following years, which Alzheimer meticulously described (Maurer and Maurer 1998; Jürigs 1999). But throughout the history of Alzheimer’s disease, cognitive symptoms have always been in the foreground. Ian Hacking (1999) believes that this is because memory is more easily measured than emotions, such as irritability or jealousy.

Since 1992, there has been a renewed interest in behavioral and psychological problems. In 1995, the International Psychogeriatric Association (IPA)—with an “unrestricted grant from Jansen Pharmaceutica”—organized an international consensus conference on the topic:

The development of the Consensus Statement on Behavioral and Psychological Symptoms of Dementia (BPSD) represents a first step toward recognizing that these are *core symptoms of dementia* and that it is as essential to study and treat them as it is to study and treat any other aspects of dementing disorders. It is to be hoped that by better defining BPSD, we will develop better standardized measures and scales which we can use to further study the *symptom clusters* and assess the outcome of our treatment interventions. (Finkel 1996; emphases added)

If there are behavioral symptoms that can be treated or even cured, a person displaying those symptoms must be defined beyond his or her cognitive functioning. And if daily activities are at the center of medical interventions, it is an acting person who is being treated, someone who will eventually, at least for some time, be functional again (for functionality as a “new paradigm” for successful living, see Katz and Marshall 2004).

The psychiatrist Alexander Kurz (1998) writes that a major reason for this new interest is the limited usefulness of cholinergic agents and nootropics (memory-enhancing medications) to date, while behavioral and psychological problems can be easily medicated with traditional psychiatric medications, opening up a new and promising market. While the first drug to treat

Alzheimer's, Tacrine, was described as improving only memory, newer medications also improve functioning in daily life activities and decrease behavioral problems.²² On the home page of Pfizer's Web site (<http://www.aricept.com>, accessed August 2003) we find the following description of the drug Aricept, in which improvements in everyday activities are highlighted more than are those in memory. "Such medications [as Aricept] are now available: acetylcholinesterase inhibitors have been shown to stabilize Alzheimer's disease and help slow the progression of the symptoms of the disease. Several studies have revealed that these medications have a *positive impact on daily activities, behaviour, and overall functioning, including memory and orientation of time and place*. Other studies have demonstrated that some of these drugs may be safe and effective over the long-term, significantly delaying the worsening of symptoms" (emphasis added).

Janssen-Cilag defines dementia by emphasizing daily activities of patients and caregivers. "Dementia, a progressive brain dysfunction, leads to a gradually increasing restriction of *daily activities*. The most well-known type of dementia is Alzheimer's disease. Dementia not only affects patients, but *also those surrounding them*, as most patients require care in the long-term (Janssen-Cilag Web site [<http://dementia.com>], accessed August 2003; emphases added).

The concept of BPSD is strongly linked to the IPA, which as noted earlier, received funding from the pharmaceutical company Jansen Pharmaceutica. The Alzheimer's Association, which defines Alzheimer's as "a complex disease that affects the brain" (<http://alz.org>, accessed August 2003), separates these symptoms on their Web site. There, "symptom management" is a subitem, not linked to a concept such as BPSD and, it seems, also relatively separated from medical interventions. The choice of quoted articles suggest that it is more of a topic for nonphysicians. This can be contrasted with an IPA publication in which one author recently defined Alzheimer's as "characterized by deterioration in the ability to perform activities of daily living (ADL) in addition to loss of cognitive function and behavioral changes" (Potkin 2002). IPA has also published supplements of its journal *International Psychogeriatrics* (Finkel 1996; Finkel and Burns 2000), and an educational pack on the topic has been distributed to the health professionals of the association.

BPSD brings together at one table "correlators" and "interpreters," who then publish together, such as in the IPA supplements. For instance, in the IPA publication following the 1996 consensus conference, the well-known Alzheimer's researcher Zaven Khachaturian (1996) writes, "We also should strive to *maintain a patient's ability to function independently* for as long as possible. Although drug treatment has a role, we must not overlook *psychosocial and environmental therapies*, which may be particularly effective in decreasing caregiver burden" (494; emphasis added).

The multidisciplinary is nevertheless limited. In these publications, most

topics are covered by doctors, and the few non-MDs who are included use the same language as that of the doctors—one of scales, measures, and burden. Furthermore, what became very clear in the interviews I conducted with doctors in Brazil and Canada before this BPSD shift occurred was that these doctors were not treating dementia, but “improving a bit the patient’s quality of life.” Doctors until now have been limited to treating symptoms such as sleeping problems or depression (which are now BPSD symptoms) as well as administering neuropsychological testing and some medication with limited efficacy in Alzheimer’s. The difference is that at the time of the interviews these BPSD symptoms were at the periphery of Alzheimer’s; now, the symptoms are becoming more central to the category, and doctors thus treat dementia itself.

One of the possible consequences of this new way of clustering symptoms is that the involvement of the pharmaceutical industry could mean a total medicalization of dementia. General knowledge would be that medication is the quickest and most cost effective approach, and only if it fails, should there be more time-consuming activities led by other health professionals. This kind of economic ratio is evident in the following quotation: “Of those patients with dementia who had documented BPSD, 70% were moved to a higher MM [management minutes] category solely because of BPSD. . . . Although the possibility of eradicating all behavioral problems in an institutionalized dementia population is unlikely, the advent of new medications designed to treat these problems makes it more likely that at least some level of control . . . might be possible (O’Brien, Shomphe, and Caro 2000, 55).

A stronger narrative of a link between certain symptoms and neuropathology might also veil environmental influences. Reading the descriptions by pharmaceutical companies of certain Alzheimer’s drugs, one gets the impression that the available medications treat a general and indistinguishable bundle of symptoms. The IPA BPSD expert team does not use this kind of unifying approach but divides up the symptoms, as does the Alzheimer’s Association. But as Finkel (2000, 11, quoting Reisberg et al.) writes, “[T]here is thus evidence that BPSD is a *distinct syndrome* that should be studied independently of functioning and cognition in clinical trials” (emphasis added). In statements such as these, the heterogeneity of symptomatology and course that is found in a syndrome such as Alzheimer’s is reduced to the notion of “general functioning.”

This story could be told as one of greed, of profit as the main motive for concentrating on these symptoms and the reshaping of the dementia category. But it could be also told in a different way. The so-called medicalization of certain symptoms might be an important means of providing for the continuation or extension of personhood, via the redirection of the medical gaze from managing memory to the highly disturbing symptoms that are responsible for the institutionalization of many people with dementia (Kurz 1998). Much of the suffering that Bernard Heywood (1994) writes about, when in the 1980s he was

caring for his neighbor Maria, could have been diminished by treating with drugs—sensitively—her sleeping problems or some of her more frightening hallucinations. Such treatment might have preserved and extended the personhood of this “poor child.” The impact of this quite recent reshaping of dementia is still to be seen.

Conclusion

We prefer all sorts of abstract nonsense nouns—the self, the subject—to what does make sense, the soul.

—Ian Hacking, “Memory Sciences, Memory Politics”

One of the goals of this volume is “to understand what senility is becoming,” as Lawrence Cohen has formulated it in the introduction. In this section I will point out one possibility of what senility *might* become through a rethinking of personhood in a way that might overcome some of the limitations of the concept. It has been suggested that when talking about personhood in the context of Alzheimer’s, one frequently means extending life in life. This relatively recent trend in Alzheimer’s care has been discussed through consideration of two structuring forces: the dichotomic and interrelated traditions of hermeneutic versus objectifying science, and the work on “personhood” as a work on (life)time and inclusion, or a negotiation of biosocial death.

Biosocial Death

Although outlined only briefly, the four chosen “ethical scenarios” provide insight into some of the authoritative spaces in which a person with dementia can live, what Nikolas Rose calls the “diverse apparatuses and contexts in which a particular relation to the self is administered, enjoined, and assembled” (1998, 194). The argument here is that although the boundaries between life and biosocial death are constantly changing, much of what constitutes the new sensibilities of personhood are derived from the same premises—personhood is conceived as an interior essence, and in the case of dementia, personhood is the reduced remainder of the once complete (DeBaggio’s half face). Many attempts to endow personhood appear to be related to a politics of pity, partly because of this “remainder,” which is difficult to interact with as a “new whole.” Although this idea of personhood undoubtedly makes possible caring for a person who otherwise would have been considered a “shell,” one challenge could be to overcome the notion that cognition is the decisive carrier of personhood. A shortcoming of this chapter is that the multiple and heterogeneous attempts to preserve personhood (to consider someone as one of us) within the personhood movement has not been given enough space. A more expansive ethnography is needed.

Self and Memory

Personhood, self, and memory are not unproblematic natural categories. A vast literature on memory exists, but little has been said about how to disentangle memory, identity, and the self. Adherents to the personhood movement (which is not as homogeneous as the name suggests) have repeatedly made the suggestion that memory is not merely a neural activity but should be redefined as “interactive and not individualized” (Kitwood 1997; Basting 2003). Whether the level of health/therapeutic care is enough to reach this goal and whether health professionals can even inculcate this approach at a time when this way of thinking has not spread in a more general way throughout society, remains an open question (see Lambek 1996).

Some social scientists, though, have pointed to some new understandings of life itself. In all four ethical scenarios, extending life in life was limited by the administration of an interiorized self, primarily defined as cognition, even when cognition was said to be secondary in some psychological approaches. If memories were exteriorized, the boundaries of the self would be blurred and the therapist/caregiver transformed into part of a social brain (if we perceive it as the site of memory). Everybody who has worked with people suffering from senility knows some couples in which the healthy member functions as a mental walking stick for the forgetful partner. A typical sign for this is a constant quest for reaffirmation of what has been said (for example, in the question “Isn’t it?” directed to the healthy partner). But the limitations of this are obvious, especially when the relationship is not a good one or because of the limited time of a therapy session if it is the therapist who acts as the support.

What about objects extending memory? As Canguilhem (1992) put it more than fifty years ago, “Machines can be considered as organs of the human species” (55). Robert Davis, who writes about his own senility, describes some of the tools that help him to become a partial “cyborg,” explaining that books are easier to understand on tape recordings than when read to oneself, and the use of a computer is preferable to handwriting: “Strangely, when I attempt to communicate in my own handwriting I leave words out . . . and write in a scrawl, legible only to my wife. . . . Much to my surprise, the thoughts appeared much more completely in the typewritten material. . . . Now I am able to write letters and feel that I am not totally isolated from the world of intelligent people” (1989, 97).

This kind of extension (of life in life *and* of self), by blurring the boundaries of self and other, is one way to continue thinking personhood. This extension can be other persons: for example, Deborah Hoffman in the film *Complaints of a Dutiful Daughter* (1994) describes the forgotten past to her mother and becomes momentarily part of an extended or interpersonal memory. The extensions can also be objects, which become humanized in their integration into personhood. As Emily Martin, relying on Donna Haraway’s work on cyborgs, comments: “Per-

haps it is the weight of human-centered accounts that has prevented us from seeing that human consciousness has very frequently stretched beyond the border of the skin. Perhaps it was the dominance of the ideology of individualism in the West that shut our ears to ways our identities never were single” (1996, 269)—our ears and our (divided) gaze.

NOTES

I am grateful for the comments of Lawrence Cohen and Jennifer Cuffe, as well as those made by two anonymous readers. This chapter is dedicated to the patients and staff of the CDA at the Institute of Psychiatry/Federal University of Rio de Janeiro—a little bit more to the interpreters than to the correlators.

1. In this chapter, I am mixing Brazilian and “international” sources, since I am focusing on elements of Alzheimer’s culture that are shared across several national boundaries. Elsewhere (e.g., Leibing 2002a), I have focused on local aspects.
2. At that time, in 1995, the psychogeriatric clinic consisted of one room within the general outpatient clinic, which was operated by one psychiatrist, one resident, and two psychologists. Later, this unit expanded and was given its own building, and it became a center for clinical practice, teaching, and research.
3. All names “from the field” are pseudonyms.
4. Some people are opposed to the label *caregiver* because it somewhat professionalizes the act of helping others. This category is, nevertheless, an important element of the culture of chronic diseases: it provides a vocabulary and behavioral codes in addition to a notion of shared suffering. It gives positive value to (mostly female) practices that had previously been taken for granted and were largely invisible.
5. This propensity to characterize Alzheimer’s disease as stemming from one’s life circumstances is not a pattern exclusive to Brazil but is also found in Latin communities in the United States (Levkoff and Hinton 1999), for example, in Cleveland (Rob Friedland, personal communication); I noted it in Montreal when I was interviewing health professionals there. I will deal with this “international” feature in a forthcoming article.
6. A depressive symptomatology accounted for the visits of more than half the elderly who came to the unit. Depression plays different roles in dementia: it can be the first sign of the condition—something that Alois Alzheimer had suggested in 1898; it can be part of dementia (understood as neuropathological in origin, as reactive to the symptoms of the disease, or both); or it can be the cause of a so-called pseudodementia, in which depression or anxiety produces similar symptoms. Depression earlier in life can also be a risk factor for dementia in old age, although there is no consensus on this (see, for example, McGuire and Rabins 1994, 246–248).
7. This is true for the middle and upper classes. During research in a shantytown in Rio de Janeiro, a colleague and I found that dementia was not an important preoccupation for discussing aging (Leibing and Groisman 2000), partly because of its association with madness.
8. *Personhood*, or *the person within*, refers to a number of concepts that are being used interchangeably at times, at other times with different, but overlapping meanings. Although not always used in the same ways, the following terms connote certain attributes: insight: quantifiable; personhood: communicable; awareness: compliance; self: essence; subjectivity: reflexivity (for different models of the self used in the social sciences regarding Alzheimer’s research, see also Herskovits 1995, 159).

9. Nils Gellerstedt undertook one of the largest early studies of the brains of people who were healthy before their deaths. From the fifty brains Gellerstedt examined, 86 percent had senile plaques and 78 percent showed tangles typical of dementia. Gellerstedt concluded that "these formations, whether or not they are found in high quantity, do not permit a secure affirmation about the prior mental state of the patient" (1932/33, 396). Gaetano Perusini had already come to the same conclusion in 1911, exactly contrary to the findings of the Newcastle study thirty years later (see below).
10. Since it was not a unit exclusively for Alzheimer's patients, the center was finally called the "Center for Persons with Alzheimer's Disease and other Mental Disorders of Old Age." It became better known under its abbreviation, as the CDA.
11. The self is "endowed with reflexivity and agency," as Sökefeld (1999) writes.
12. To analyze these roots goes beyond the scope of this chapter. See, for example, Duarte 2002; Gay 1995; Klemm and Zöller 1997; Russo 1997; Taylor 1989; and Luhrmann 2001. See also Geertz 1994 and Latour 2004. Stephen Katz (1996) provides a lucid history of gerontological knowledge. He argues that gerontology often divides the definition of the aging body into two: one that is associated with biology and the other with psychology.
13. In this chapter, I am using *dementia* and *Alzheimer's disease* almost interchangeably. The more general notion *senility* would mean that the starting point is not a priori a clinical or pathophysiological state but a "set of practices located in time and space, practices in and through which bodies *come to matter* in particular ways" (Cohen 2001; emphasis in the original). However, since I am talking here explicitly about medical categories, I stay with the terminology created within this specific context.
14. Some people, generally arguing against euthanasia, defend the notion that some comatose people actually are aware of the world around them but are incapable of expressing themselves, imprisoned in a damaged body. The medical doctor Mihai D. Dimancescu (1999) wrote for the Coma Recovery Association about another form of biosociality: "Many a recovered patient has related events that occurred when everybody believed they were still in a coma. I was impressed by twenty three year old Judy, who remained unresponsive in an intensive care unit bed for three months. . . . One day Judy did wake up and gradually regained her speech. . . . She told me that she 'always remembered that darn professor refusing to stop by her bed,' saying that she would not wake up."
15. This correlation could only be obtained because a high number of people without cognitive impairment and without neuritic plaques were included in the study. This is why in 1993, one of the authors, Sir Martin Roth, disassociated himself from this result (Bauer 1994).
16. "Imaging Technique Shows Brains of Alzheimer's Patients Similar to Children," alzheimersupport.com, December 5, 2003.
17. Jerson Laks, MD, thinks that it is the vascular form of dementia that often allows for the preservation of insight for a longer period of time than Alzheimer's disease (personal communication). Peter Whitehouse, MD, doubts that the book could have been written at all by a person suffering from a dementia (personal communication).
18. We do not know much about how memory loss is experienced in contexts in which a different approach to cognition, memory, and the aging body exists. Although memory loss is not perceived everywhere to be equally negative, aberrant behavior seems to be a problem in many societies (see Cohen 1998, on India; Barker 1997, on Polynesia; Traphagan 2000, on Japan).

19. Different from the picture of DeBaggio's partial face—the diminished self—the image on the cover of McGowin's book is that of her (entire) face in gradually fading shades.
20. An interesting finding from Feil is that her techniques do not work for early-onset dementia. The underlying assumption that this form is fatalistically genetic in origin is opposed to the "mysterious" late-onset dementia, which is sometimes linked to the person's life (see note 5).
21. A further step in "life extension" is the attempt to understand the nonverbal signs of elderly demented persons (Hubbard et al. 2002; Hamilton 1994).
22. According to Medline Plus (1998), "Tacrine (TAK-reen) is used to treat the symptoms of mild to moderate Alzheimer's disease. Tacrine will not cure Alzheimer's disease, and it will not stop the disease from getting worse. However, Tacrine can improve *thinking ability* in some patients with Alzheimer's disease" (emphasis added).

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